

# Establishing Surveillance for Diabetes in American Indian Youth

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**OBJECTIVE** — To determine prevalence estimates in order to monitor diabetes, particularly type 2 diabetes, in American Indian youth.

**RESEARCH DESIGN AND METHODS** — To explore the feasibility of developing a case definition using information from primary care records, all youth aged <20 years with an outpatient visit or hospitalization for diabetes were identified from the Billings Area Indian Health Service database in Montana and Wyoming from 1997 to 1999, and the medical records were reviewed. Classification for probable type 1 diabetes was based on age  $\leq 5$  years, weight per age  $\leq 15$ th percentile at diagnosis, or positive results of islet cell antibody test. Classification for probable type 2 diabetes was based on weight per age  $\geq 85$ th percentile or presence of acanthosis nigricans at diagnosis, elevated C-peptide or insulin, family history for type 2 diabetes, or use of oral hypoglycemic agents with or without insulin or absence of current treatment 1 year after diagnosis.

**RESULTS** — A total of 52 case subjects with diabetes were identified, 3 of whom had diabetes secondary to other conditions. Of the remaining 49 case subjects, 25 (51%) were categorized as having probable type 2 diabetes, 14 (29%) as having probable type 1 diabetes, and 10 (20%) could not be categorized because of missing or negative information. Prevalence estimates for diabetes of all types, type 1 diabetes, and type 2 diabetes were 2.3, 0.6, and 1.1, respectively, per 1,000 youth aged <20 years.

**CONCLUSIONS** — Our definitions may be useful for surveillance in primary care settings until further studies develop feasible case definitions for monitoring trends in diabetes among youth.

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Until recent years, all diabetes in childhood was assumed to be classic immune-mediated diabetes. Although type 2 diabetes was described among Pima Indian children in 1979, only recently has an awareness of type 2 diabetes in Indian and non-Indian youth grown (1–4). An ongoing study in Pima Indians, among whom type 1 diabetes has not been recognized, has shown that the prevalence of type 2 diabetes in youth in-

creased two- to threefold in a 30-year period (5,6). The risk factors for type 2 diabetes in Pima youth have been described and include exposure to maternal diabetes in utero (5,7). Although the emergence of type 2 diabetes among youth from other Indian and non-Indian populations has been described, estimates of the changing incidence and prevalence are lacking (5,8–12).

Although type 2 diabetes has been

recognized as a public health problem for Indian youth, and a surveillance system is needed to monitor trends, no standardized case definition exists (13). Most of the published case series came from pediatric referral centers relying on classifications based on clinical presentation and disease course, and some included testing for islet-cell antibodies and residual insulin secretory capacity (8–21). The recent consensus statement on type 2 diabetes in children proposed a research classification based on these laboratory tests (22). However, using these tests for surveillance may not be practical because they are not widely available or standardized.

In 1999, the Montana Department of Public Health and Human Services and the Billings Area Indian Health Service (IHS) established surveillance for type 2 diabetes in American Indian youth in Montana and Wyoming. Primary care is available at no cost through IHS to all American Indians living on or near the reservations in these states. Our surveillance effort sought to examine the feasibility of using data from medical records of Indian youth who received care for diabetes at these facilities to classify and estimate the prevalence of type 1 and type 2 diabetes.

## RESEARCH DESIGN AND METHODS

All American Indian youth aged <20 years with one or more outpatient visits or hospitalizations coded for diabetes (International Classification of Diseases, 9th revision, Clinical Modification codes 250.0–250.9) as a reason for an outpatient visit or as a diagnosis on hospitalization from 1997–1999 were identified from the IHS database in Montana and Wyoming, and their medical records were reviewed. The study was approved by the Billings Area IHS Institutional Review Board as well as tribal health directors and service unit directors.

Demographic and clinical information was collected, and the diagnosis was confirmed by documentation of diagnostic blood glucose values and/or treatment with antidiabetic therapies. Laboratory information (islet-cell antibody testing,

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**Abbreviations:** IHS, Indian Health Service.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

Table 1—Frequency of documentation and presence or absence of selected characteristics overall and by probable type of diabetes

Documentation at diagnosis or in first year	All	Type of diabetes		
		Type 2	Type 1	Unknown
<i>n</i>	49	25	14	10
Age ≤5 years*	8/40 (1)	0/25 (0)	8/6 (0)	0/9 (1)
Positive islet-cell antibody*	2/11 (36)	0/11 (14)	2/0 (12)	0/0 (10)
Weight/age ≤15th percentile*	4/34 (11)	0/22 (3)	4/5 (5)	0/7 (3)
Weight/age ≥85th percentile†	21/17 (11)	21/1 (3)	0/9 (5)	0/7 (3)
Acanthosis nigricans noted†	6/10 (33)	6/7 (12)	0/3 (11)	0/0 (10)
Elevated C-peptide or insulin†	5/9 (35)	5/5 (15)	0/2 (12)	0/2 (8)
Family history of type 2 diabetes†	12/14 (23)	11/6 (8)	1/5 (8)	0/3 (7)
Oral hypoglycemic agent with or without insulin or no current medication >1 year after diagnosis†	17/31 (1)	16/9 (0)	1/12 (1)	0/10 (0)

Data are *n*: presence/absence (not documented). \*Classification criteria for type 1 diabetes; †classification criteria for type 2 diabetes.

C-peptide, or insulin) was collected through the first year after diagnosis, and fasting C-peptide levels >3.0 ng/ml (normal range 0.5–3.0) and insulin levels >22.0 μU/ml (normal range 0.0–22.0) were considered “elevated.” Additionally, information regarding the course of treatment with insulin and other hypoglycemic agents was collected for the entire period of follow-up, and HbA<sub>1c</sub> values were abstracted from the most recent clinic visit. Weight-per-age percentiles were calculated based on National Health and Nutrition Examination Survey I age and sex population estimates (23). We also reviewed the medical record of each subject’s mother, when available, for evidence of exposure to maternal diabetes during pregnancy.

Based on the data available in the medical records and the current understanding of the types of diabetes in youth, we considered children with diabetes as having probable type 1 diabetes if age was ≤5 years, weight per age was ≤15th percentile at diagnosis, or results of islet-cell antibody test were positive <1 year after diagnosis. We considered children to have probable type 2 diabetes if weight per age at diagnosis was ≥85th percentile, acanthosis nigricans was noted, C-peptide or insulin was elevated within 1 year of diagnosis, there was a family history of type 2 diabetes, oral hypoglycemic agents with or without insulin were used at follow-up >1 year from diagnosis, or there was no current pharmacological treatment 1 year after diagnosis. Prevalence estimates were calculated overall by probable type of diabetes, age, and sex. Characteristics that were not part of the

case definition (e.g., hospitalization and symptoms at diagnosis and most current HbA<sub>1c</sub> value) were also compared with those that were classified as type 1 or type 2 diabetes. No attempt was made to identify maturity-onset diabetes in youth as a distinct type of diabetes in this population.

We used the 1996 IHS user population of youth aged ≤19 years. This well-defined population of Northern Plains Indians included only enrolled American-Indians who lived on or near the reservation and had used the same IHS or tribal facilities at least once in the preceding 3 years (*n* = 22,881). Of these youth, 21% received services from the Blackfeet service unit, 20% from Crow, 19% from Wind River, 17% from Fort Peck, 13% from Northern Cheyenne, and 9% from Fort Belknap. The primary tribal groups living on these reservations include the Arapahoe, Assiniboine, Blackfeet, Crow, Gros Ventre, Northern Cheyenne, Shoshone, and the Yanktonai and Sisseton Wahpeton Sioux (24). The overall 1996 user population is somewhat larger than the 1990 census estimate of American-Indian youth living in counties on or near these reservations (*n* = 17,047) (25).

**RESULTS** — A total of 52 cases of diagnosed diabetes in individuals <20 years of age were confirmed by review of medical records. Three case subjects had diabetes secondary to other conditions, including steroid therapy for asthma (*n* = 1), pancreatic fistula (*n* = 1), and pancreatitis (*n* = 1), and were excluded from further analyses. Among the remaining 49 case subjects, the median age at diagnosis

was 11 years (range 1–19) and the median current age was 15 years (2–19). Just over half of the case subjects were male (51%). The heritage of case subjects was as follows: 8% of the subjects were full American Indian, 42% were one-fourth to three-fourths American Indian, 10% were less than one-fourth American Indian, and 39% were unknown. The mean follow-up after diagnosis for these case subjects was 42 months (range 0–154). The frequency of documentation and the presence or absence of clinical, laboratory, and therapy information for the 49 case subjects are shown in Table 1. Additionally, date of diagnosis was available in 98% of subjects, height was available in 55%, and weight was available in 78%. Prenatal records were available for 27 of the 49 case subjects, and exposure to maternal diabetes during pregnancy was documented in 11% (3 of 27) of these case subjects.

Based on our proposed surveillance classification, 25 case subjects (51%) were categorized as having probable type 2 diabetes, 14 (29%) as having probable type 1 diabetes, and 10 (20%) could not be categorized. Table 1 also shows the frequency of documentation and the presence or absence of selected characteristics by probable type of diabetes. Among case subjects classified as having probable type 2 diabetes, BMI was <85th percentile in 1 subject (5%), acanthosis was not noted in 7 of 13 subjects (54%), 5 of 10 subjects (50%) did not have an elevated C-peptide or insulin levels, and 6 of 17 subjects (35%) did not have a family history of type 2 diabetes. Of the 10 uncategorized case subjects, 7 had a normal weight for

age at diagnosis (3 had no documented information on weight), 2 had “normal” C-peptide and/or insulin levels recorded (8 were not documented), and 3 had no family history of type 2 diabetes (7 had no documentation of family history). All youth exposed to maternal diabetes in utero were classified as having type 2 diabetes.

Case subjects defined as having type 1 diabetes or unknown classification had somewhat higher mean glucose values at diagnosis (540 and 279 mg/dl, respectively; mean 656 mg/dl and SD 160) compared with subjects defined as having type 2 diabetes (mean 362 mg/dl, SD 200). The proportion of case subjects hospitalized at diagnosis (52 vs. 71%) or with ketonuria (50 vs. 78%), ketoacidosis (25 vs. 67%), or weight loss (25 vs. 43%) at diagnosis were higher among case subjects classified as having type 1 diabetes than in those classified as having type 2 diabetes. At follow-up, the mean HbA<sub>1c</sub> values were generally elevated (mean 8.8%, range 4.5–15.0) and were somewhat higher for case subjects classified as having type 1 diabetes (mean 9.6%, SD 2.4) or unknown classification (9.7%, 2.4) than those classified as having type 2 diabetes (8.1%, 2.6).

The prevalence of diabetes (all types, including secondary diabetes) was 2.3 per 1,000 youths aged 0–19 years. The estimated prevalence of probable type 2 diabetes (1.1 per 1,000) was approximately twofold higher than the estimated prevalence of probable type 1 diabetes (0.6 per 1,000). The estimated prevalence of probable type 2 diabetes increased with age, from ~0.3 per 1,000 for those aged 5–9 years to 2.7 per 1,000 for those aged 14–19 years, whereas the estimated prevalence of probable type 1 diabetes remained relatively constant by age category (0.6–0.8 per 1,000 for those aged 0–4 and 14–19 years). Type 2 diabetes was more common among girls than boys (1.5 vs. 0.7 per 1,000), a finding that was not observed among the case subjects classified as having type 1 diabetes (0.4 vs. 0.9 per 1,000).

**CONCLUSIONS**— Our review of available information in medical records at the time of diagnosis and follow-up leads to several implications for the development of a surveillance system for diabetes in youth. It was feasible to classify most case subjects and to estimate the

prevalence of diabetes by type among American Indian youth, based on information available in the primary care setting. However, missing data limited our ability to classify 20% of case subjects.

Our estimated prevalence of type 2 diabetes (1.1 per 1,000 case subjects) was similar to the rates described in First Nations youth in Canada, which ranged from 0.23 to 2.5 per 1,000 case subjects (17–20). Among Pima Indians, who are actively screened for diabetes, the prevalence of type 2 diabetes was much higher: 38 per 1,000 among boys aged 15–19 years and 53 per 1,000 among girls from 1987 to 1996 (5). High rates in Pima Indians are not surprising because the rate of diabetes is higher in the Pima than in the Northern Plains Indians, and screening in the Pima communities likely detects case subjects that would otherwise be undiagnosed (26). The prevalence of diabetes (all types) among youths aged 15–19 years receiving services from all IHS service areas was 4.5 per 1,000 in 1996 (12). As previously reported, we found higher prevalence rates of type 2 diabetes in girls than in boys and in adolescents than in young children (9–11,17–19,21).

As expected, the prevalence of type 1 diabetes in our study (0.6 per 1,000) was lower than the estimate of 1.7 per 1,000 from other non-Indian populations (27). However, no case of type 1 diabetes has been reported in the literature in any child or adolescent known to be of full American Indian heritage, and none of the probable case subjects of type 1 diabetes in our study population were known to be of full American Indian heritage (6).

The level of metabolic control at follow-up was poor both in our study and in others (15,18), regardless of the type of diabetes. Therapies to improve metabolic control must, of course, be tailored to the underlying disease processes in each case. These observations emphasize the need for developing accurate clinical definitions to classify diabetes by type in youth from all populations.

There are a number of limitations to this study. We incorporated elements into the case definitions to maximize the sensitivity for type 2 diabetes. Therefore, we believe that all case subjects classified as having type 1 diabetes very likely had true type 1 diabetes, but some case subjects classified as having type 2 diabetes may have had type 1 diabetes or elements of

both disease processes. We proposed that children who were underweight at the time of diagnosis were likely to have type 1 diabetes because thin children were unlikely to have obesity-related insulin resistance as part of the pathogenesis of their diabetes. Although there are no normal values for C-peptide or insulin for children according to age and sex, we used values above normal cutoffs for adults to indicate that the case subject likely had some degree of insulin resistance. The lack of standardization for children currently limits the widespread use of these parameters, as noted in the American Diabetes Association consensus statement (22). Known risk factors for type 2 diabetes, including obesity, positive family history, and presence of acanthosis nigricans, were also used to classify case subjects (3–4,7,9–11,13–20). The use of oral antidiabetic therapies or the absence of current pharmacological treatment after >1 year of follow-up suggested that the case subject was not strictly insulin dependent. We used an age at diagnosis of ≤5 years to indicate that the case subject was likely to have type 1 diabetes because few children with type 2 diabetes have been reported to be <5 years of age, and studies have shown that young children with diabetes are more likely than older children to have islet-cell antibodies (13,28). However, youth may have elements of multiple disease processes because obesity is increasing among all children in the U.S., including those with type 1 diabetes (29). In addition, recent studies have reported overweight children with both acanthosis nigricans and autoimmune markers (30). It is interesting to note that no child with antibodies documented at the time of diagnosis in this study was overweight, had acanthosis nigricans, or had elevated C-peptide or insulin levels at diagnosis. Finally, diabetic ketoacidosis at diagnosis was not incorporated into the case definition because it does not rule out type 2 diabetes in children (13).

In addition to misclassification, our type-specific estimates of diabetes were obvious underestimates because 20% of case subjects could not be classified. American Indian youth who received services solely from non-IHS providers also would not have been identified. Any such children would not have been included as case subjects or as users unless they had visited the facilities for reasons unrelated



to diabetes. Because supplies and medications are available at no cost, we believe that most American Indian children and adolescents receiving care for diabetes and living in the vicinity of reservations in Montana and Wyoming received at least part of their care through the IHS or tribal health system. Finally, any asymptomatic youth in these communities with undiagnosed diabetes would not have been included in our estimates. Because it is unlikely that case subjects with type 1 diabetes would remain undetected clinically for prolonged periods, this method of ascertaining case subjects provided a very conservative estimate of diabetes rates overall and specifically for type 2 diabetes.

In summary, we have illustrated the challenges of developing surveillance case definitions to differentiate the types of diabetes in youths followed in primary-care settings. Further study is needed to develop and validate feasible surveillance definitions that can be applied widely outside pediatric referral centers. Population-based studies that characterize both residual  $\beta$ -cell function and multiple autoimmune antibodies serially are needed to define the natural history of diabetes and clarify the potential heterogeneity of the disease in youth. Ultimately, however, simple surveillance definitions for type 2 diabetes, such as the preliminary ones presented here, are needed to monitor trends in the prevalence of diabetes over time and to guide public health efforts to control this growing problem, especially for American Indian populations, who bear a high burden from type 2 diabetes.

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