

# Prevalence of Diagnosed Diabetes Among American Indians and Alaska Natives, 1987

Estimates from a national outpatient data base

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**OBJECTIVE** — To estimate the prevalence of diagnosed diabetes among American Indians and Alaska Natives served by the IHS.

**RESEARCH DESIGN AND METHODS** — This was a cross-sectional study of the 1987 IHS national outpatient data base.

**RESULTS** — Prevalence rates of diagnosed diabetes determined from the IHS outpatient data base were consistent with recent studies of diabetes in different IHS areas. IHS-wide, age-adjusted prevalence was 69/100,000, or 2.8 times the U.S. rate. There was considerable variation in prevalence rates of diabetes throughout the country, with rates ranging from 15.3/100,000 in Alaska to 119.2/100,000 in southern Arizona.

**CONCLUSIONS** — This study documented the high prevalence of diabetes among American Indians and Alaska Natives and the wide variation in rates between different tribal groups. This study also demonstrated the feasibility of using an outpatient data base to estimate rates of disease that have uniform methods of diagnosis and result in frequent clinic visits.

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IHS, INDIAN HEALTH SERVICE; NHANES, NATIONAL HEALTH AND NUTRITION EXAMINATION SURVEY; APC, AMBULATORY PATIENT CARE.

Most chronic disease surveillance has been conducted with hospital discharge data, mortality statistics, and national health interview surveys (1–5). Although data from ongoing national health interview surveys can be used as a reference, they may not be applicable in different ethnic groups or regions of the country. Many of these surveys are conducted by telephone and thus may underrepresent populations of lower socioeconomic status who may not have telephones. Hospital discharge data can best be used to estimate incidence of a disease that universally requires hospitalization. Estimating rates from mortality data is most useful as a surrogate measure for diseases that are in and of themselves fatal. Because most morbidity associated with chronic diseases is seen in outpatient settings, not hospitals, prevalence estimates from hospital discharges or mortality data will greatly underestimate the true health burden from chronic diseases (1,3–8).

With the growing interest in primary care research (9–14), population-based outpatient data offer a potential source for estimating the prevalence of chronic and noncommunicable diseases. These estimates can then be used to project health-care demands. In many instances these data are routinely collected for administrative purposes and are readily available. Such data have been used in a limited scope in clinic-based, community-oriented primary care research (8,10,15,16). To determine whether an ambulatory patient care data base from numerous different types of health-care facilities can reliably be used to estimate the prevalence of disease in a population, we examined the IHS National APC data base and estimated the prevalence in 1987 of diagnosed diabetes among American Indians and Alaska Natives.

This study has two purposes. By estimating the 1987 prevalence rates of diagnosed diabetes for the American Indian and Alaska Native populations served by the IHS, it updates and ex-

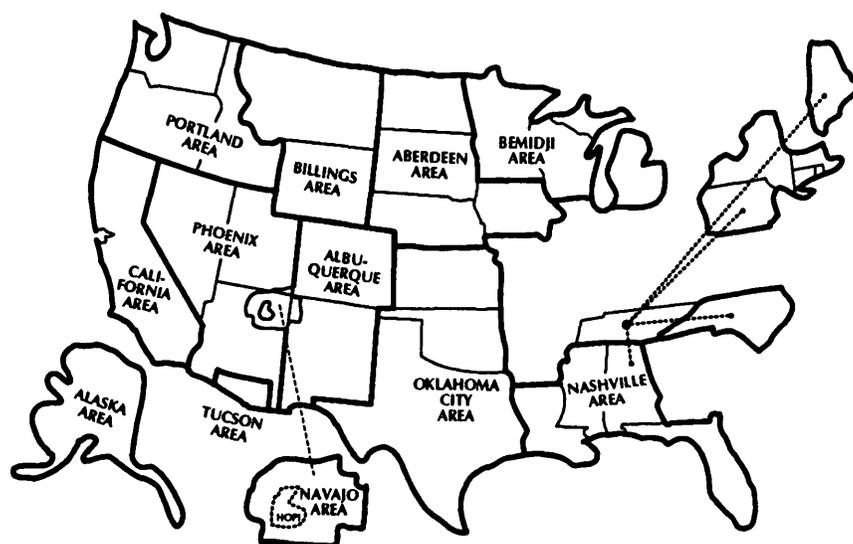


Figure 1—IHS areas.

pands the 1984 summary of 44 studies published between 1940 and 1981 on diabetes in different tribal groups (17). In addition, this study documents the ability to use a multicentered outpatient data base as a surrogate measure for estimating disease rates.

#### RESEARCH DESIGN AND METHODS

At IHS facilities, clinical diagnoses and demographic information for each outpatient encounter—whether the patient was seen by a physician, nurse, or laboratory technician, or seen only to fill prescriptions from private providers—were collected in a standard format that has been in place without change since 1980. The 432 IHS facilities that use this system of data collection were included in this investigation. These facilities provided care for ~86% of the 1987 estimated IHS service population of 1,016,815 (18).

Data from outpatient visits for fiscal year 1987 (1 October 1986–30 September 1987) were examined to find people with a diagnosis of diabetes. IHS providers used the National Diabetes Data Group criteria for diagnosing diabetes (19). Unique patient identifiers

were used to exclude duplicate records for people with multiple visits to one or more facilities. No chart reviews were performed. Data were sorted and examined by IHS administrative areas (Fig. 1).

Estimates of the prevalence of diagnosed diabetes were computed using the 1987 population figures projected from the 1980 U.S. census (20) for the service delivery areas included in the study. All rates were age adjusted by the direct method to the 1980 U.S. census. Because one of the purposes of this study was to determine whether outpatient data could be used as a reliable surrogate measure of diabetes prevalence without having to perform costly and time-consuming chart reviews, results were compared with recent studies of diabetes prevalence in four different IHS regions (21–24). Three of these comparison studies were conducted for entire IHS areas and were based on locally maintained registries of people with diabetes. All of these registries were verified by chart reviews and were routinely updated. The other study was a screening study conducted in one reservation community.

We used  $\chi^2$  tests to compare IHS

prevalence rates with U.S. data from the 1979–1981 National Health Interview Survey where people reported being told by a physician that they had diabetes (25). Data from population screenings such as NHANES were not used for comparisons for three reasons: 1) the IHS data base contains information only on individuals with diagnosed diabetes, 2) formal screening for diabetes is not routinely done in IHS facilities, and 3) the IHS data were not available in the same age-groups as the NHANES data.

**RESULTS**— The estimated age-adjusted prevalence rate of diagnosed diabetes among American Indians and Alaska Natives was 69/1000 for all age-groups and 88.7/1000 for people aged  $\geq 15$  yr. Diabetes rates varied considerably in different parts of the country. The prevalence for all ages ranged from a low of 15.3/1000 in Alaska to a high of 119.2/1000 in the Tucson area. Age-specific, crude, and age-adjusted rates by IHS area are shown in Table 1. Comparison of the rates found in this investigation with results from four recent studies showed that these estimates were consistent with those studies (21–24).

An extensive survey by Schraer et al. (21) in 1985 found the age-adjusted prevalence of diabetes in Alaska to be 15.7/1000, only slightly higher than the 15.3/1000 found here for the Alaska area. A comparison of age-specific rates from both studies for the Alaska area shows extremely close agreement (Table 2).

A 1985 study by Carter et al. (22) among Indians in the Albuquerque area found a crude prevalence rate of diabetes of 59.1/1000 for all ages and 214.9/1000 for people aged  $\geq 35$  yr of age (22). The crude prevalence found in this investigation for the Albuquerque area was lower (55.3/1000 for all ages), but not significantly different. Crude rates for people aged  $\geq 35$  yr could not be compared, but for people aged  $\geq 45$  yr, this investigation found, as expected, that the prevalence was higher than the rate found by

Table 1—Age-specific, crude, and age-adjusted rates of diagnosed diabetes by IHS area, 1987

	RATE/1000 BY AGE-GROUP				CRUDE RATE/1000	AGE- ADJUSTED RATE/ 1000	RISK RATIO
	0-14 YR	15-44 YR	45-64 YR	≥65 YR			
TUCSON	0.5	60.4	306.8	270.9	75.5	119.2	4.83
ABERDEEN	1.9	35.5	264.0	322.2	59.8	105.4	4.26
PHOENIX	1.4	44.0	270.6	267.9	65.4	104.3	4.21
ALBUQUERQUE	1.2	33.7	241.8	267.9	55.3	93.8	3.80
BEMIDJI	1.7	23.5	230.9	308.1	53.0	91.6	3.71
NASHVILLE	1.2	35.3	196.9	277.7	62.7	86.8	3.51
BILLINGS	1.9	28.2	203.1	286.5	49.9	85.9	3.48
ALL IHS AREAS	1.3	25.3	172.3	203.8	45.1	69.0	2.79
OKLAHOMA	2.3	25.6	140.3	175.6	48.6	59.9	2.43
NAVAJO	0.4	16.3	153.5	162.2	32.4	56.2	2.27
PORTLAND	0.7	14.1	120.3	160.8	29.3	48.6	1.97
ALASKA	0.4	3.7	31.1	63.6	8.7	15.3	0.62
U.S.*	0.8	8.5	55.0	88.4	—	24.7	1.00

\*Source: ref. 25.

Carter for persons aged  $\geq 35$  yr: 249.7/1000 vs. 214.9/1000.

In 1986-1987, a screening study among subjects aged 20-74 yr in a Navajo community described diabetes (23). The age- and sex-adjusted prevalence of 102/1000 cannot be compared directly with our data, because of the different age-groups examined and the inclusion of both diagnosed and previously undiagnosed diabetes in the Navajo study. However, data provided by Dr. Sugarman on diagnosed diabetes allowed the comparison of rates from that study with rates found here (23). Even though the age-groups examined were not identical, age-specific rates for diagnosed diabetes show extremely close agreement (Table 2).

In a 1987 study, Freeman et al. (24) found the Indians in the Pacific Northwest (Portland area) to have a crude prevalence of diabetes of 30.6/1000, very close to the crude rate of 29.3/1000 found in this investigation. However, the age- and sex-adjusted rate in that study was 71/1000, higher than the age-adjusted rate of 48.6/1000 we found. Comparison of age-specific rates

show that Freeman et al. (24) found higher rates in most age-groups (Table 2). This discrepancy in rates was probably attributable to the Freeman study only including people living  $\leq 40$  miles of the surveyed clinics. Freeman found that in 3 of 10 Portland area reservation communities (group A), most of the Indian population lived close to the IHS facilities, whereas in the other 7 reservation communities (group B), many of the people lived  $> 40$  miles from the nearest IHS facility. When data from the Freeman study and this investigation were compared by groups A and B, the rates for group A, in which much of the population lived close to IHS facilities, show extremely close agreement. For group B, however, there are substantial differences in the older age-groups (Table 2).

For all IHS patients, the age-adjusted rate of diagnosed diabetes of 69.0/1000 was 2.79 times the U.S. all-races rate of 24.7/1000 (25) (Table 3). When compared with other ethnic groups in the country, IHS patients had significantly higher rates, ranging from 1.67 times the rate for blacks to 3.01 times the rate for whites. Of the 11 IHS

areas examined, all but one had a prevalence rate of diagnosed diabetes significantly higher than the U.S. rate (Table 1). The Alaska area had a rate significantly lower than the U.S. rate.

**CONCLUSIONS**— This investigation used the IHS national outpatient data base to estimate the prevalence of diagnosed diabetes among American Indians and Alaska Natives. This investigation also tested whether an outpatient data base developed primarily for administrative purposes can be used as a reliable surrogate measure to estimate disease rates without the necessity of performing chart reviews. The prevalence rates of diagnosed diabetes were consistent with recent prevalence studies (21-24), demonstrating the high rates for American Indians. In addition, the variation in diabetes prevalence between different Native American groups found in this study also was observed in the comparison studies (17,21-24). Thus, the results obtained from the IHS outpatient data probably are reliable surrogate measures of the prevalence of diagnosed diabetes, indicating that the IHS APC data bases

Table 2—Comparison of age-specific prevalence rates/1000 of diagnosed diabetes by IHS area, IHS outpatient data compared with published studies

		IHS OUTPATIENT			
		AGE-GROUP (YR)	DATA	AGE-GROUP (YR)	SUGARMAN* (23)
ALASKA AREA	0-14		0.4	0-14	0.2
	15-44		3.7	15-44	2.4
	45-64		31.1	45-64	32.0
	≥65		65.6	≥65	66.9
	TOTAL (CRUDE)		8.7		8.3
		IHS OUTPATIENT			
		AGE-GROUP (YR)	DATA	AGE-GROUP (YR)	SUGARMAN* (23)
NAVAJO AREA	15-44		16.3	20-44	15.7
	45-64		153.5	45-64	149.6
	≥65		162.2	65-74	162.8
		IHS OUTPATIENT			
		AGE-GROUP (YR)	DATA	AGE-GROUP (YR)	FREEMAN (24)
PORTLAND AREA	0-14		0.7	0-14	1.2
	15-44		14.1	15-44	25.8
	0-44		8.8	0-44	10.1
	45-64		120.3	45-64	184.8
	≥65		160.7	≥65	226.0
TOTAL (CRUDE)		29.3		37.7	
		GROUP A		GROUP B	
		IHS OUTPATIENT		IHS OUTPATIENT	
		AGE-GROUP (YR)	DATA	AGE-GROUP (YR)	FREEMAN (24)
PORTLAND AREA	0-14		0.6	0-14	0.4
	15-44		20.5	15-44	15.5
	45-64		197.8	45-64	157.7
	>65		251.1	>65	198.4
	TOTAL (CRUDE)		46.0		33.5

\*The Sugarman study included both diagnosed and previously undiagnosed diabetes. Data presented here are for diagnosed diabetes only and were received from Dr. Sugarman.

may be effectively used for surveillance of chronic diseases.

From NHANES data, it is estimated that ~50% of people with diabetes are undiagnosed (26). Because IHS providers are aware that diabetes is much more prevalent in Indian communities

than in the general U.S. population, because there are numerous community education programs in Indian communities, and because health care is free, it is likely that the percentage of undiagnosed diabetic people in the IHS system is lower than that found in NHANES. Only

one community survey in an Indian community has explored this issue (23). That study found that only 25% of people with diabetes were undiagnosed. Thus, although estimates of diabetes prevalence from local registries and the IHS outpatient data base are in close

**Table 3—Prevalence of diagnosed diabetes in American Indians and Alaska Natives (1987) compared with other ethnic groups in the U.S. (1980)**

ETHNIC GROUP	RATE/1000*	RISK RATIO	95% CI
AMERICAN INDIAN/ALASKA NATIVE	69.0	1.00	—
U.S. ALL RACES†	24.7	2.79	2.42–3.22
WHITE	22.9	3.01	2.60–3.49
HISPANIC	31.7	2.18	1.91–2.48
BLACK	41.3	1.67	1.48–1.88

\*All rates age adjusted to the 1980 U.S. population.

†Source: ref. 25.

agreement, they probably underestimate the true prevalence.

Even though the prevalence rates found in this investigation were consistent with results from recent studies, there are limitations to the data used. These limitations would tend to underestimate the prevalence of diabetes in the IHS service population. Because the data used for determining prevalence rates covered only a 12-mo period, people with diabetes were not counted if they did not seek care within those 12 mo. In the 1979–1980 National Health Interview Survey, 87% of individuals with diabetes reported a physician visit within the previous year (27). IHS quality assurance audits showed that 90–94% of IHS patients with diabetes sought health care within a 12-mo period. Because the IHS data system captures no more than two diagnoses per visit, it is possible that a person with diabetes presented for other health problems and diabetes was not coded. No information was available on people eligible for health care in the IHS system who sought their care elsewhere. However, because health care and medications received from IHS facilities are free and IHS facilities often are the only accessible facility, most Indians seek at least some of their care from the IHS. The 1987 prevalence rates of diagnosed diabetes estimated from IHS ambulatory patient care data, although slightly lower than the rates found in the comparison studies (21–24), were not significantly lower. Thus, we do not feel these poten-

tial limitations in the methods to be a major source of bias in this study.

This study demonstrated that the IHS APC data base can be used to calculate reasonably accurate prevalence rates of diagnosed diseases, especially in areas where most of the population lives close to IHS facilities. Because these data have been collected in the same way for many years, there is sufficient consistency in the data over time to determine trends. The prevalence estimates obtained from the IHS outpatient data are probably reliable surrogate measures of the prevalence of diagnosed diabetes. These results suggest that ambulatory patient care data bases may be effectively used for surveillance of any disease with moderate to high prevalence, if these diseases have uniform methods of diagnosis and result in frequent clinic visits (e.g., diabetes, hypertension, chronic obstructive pulmonary disease, epilepsy, and asthma).

The prevalence of diagnosed diabetes in the IHS as measured by outpatient encounters demonstrates the high rate for American Indians when compared with other ethnic groups in the country. The results also show considerable variation in rate by IHS area. Obesity, a major risk factor well documented in the development of diabetes among Indians, may be widespread among American Indians and Alaska Natives (28–30). The IHS outpatient data base contains no data on height or weight. Thus, no data were available to compare

the prevalence of obesity among the different IHS areas. A higher degree of Indian blood quantum has also been associated with increased risk of diabetes (17,31). Again, the IHS data base contained no consistent data to examine this issue. To understand the observed differences in the prevalence of diagnosed diabetes among different American Indian and Alaska Native groups, further studies are needed.

The use of outpatient data bases presents a challenging approach to surveillance of chronic and noncommunicable diseases. They provide a valuable research tool in the development of public health programs at local, regional, or national levels. Although it may not always be possible to get detailed information, reliable estimates of the prevalence of diagnosed diseases and, possibly, estimates of incidence of some diseases can be obtained at a reasonable cost (8,32, 33). These data can provide baseline information describing the magnitude of the problem and characterizing regional variation in disease rates before expensive primary data collection is undertaken (32,33). Ambulatory data bases that have collected data in the same manner over time and have a reasonably stable base population can also be used to measure trends over time, to help plan the distribution of health resources, and to assess the impact of public health programs (8,32,33). Further studies on the use of these data systems are needed.

## References

1. Centers for Disease Control: Chronic disease reports in the Morbidity and Mortality Weekly Report (MMWR). *MMWR* 38 (Suppl. S-1):1–8, 1989
2. Amler RW, Dull HB, Eds.: *Closing the Gap: The Burden of Unnecessary Illness*. New York, Oxford University Press, 1987
3. Gillum RF: Community surveillance for cardiovascular disease—methods, problems, applications—a review. *J Chron Dis* 31:87–94, 1978
4. Kircher T, Nelson J, Burdo H: The au-

- topsy as a measure of accuracy of the death certificate. *N Engl J Med* 313: 1263-69, 1985
5. Gittlesohn A, Senning J: Studies on the reliability of vital and health records. Part I. Comparison of cause of death and hospital record diagnoses. *Am J Public Health* 69:680-89, 1979
  6. Institute of Medicine: *Report of a Study: Reliability of National Hospital Discharge Survey Data*. Washington, DC, National Academy of Sciences, 1980
  7. National Center for Health Statistics: *Multiple Causes of Death in the United States*. Monthly Vital Statistics Report (Suppl. 2, No. 10). Hyattsville, MD, 1984 (DHHS publ. no. PHS 84-120)
  8. Green LA, Calonge BN, Fryer GE, Reed FM: Age/sex registries in primary care research. *Fam Med* 20:185-88, 1988
  9. Christoffel KK, Binns HJ, Stockman JA 3rd, McGuire P, Poncher J, Unti S, Typilin B, Casin G, Siegel W: Practice-based research: opportunities and obstacles. *Pediatrics* 82:399-406, 1988
  10. Iverson DC, Calonge BN, Miller RS, Niebauer LJ, Reed FM: The development and management of a primary care research network, 1978-87. *Fam Med* 20: 177-81, 1988
  11. Williamson HA, Hector MG, LeFevre M, White RD: Establishing a rural family practice research network. *Fam Med* 20: 51-54, 1988
  12. Solberg LI, Mayer TR, Seifert MH, Cole PM: The Minnesota AFP research panel: a model for collaborating family physician research. *Fam Med* 15:139-42, 1983
  13. Nutting PA, Ed: *Community-Oriented Primary Care: From Principle to Practice*. Washington, DC, U.S. Govt. Printing Office, 1987
  14. Nelson EC, Kirk JW, Bise BW, Bernard W, Bise MS, Chapman RJ, Hale FA, Stamps PL, Wasson JH: The cooperative information project. Part 1: A sentinel practice network for service and research in primary care. *J Fam Pract* 13:641-49, 1981
  15. Green LA, Reed FM, Miller RS, Iverson DC: Verification of data reported by practices for a study of spontaneous abortions. *Fam Med* 20:189-91, 1988
  16. Nelson EC, Kirk JW, Bise BW, Chapman RJ, Hale FA, Stamps PL, Wasson JH: The cooperative information project. Part 2. Some initial clinical, quality assurance, and practice management studies. *J Fam Pract* 13:867-76, 1981
  17. Sievers ML, Fisher HR: Diabetes in North American Indians. In *Diabetes in America*. National Diabetes Data Group, Eds. Washington, DC, U.S. Govt. Printing Office, 1985, p. XI 1-20 (DHHS publ. no. NIH 85-1468)
  18. Indian Health Service: *IHS Chart Series Book, April 1988*. Washington, DC, U.S. Govt. Printing Office, 1988 (O-217-547: QL3)
  19. National Diabetes Data Group: Classification and diagnosis of diabetes mellitus and other categories of glucose tolerance. *Diabetes* 28:1039-57, 1979
  20. Department of Commerce, Bureau of the Census: *1980 Census of the Population*. Washington, DC, U.S. Govt. Printing Office, May 1981
  21. Schraer CD, Lanier AP, Boyko EJ, Gohdes DM, Murphy NJ: Prevalence of diabetes mellitus in Alaskan Eskimos, Indians, and Aleuts. *Diabetes Care* 11:693-700, 1988
  22. Carter JC, Horowitz R, Wilson R, Saverio S, Sinnock P, Gohdes DM: Diabetes among American Indians in New Mexico. *Public Health Rep* 104:665-69, 1989
  23. Sugarman J, Percy C: Prevalence of diabetes in a Navajo Indian community. *Am J Public Health* 79:511-13, 1989
  24. Freeman W, Hosey G, Diehr P, Gohdes DM: Diabetes in American Indians of Washington, Oregon, and Idaho. *Diabetes Care* 12:282-88, 1989
  25. National Center for Health Statistics, Drury TF, Powell AL: *Prevalence, Impact, and Demography of Known Diabetes in the United States*. Advance data from Vital and Health Statistics. No. 114. Washington, DC, U.S. Govt. Printing Office, February 1986
  26. National Center for Health Statistics, Hadden WC, Harris MI: *The Prevalence of Diagnosed Diabetes, Undiagnosed Diabetes, and Impaired Glucose Tolerance in Adults 20-74 Years of Age, United States, 1976-1980*. Vital and Health Statistics, Series 11, No. 237. Washington, DC., U.S. Govt. Printing Office, February 1987 (DHHS publ. no. PHS 87-1687)
  27. National Center for Health Statistics, Drury TF: *Health Practices and Perceptions of U.S. Adults with Non-insulin Dependent Diabetes: Data from the 1985 National Health Interview Survey of Health Promotion and Disease Prevention*. Advance data from Vital and Health Statistics. No. 141. Public Health Service, Hyattsville, MD, September 1987
  28. Knowler WC, Pettitt DJ, Savage PJ, Bennett PH: Diabetes incidence in Pima Indians: contributions of obesity and parental diabetes. *Am J Epidemiol* 8:107-13, 1982
  29. Jackson MY: Nutrition in American Indian health: past, present, and future. *J Am Dietetic Assoc* 86:1561-65, 1986
  30. Broussard B, Valway S, Gohdes D: Hypertension and nutrition in American Indians and Alaska Natives. In *Proc. 2nd Annual Nutrition Workshop, Nashville, Tennessee, 1988*. Enwonwou CO, Ed. 1989, p. 87-115.
  31. Lee RT, Anderson PS, Bryan SJ, Bahe C, Coniglione T, Cleves M: Diabetes, parental diabetes, and obesity in Oklahoma Indians. *Diabetes Care* 8:107-13, 1985
  32. Laszlo J: Health registry and clinical database technology: with special emphasis on cancer registries. *J Chron Dis* 38:66-78, 1975
  33. Connell FA: The use of large databases in health care studies. *Ann Rev Public Health* 8:51-74, 1987