CHAPTER 2

PREVALENCE AND INCIDENCE OF TYPE 1 DIABETES AMONG CHILDREN AND ADULTS IN THE UNITED STATES AND COMPARISON WITH NON-U.S. COUNTRIES

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The findings and conclusions in this chapter are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

SUMMARY

Type 1 diabetes is one of the most common chronic diseases of childhood in the United States, accounting for nearly 98% of all cases of diabetes in children age <10 years and over 87% of all cases in youth age 10–19 years. However, the disease can occur at any age. Type 1 diabetes primarily results from an immune attack to the insulin-producing beta cells of the pancreas, which results in insulin deficiency and high blood glucose concentrations. If left untreated, this disease is fatal. The optimal treatment of type 1 diabetes includes basal and multiple doses of insulin using injections or an insulin pump, frequent checking of blood glucose concentrations, and adjusting insulin doses for carbohydrate intake and physical activity. Individuals with type 1 diabetes are at risk of acute complications (e.g., severe hypoglycemia, diabetic ketoacidosis) and chronic complications, including both macrovascular and microvascular diseases, and may experience a shorter life expectancy than the U.S. general population.

Estimates of the prevalence and incidence of type 1 diabetes in U.S. youth age <20 years in all major U.S. race/ethnicity groups come from the SEARCH for Diabetes in Youth study (SEARCH). SEARCH reported that in the United States, in 2009, an estimated 167,000 youth lived with type 1 diabetes. The overall prevalence (cases/1,000) was 1.93. It was similar in boys and girls and increased with age from 0.82 in children age 0–9 years to 2.97 in youth age 10–19 years.

In 2008–2009, among youth age <20 years, the incidence of type 1 diabetes was 22.0 per 100,000 per year. By applying age-, sex-, and race/ethnicity-specific incidence rates to the U.S. youth population, SEARCH estimated that each year approximately 18,000 new cases of type 1 diabetes occur in youth age <20 years.

Data on the prevalence and incidence of type 1 diabetes in U.S. adults are very limited. Using data collected by the National Health and Nutrition Examination Surveys in 1999–2010, the estimated overall prevalence of type 1 diabetes, defined as being on insulin since diagnosis, current insulin use, and age of onset <30 or <40 years, was 2.6 per 1,000 and 3.4 per 1,000, respectively, corresponding to 740,000 to 970,000 people of the U.S. civilian, noninstitutionalized population. During 1990–2005, among U.S. military personnel age 18–44 years, the overall age-adjusted incidence of insulin-requiring diabetes was 17.5 per 100,000 person-years in men and 13.6 per 100,000 person-years in women.

Diabetes registries in the United States have reported that the incidence of type 1 diabetes in children is increasing. Data from the SEARCH study showed that among non-Hispanic white youth, the incidence (per 100,000 per year) increased from 24.4 in 2002 to 27.4 in 2009, a relative increase of 2.7% per year.

Type 1 diabetes surveillance is crucial for understanding the disease burden at the population level, for identifying subgroups most at risk, for planning health care delivery, and for advancing the understanding of the pathogenesis of the disease both in childhood and adulthood. However, surveillance efforts of type 1 diabetes encounter a number of challenges, including distinguishing types of diabetes both in youth and in adults and the lack of common case definition and ascertainment methodology. Surveillance strategies based on large administrative databases and electronic health records might be useful to fill these gaps. However, the feasibility, accuracy, and costs of these approaches need to be evaluated.

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INTRODUCTION

Type 1 diabetes affected one in every 518 (1.93 per 1,000) youth age <20 years in the United States in 2009 (1). It accounted for nearly 98% of all cases of diabetes in children age <10 years and 87% of all cases in youth age 10–19 years (1). Every year approximately 18,000 new cases of type 1 diabetes occur in U.S. youth (2). Type 1 diabetes is among the most common chronic diseases of childhood (Table 2.1). The most frequent chronic diseases in children and adolescents are asthma and attention deficit/hyperactivity disorder, with prevalences of 95 and 90 per 1,000 (3,4,5), respectively, followed by autism spectrum disorders at age 8 years (15 per 1,000) (6). In 2011, 1.8 per 1,000 children age 10–19 years were ever diagnosed with cancer (7). Moreover, in persons age <20 years, the incidence of all cancers combined is similar or lower than that of type 1 diabetes (17.5/100,000/year vs. 22/100,000/year, respectively) (Table 2.1) (2,8). The frequencies of familial hypercholesterolemia (2 per 1,000) (9) and of Down syndrome (1.45 per 1,000) (10) are also very similar to that of childhood type 1 diabetes.

Because of the young age of onset, individuals with type 1 diabetes are exposed to the diabetes milieu for a longer period and, therefore, are likely to develop diabetic complications during their working age and to have a reduced life expectancy compared to individuals without diabetes (11,12,13,14,15). A diagnosis of diabetes during childhood carries also an economic and social burden. A population-based longitudinal study of school-aged children followed to early adulthood reported that children with diabetes experienced less schooling and, as young adults, lower wages and higher unemployment rate than their counterparts without diabetes (16).

This chapter summarizes epidemiologic data on the burden of type 1 diabetes in childhood and adulthood in the United States and how it compares to that in other countries. To help the reader better understand these prevalence and incidence data, the various case definitions and surveillance systems used for type 1 diabetes are briefly described. Chapter 15 *Diabetes in Youth* also describes the burden of type 1 diabetes in children and adolescents, along with other aspects of diabetes in youth, such as type 2 diabetes, risk factors, and diabetic complications in this age group.

DATA SOURCES AND LIMITATIONS

Because of the lack of population-based data on the incidence and prevalence of type 1 and type 2 diabetes among U.S. youth, the Division of Diabetes Translation of the Centers for Disease Control and Prevention (CDC) and the National Institute of Diabetes and Digestive and Kidney Diseases launched the SEARCH for Diabetes in Youth study (SEARCH) in 2000. SEARCH has established multisite diabetes registries for monitoring the incidence and prevalence of type 1 and type 2 diabetes in youth age <20 years in major U.S. race/ethnicity groups (17). Youth with diabetes are being identified in geographically defined populations in the states of Ohio, Washington, South Carolina, and Colorado, among members of a health management organization in Southern California, and from selected American Indian reservations in Arizona and New Mexico. To assess annual incidence, these sites conduct active surveillance in approximately 5.5 million children age <20 years (~6% of the U.S. population age <20 years). To assess prevalence, approximately 3.4 million children age <20 years were under surveillance in 2001 and in 2009. SEARCH does not conduct national surveillance; however, the population under surveillance at these sites is comparable in terms of age, race/ethnicity, household income, and parental education to the U.S. population (1).

The data on the prevalence and incidence of type 1 diabetes in U.S. adults are sparse. The prevalence estimates in adults reported in this chapter come from data collected by the National Health and Nutrition Examination Surveys (NHANES)

TABLE 2.1. Prevalence and Incidence of Selected Common Chronic Diseases in U.S. Children and Adolescents

STUDY (REF.)	DISEASE	YEARS	AGE (YEARS)	PREVALENCE (CASES/1,000)	INCIDENCE (CASES/100,000/YEAR)
SEARCH (1,2)	Type 1 diabetes	2009	0–19	1.93	
		2008–2009			22.0
NCHS/CDC (3)	Asthma	2008–2010	0–17	95	
BRFSS/ACBS (4)	Asthma	2006–2008	0–17		1,250
NCHS/CDC (5)	Attention deficit/hyperactivity disorder	2007–2009	5–17	90	
ADDM Network (6)	Autism spectrum disorders	2010	8	14.7	
CDC/NCI (7,8)	Childhood cancer	2006–2010	0–19		17.5
		2011	0–9	0.9	
			10–19	1.8	
CDC/NCI (9)	Familial hypercholesterolemia	1973		1–2	
NBDPN (10)	Down syndrome	2004–2006	at birth	1.45	

ACBS, Asthma Call-back Survey; ADDM, Autism and Developmental Disabilities Monitoring; BRFSS, Behavioral Risk Factor Surveillance System; CDC, Centers for Disease Control and Prevention; NBDPN, National Birth Defects Prevention Network; NCHS, National Center for Health Statistics; NCI, National Cancer Institute; SEARCH, SEARCH for Diabetes in Youth Study.

SOURCE: References are listed within the table.

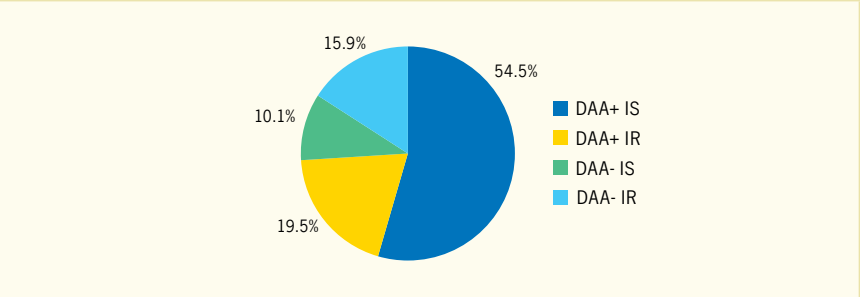
in 1999–2010 (18). Because the NHANES does not collect data on type of diabetes, the identification of participants with type 1 diabetes was based on age of onset and insulin treatment patterns. This approach may have misclassified some cases of type 2 diabetes as type 1 diabetes.

Data on incidence of type 1 diabetes in U.S. adults presented in this chapter derive from a single study conducted among U.S. active duty military personnel age 18–44 years (19). This study used hospitalization and outpatient clinic data from 1990–2005 for identifying newly diagnosed cases of diabetes that required insulin treatment since diagnosis. Because persons with insulin-requiring diabetes are not enrolled in the U.S. military, first encounters of insulin-requiring diabetes were considered incident cases. Some of the insulin-requiring cases were likely due to type 2 diabetes; since type 2 diabetes is so much more common than type 1 diabetes, even a small amount of misclassification of type 2 as type 1 can have a substantial impact on incidence estimates. However, the review of hospital discharges revealed that most of the cases received a clinical diagnosis of type 1 diabetes and were discharged on insulin treatment. Another limitation of this study is that estimates cannot be generalized to the U.S. adult population as the military population is not a probability representative sample of the U.S. population.

HOW IS TYPE 1 DIABETES DEFINED?

Definitions of "type 1 diabetes" may differ based on the goals of a given activity and the information available. Goals may include etiologic study, clinical care, or public health surveillance. In 1997, an expert committee convened by the American Diabetes Association and the National Institutes of Health defined diabetes as a spectrum of metabolic diseases caused by defects in insulin secretion, insulin action, or both (20). Based on this etiologic approach, the majority of diabetes cases cluster into two categories: type 1 diabetes, caused by an absolute deficiency of insulin, usually due to the autoimmune destruction of the beta cells of the pancreas, and type 2 diabetes, resulting from a combination of insulin resistance and beta cell failure. The hallmarks of the underlying pathophysiologic process of type 1 diabetes are the loss of endogenous insulin secretion and presence of autoantibodies against components of the insulin-producing beta cells (also known as diabetes autoantibodies [DAA]). In etiologic research and prevention trials aimed at the preservation of the beta cell function, type 1 diabetes is usually defined on the basis of DAA and fasting or stimulated C-peptide concentrations, measures of endogenous insulin production (21).

FIGURE 2.1. Distribution of Etiologic Categories of Diabetes in Newly Diagnosed Youth Age <20 Years, the SEARCH for Diabetes in Youth Study, U.S., 2002–2006



DAA+: Positive for IA2 or GADA autoantibody.
Insulin Sensitivity (IS) = exp[4.64725-0.02032*(waist, cm)-0.09779*(A1c, %)-0.00235*(Triglycerides, mg/dL)]
Insulin Resistant (IR) = IS index below the 25th percentile (IS <8.15) for 1999–2004 NHANES youth
A1c, glycosylated hemoglobin; DAA, diabetes autoantibodies; GADA, 65-kD isoform of glutamic acid decarboxylase; IA-2, insulinoma-associated-2 antibodies; NHANES, National Health and Nutrition Examination Survey.

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Children and Adolescents

In clinical settings, limited resources may prevent the assessment of the etiologic markers, and classification of type 1 diabetes is commonly based on clinical characteristics, including the age of onset and the need for insulin to control hyperglycemia soon after diagnosis. This approach presents some pitfalls. In adolescents, type 2 diabetes is becoming more common (1), and therefore, onset during adolescence does not necessarily imply the presence of type 1 diabetes. Similarly, although treatment with insulin is a requisite of type 1 diabetes, it is frequently necessary to control hyperglycemia even in youth with type 2 diabetes (22,23). On the other hand, the presence of obesity does not necessarily indicate a diagnosis of type 2 diabetes, as individuals with type 1 diabetes may also be obese as a result of the increased prevalence of obesity in the youth population (24,25). In addition, the concept of absolute insulin deficiency as a requisite of type 1 diabetes has been challenged, as some individuals may retain residual insulin production long after diagnosis (26,27,28). This underscores the complexity in the etiologic classification of type of diabetes and, at the same time, the need for correctly classifying type of diabetes in youth for establishing the most appropriate therapeutic and preventive strategies and for public health surveillance.

To overcome these limitations, SEARCH has used the presence of diabetes autoimmunity and insulin sensitivity as markers of diabetes etiology (29). Autoimmunity was defined as the presence of DAA against the 65-kD isoform of glutamic acid decarboxylase (GADA) and insulinoma-associated-2 autoantibodies (IA-2). The two etiologic measures identify four mutually exclusive groups of individuals: DAA positive and insulin sensitive, DAA positive with insulin resistance, DAA negative and insulin sensitive, and finally, DAA negative and insulin resistant. Among newly diagnosed SEARCH participants, the majority of diabetes cases (55%) were DAA positive and insulin sensitive, while 16% lacked evidence of autoimmunity and were insulin resistant (Figure 2.1). About 20% of the new-onset cases fell into the group with autoimmunity and insulin resistance. Because of the increase in obesity in the youth population (25), this group probably

represents the onset of autoimmune diabetes in obese individuals. Indeed, their human leukocyte antigen (HLA) risk alleles and DAA titers did not differ from those of the group with autoimmunity and insulin sensitivity (29). Finally, about 10% of individuals presented with neither autoimmunity nor insulin resistance. This group probably includes individuals with monogenic diabetes (30) (see Chapter 7 *Monogenic Forms of Diabetes*) or individuals whose autoimmunity had already disappeared or presented with other immune markers than those measured in the SEARCH study. In this last group, further testing may be warranted to define etiology.

While the approach used by SEARCH offers a practical framework for defining type of diabetes in research and clinical settings, it may not be applicable in population-based surveillance, because often these etiologic markers are not routinely measured or easily accessible.

Public health surveillance of type 1 diabetes, historically, has been based on registries, with type 1 diabetes defined as onset during childhood (usually before age 15 years) and requiring insulin treatment soon after diagnosis (31,32,33,34,35,36). Because of the occurrence of type 2 diabetes in adolescence, recent surveillance efforts of childhood diabetes have tried to discriminate between type 1 and type 2 diabetes. In youth age <20 years, SEARCH found that type of diabetes as reported by the health care provider (1,37,38) was in good agreement with the etiologic markers of type 1 or type 2 diabetes (29). For example, among individuals with positive DAA, 99% of the insulin sensitive group and 92% of the insulin resistant group were classified as having type 1 diabetes by their providers. On the other hand, 76% of youth without DAA and insulin resistant were classified as having type 2 diabetes. This suggests that for public health surveillance in youth, type of diabetes as indicated by the health care provider could be reasonably accurate.

Using type of diabetes as indicated by the health care provider as a gold standard and data from electronic health records of a large managed health care organization, SEARCH found that having at least one International Classification of Diseases, Ninth Revision-Clinical Modification (ICD-9-CM) code of type 1 diabetes for an outpatient visit (ICD-9-CM code 250.x1 or 250.x3) correctly identified youth with type 1 diabetes, with sensitivity, specificity, positive predictive value, and negative predictive value of 95%, 93%, 98%, and 84%, respectively (39). Similar findings were reported from a study conducted among 57,767 children age <20 years seen at the multipayer integrated University of North Carolina Health Care System in 2011 (40). This study used billing data, patient problem lists, laboratory test results, and diabetes-related medications to identify diabetes cases and validation by medical chart review. The most accurate algorithm for identifying type 1 diabetes required the ratio of the number of type 1 diabetes billing codes to the sum of the number of type 1 and type 2 billing codes to be ≥0.5, with sensitivity, specificity, and positive predictive value of 96%, 92%, and 98%, respectively. This algorithm performed equally well across race/ethnicity groups (non-Hispanic white vs. "other") and age groups (<10 years vs. ≥10 years), with the exception of specificity in children <10 years of age (83%). In the province of British Columbia, Canada, a classification algorithm of type of diabetes among children using a combination of age of onset and insulin and glucose strips prescriptions, obtained 99% sensitivity, 78% specificity, and 98% positive predictive value for identifying type 1 diabetes (41). While this approach is feasible in single-payer health care systems, its application in settings with fragmented health care delivery systems may be more challenging.

Adults

Although about half of type 1 diabetes cases occur in adulthood (42,43,44), there is a paucity of data on adult-onset type 1 diabetes. One of the reasons for this gap is difficulty in establishing type of diabetes and lack of a standardized case definition in adults. In the study using data from the NHANES 1999–2010, type 1 diabetes was defined as self-reported age at diagnosis <30 or <40 years and initiation and continual use of insulin since diagnosis (18). As indicated above, this approach may misclassify some cases of type 2 diabetes requiring insulin soon after diagnosis as type 1 diabetes and, by definition, miss type 1 diabetes cases with older age of onset.

A study conducted in Massachusetts used electronic health records data from a large, multisite, multispecialty ambulatory practice serving ~700,000 adult patients to distinguish type 1 and type 2 diabetes. An algorithm incorporating laboratory test results, diagnosis codes, and drug and diabetes supply prescriptions obtained for type 1 diabetes a sensitivity of 65% (95% confidence interval [CI] 36%–100%) and a positive predictive value of 88% (95% CI 78%–98%), and for type 2 diabetes, a sensitivity and positive predictive value of 100% (95% CI 99%–100%) and 95% (95% CI 88%–100%), respectively (45). The algorithm-assigned type of diabetes was validated with medical chart review in a small subsample.

In Finland, diabetes surveillance of young adults (age 15–39 years) defined type 1 diabetes as a hospital diagnosis (usually based on clinical characteristics, C-peptide concentrations, and in some of the patients, presence of DAA), permanent eligibility for free-of-charge medications, and continuous insulin treatment from diagnosis (46).

In the Italian region of Piedmont, in individuals age 0–29 years, a diagnosis of type 1 diabetes was based on permanent insulin treatment within 6 months of diagnosis, fasting C-peptide ≤0.20 nmol/L (≤60.06 ng/dL), or presence of DAA (47).

In England in 2011, the Royal College of General Practitioners and the National Health Service Diabetes issued guidelines for identifying type of diabetes in primary care settings (48). They defined type 1 diabetes as age of onset <35 years and continuous use of insulin within 6–12 months after diagnosis or as age of onset ≥35 years and continuous treatment with insulin from diagnosis.

Given this large variability in case definition, surveillance of type 1 diabetes, especially in adults, would greatly benefit from standardized case definition. This would facilitate comparisons of type 1 diabetes incidence and prevalence across populations and geographic areas.

CURRENT SURVEILLANCE SYSTEMS OF TYPE 1 DIABETES

The CDC describes public health surveillance as "the ongoing and systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation, and evaluation of public health practice" (49). Public health surveillance of diabetes and its complications is crucial to track and characterize the burden of the disease, formulate health care policy, identify high-risk groups, develop strategies to reduce the burden of this disease, and monitor progress of primary and secondary prevention programs.

The National Diabetes Surveillance System of the CDC utilizes three active national surveys—the NHANES, Behavioral Risk Factor Surveillance System, and National Health Interview Survey—to monitor diabetes prevalence, incidence, and trends (2). However, none of these three sources of data clearly distinguish between types of diabetes, and thus, there is no national surveillance system for type 1 diabetes. This is, in part, due to the fact that type 1 diabetes is a relatively rare condition, and none of these national surveys has a sample large enough to accurately assess type 1 diabetes prevalence or incidence at the state or national level or in population subgroups.

SEARCH identified prevalent cases of diabetes in 2001 and 2009 and, starting in 2002, all newly diagnosed (incident) cases in subsequent calendar years. Diabetes cases are considered valid if diagnosed by a physician. The identification of prevalent cases occurs through the use of hospital, outpatient clinic, and laboratory databases, as well as direct case reports from health care providers (1,50). Networks of health care providers are the primary source of identification of incident cases (37). Unique, validated diabetes cases are then anonymously registered at the central registry located at the Wake Forest University.

Other regional diabetes registries, including the Allegheny County, Colorado Insulin Dependent Diabetes, Philadelphia, Chicago, and the Wisconsin registries, used hospital records as a primary source for case ascertainment for assessing incidence rates (34,51,52,53).

The Indian Health Service (IHS) provides health services to American Indians and Alaska Natives. Some studies have employed the IHS national outpatient database and/or hospitalization data for diabetes surveillance among American Indians and Alaska Natives age <20 years (54). However, these studies did not distinguish type of diabetes and only measured prevalence.

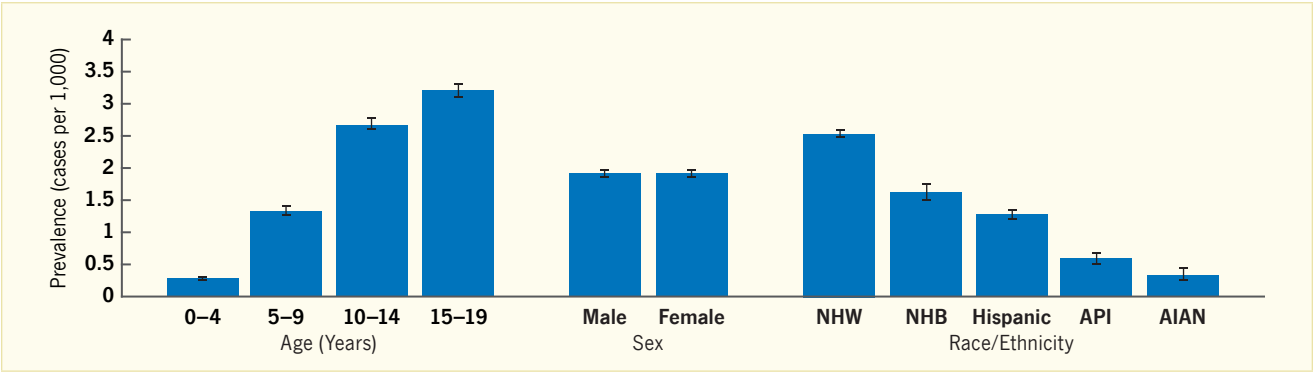
Childhood type 1 diabetes surveillance efforts carried out worldwide, including the World Health Organization DIAbetes MONDiale (DIAMOND) project and the EUROpe and DIABetes (EURODIAB) study (31,32), have estimated type 1 diabetes incidence using networks of diabetes registries and standardized protocols. Together, these two studies included over 65 million children at risk. Some high income countries have established nationwide registries, including Finland (33), Sweden (55), United Kingdom (56), New Zealand (57), and Australia (58).

PREVALENCE IN THE U.S. POPULATION AGE <20 YEARS BY AGE, SEX, AND RACE/ETHNICITY

The most recent estimates of the number of U.S. youth age <20 years with type 1 diabetes come from SEARCH (1). Using standardized methods for case definition, ascertainment, and validation, SEARCH identified and validated cases of physician-diagnosed type 1 diabetes. From an at-risk population of over 3.4 million youth under surveillance in 2009, SEARCH identified 6,666 youth with type 1 diabetes. Capture-recapture analyses estimated that the completeness of ascertainment was at 99.3%. The overall prevalence of type 1 diabetes (cases/1,000) was 1.93 (95% CI 1.88–1.97), was similar in boys and girls, and increased with age from 0.29 in children age 0–4 years to 3.23 in youth age 15–19 years (Figure 2.2). Non-Hispanic white youth had the highest prevalence (2.55/1,000), followed by non-Hispanic black (1.63/1,000), Hispanic (1.29/1,000), Asian or Pacific Islander (0.60/1,000), and American Indian or Alaska Native youth (0.35/1,000) (Figure 2.2). By applying these prevalence rates to the 2009 U.S. resident youth population, SEARCH estimated that there were at least 167,000 youth age <20 years with type 1 diabetes.

SEARCH estimated changes in the prevalence of type 1 diabetes from 2001 to 2009 (38). Based on 4,958 cases in 2001 from a denominator of 3.3 million youth age <20 years and 6,666 cases in 2009 from a denominator of 3.4 million, prevalence (cases/1000) was 1.48 (95% CI 1.44–1.52) in 2001 and 1.93 (95% CI 1.88–1.97) in 2009. From capture-recapture analyses, case ascertainment completeness was estimated to be 92.5% in 2001 and 99.3% in 2009. After adjustment for completeness of ascertainment, prevalences for 2001 and 2009, respectively, were 1.60 (95% CI 1.56–1.65) and 1.94 (95% CI 1.89–1.99), an increase over 8 years of 21%. The prevalence increased in both boys and girls and in all age and race/ethnicity subgroups, except for the two subgroups with the lowest prevalence (children age 0–4 years and American Indians or Alaska Natives) (Figure 2.3). This increase likely reflects a true increase in disease incidence as observed in other U.S. studies (34,52,59).

FIGURE 2.2. Prevalence of Type 1 Diabetes in Youth Age <20 Years, by Age, Sex, Race, and Hispanic Ethnicity, the SEARCH for Diabetes in Youth Study, U.S., 2009



Error bars represent 95% confidence intervals. AIAN, American Indian or Alaska Native; API, Asian or Pacific Islander; NHB, non-Hispanic black; NHW, non-Hispanic white.

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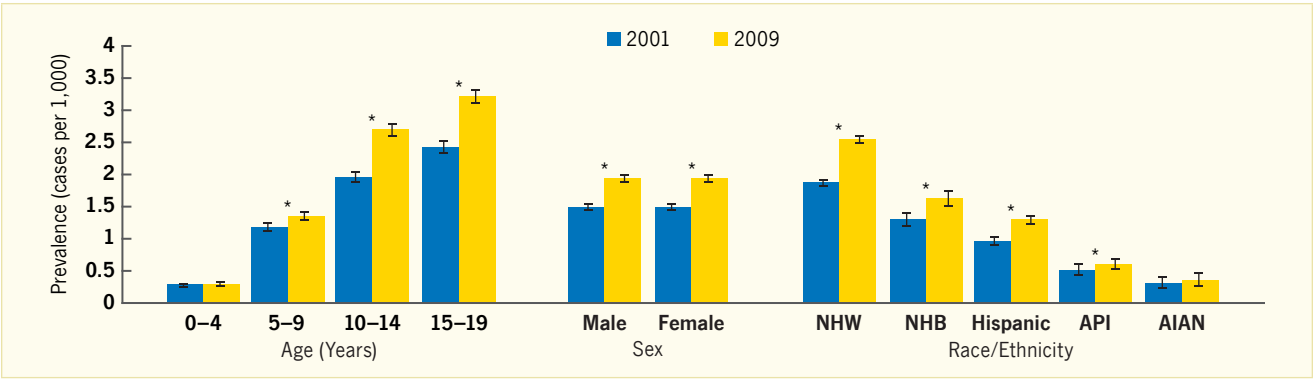
FIGURE 2.3. Prevalence of Type 1 Diabetes, by Age, Sex, and Race/Ethnicity, the SEARCH for Diabetes in Youth Study, U.S., 2001 and 2009



Error bars represent 95% confidence intervals. AIAN, American Indian or Alaska Native; API, Asian or Pacific Islander; NHB, non-Hispanic black; NHW, non-Hispanic white.

* Signifies statistically significant difference in prevalence between 2001 and 2009.

SOURCE: Reference 38

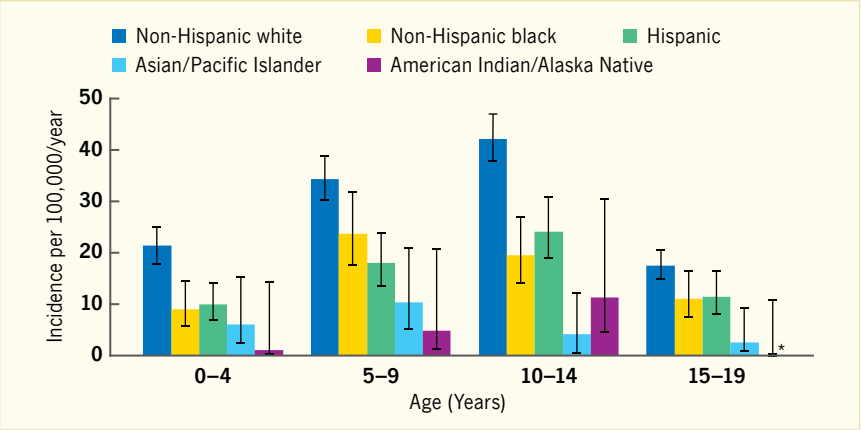
INCIDENCE IN THE U.S. POPULATION AGE <20 YEARS

Worldwide, an estimated 79,100 children age <15 years develop type 1 diabetes annually (60). By applying age-, sex-, and race/ethnicity-specific incidence rates in 2008–2009 to the U.S. youth population, SEARCH estimated that in youth age <20 years, approximately 18,000 new cases of type 1 diabetes occur per year (2). The overall incidence (per 100,000/year) was 22.0 (95% CI 21.1–22.9) and varied with age from 14.6 in children age 0–4 years to 29.6 in those age 5–9 years and 32.0 in adolescents age 10–14 years, and then declined to 12.4 in those age 15–19 years. Across all age groups, the incidence was highest among non-Hispanic whites and lowest among American Indians or Alaska Natives and Asians or Pacific Islanders, except in females age 15–19 years in whom it was similar in non-Hispanic whites, Hispanics, and non-Hispanic blacks (Figures 2.4 and 2.5). In non-Hispanic whites, the incidence peaked at age 5–9 years in females, while in males, it peaked at age 10–14 years. In non-Hispanic blacks and Hispanics, the highest incidence was in girls age 10–14 years, while boys in this age group had significantly lower incidence than girls. Thus, it appears that the traditional pubertal peak in incidence is missing in black and Hispanic boys. Interestingly, a similar sex difference has been seen in blacks in the U.S. Virgin Islands Registry (61).

In the age group 0–19 years, type 1 diabetes accounted for 79% of all new cases of diabetes: 93% for non-Hispanic whites, 67% for Hispanics, 58% for Asian or Pacific Islanders, 52% for non-Hispanic blacks, and 24% for American Indians or Alaska Natives.

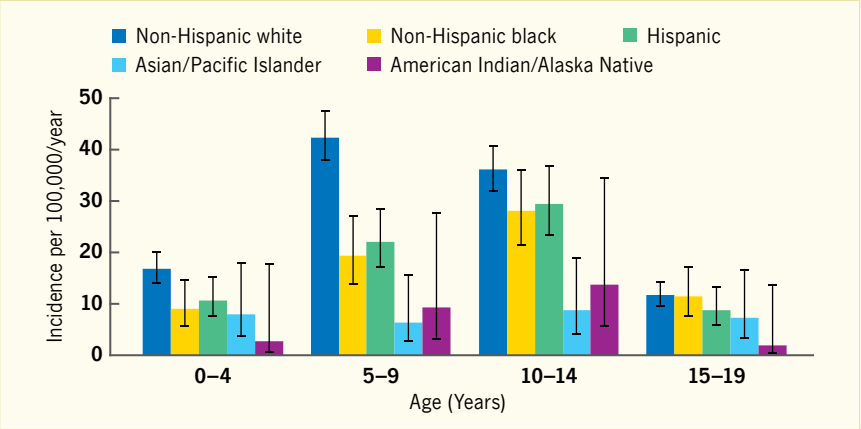
Differences in case ascertainment and completeness of ascertainment, definition of type of diabetes, age and race/ethnicity distribution of the population of children under surveillance, and time period covered, make comparison of SEARCH incidence rates with those of previous U.S. registries challenging. Table 2.2 summarizes incidence rates from type 1 diabetes registries in the United States over time. In non-Hispanic white children age <20 years, the SEARCH incidence rate of 27 per 100,000 per year in 2008–2009 was higher than that of previous U.S. registries (Table 2.2). In non-Hispanic black children age <20 years in 2008–2009, SEARCH detected an incidence rate of 16.2 per 100,000 per year, which was higher than that observed in Chicago for the period 1994–2003 in children age 0–17 years and in the 2000–2004

FIGURE 2.4. Incidence of Type 1 Diabetes in Males Age <20 Years, by Age, Race, and Hispanic Ethnicity, the SEARCH for Diabetes in Youth Study, U.S., 2008–2009



Error bars represent 95% confidence intervals.
* Value for American Indian/Alaska Native is 0.01.
SOURCE: Reference 2

FIGURE 2.5. Incidence of Type 1 Diabetes in Females Age <20 Years, by Age, Race, and Hispanic Ethnicity, the SEARCH for Diabetes in Youth Study, U.S., 2008–2009



Error bars represent 95% confidence intervals.
SOURCE: Reference 2

Philadelphia registry in children age 0–14 years (Table 2.2). Similarly in Hispanic youth, the SEARCH 2008–2009 incidence rate was higher than that reported in 1994–2003 by the Chicago Childhood Diabetes Registry (2,36) but was slightly lower than that reported for 2000–2004 by the Philadelphia registry (34). However, the majority of the Hispanic population in SEARCH is of Mexican American ancestry, while in the Philadelphia registry, Puerto Ricans, who have a higher incidence rate than Mexicans (31), are more represented.

In the U.S. Virgin Islands in 2005, the incidence of type 1 diabetes among non-Hispanic blacks age <15 years was 8.7 per 100,000 per year, but increased almost threefold in 2006 to 26.4 per 100,000 (61). The reasons for this sharp increase are unclear, but a previous "epidemic" was reported in 1984 in the U.S. Virgin Islands (62).

COMPARISON WITH INTERNATIONAL RATES

The DIAMOND project estimated the incidence of type 1 diabetes, defined as onset at age <15 years and treatment with daily insulin injections, between 1990 and 1999 across 112 centers in 57 countries with a population of children under surveillance of 84 million per year. DIAMOND reported a large variation in the age-standardized incidences of type 1 diabetes worldwide ranging from 0.1 per 100,000 per year in parts of China and Venezuela to 40.9 in Finland (31). Among European countries, there was also a wide variation with age-standardized incidences ranging from 40.9 in Finland and 37.8 in Sardinia, Italy, to 7.6 in Krakow, Poland, and 5.9 in Bucharest, Romania. SEARCH incidence in non-Hispanic white children age <15 years for the time period 2002–2005 was similar to that of the European countries and ranked in the middle-high incidence range (63). These findings seem consistent with data from more recent time periods (Table 2.3).

INCIDENCE VARIATIONS BY BIRTH MONTH AND SEASONAL PATTERNS

Studies from some Northern European countries (64,65,66), Ukraine (67), and New Zealand (68) have reported that the incidence of type 1 diabetes is higher among children born in the spring compared to those born in the fall. In the United States, findings from the SEARCH study confirmed this birth-month pattern among approximately 10,000 youth with type 1 diabetes from six U.S. regions. SEARCH reported a lower risk of type 1 diabetes among children born in November to February and higher risk in children born in months around May, with similar patterns in both males and females (69). Interestingly, the birth-month effect was mostly notable for the three SEARCH regions in relatively northern areas, but it was absent for the relatively southern regions. These data suggest that environmental factors operating in the first few months of life in early winter may confer a lower risk of type 1 diabetes, while those present in the early summer may increase that risk, raising possibilities of early exposure to infections and/or allergens. Alternatively, intrauterine exposures may also differ due to different environmental exposures to the mother during the earlier months of pregnancy.

In children age <15 years, findings from the 1990–1999 DIAMOND project also demonstrated a seasonality in the onset of type 1 diabetes, with peaks in October to January and depths in June to August, with opposite patterns in countries of the southern hemisphere (Figure 2.6) (70). This was the largest study on seasonality patterns ever conducted, which included data from 105 centers worldwide and

TABLE 2.2. Incidence of Type 1 Diabetes in Youth, by Race/Ethnicity, U.S.

STUDY/REGION (REF.)	YEARS	AGE (YEARS)	STUDY METHODS	INCIDENCE CASES/100,000/YEAR (95% CI)		
				Overall	Males	Females
Non-Hispanic White						
SEARCH (2)	2008–2009	0–19	Multisite registry	27.6 (26.3–29.0)	28.7 (26.8–30.7)	26.5 (24.6–28.5)
Philadelphia, Pennsylvania (34)	2000–2004	0–14	Citywide registry	19.2 (16.8–21.5)		
Chicago, Illinois (36)	1994–2003	0–17	Citywide registry	15.3 (13.2–17.6)	16.2 (13.4–19.6)	14.3 (11.5–17.7)
Allegheny County, Pennsylvania (35)	1990–1994	0–19	Regional registry	16.5 (14.3–18.8)		
Colorado (52)	1978–1988	0–17	Statewide registry		17.1 (15.8–18.5)	15.0 (13.7–16.3)
	2002–2004				29.4 (24.3–35.6)	26.9 (23.9–30.1)
Jefferson County, Alabama (94)	1979–1988	0–19	County registry	16.8 (14.5–19.2)		
Non-Hispanic Black						
SEARCH (2)	2008–2009	0–19	Multisite registry	16.2 (14.2–18.4)	15.6 (13.0–18.7)	16.8 (14.1–20.1)
Philadelphia, Pennsylvania (34)	2000–2004	0–14	Citywide registry	14.7 (13.1–16.3)		
Chicago, Illinois (36)	1994–2003	0–17	Citywide registry	11.6 (10.5–12.9)	11.0 (9.6–12.6)	12.2 (10.5–14.2)
Allegheny County, Pennsylvania (35)	1990–1994	0–19	Regional registry	17.6 (12.8–23.5)		
U.S. Virgin Islands (61)	2001–2005	0–14	Regional registry	8.1		
	2006–2010			20.4		
Jefferson County, Alabama (94)	1979–1988	0–19	County registry	8.1 (6.3–10.1)		
Hispanic						
SEARCH (2)	2008–2009	0–19	Multisite registry	16.6 (15.0–18.5)	15.7 (13.5–18.3)	17.6 (15.2–20.4)
Philadelphia, Pennsylvania (34)	2000–2004	0–14	Citywide registry	19.6 (14.1–26.7)		
Chicago, Illinois (36)	1994–2003	0–17	Citywide registry	9.1 (7.9–10.4)	8.7 (7.2–10.5)	9.5 (7.9–11.5)
Colorado (52)	1978–1988	0–17	Statewide registry		7.6 (5.8–9.7)	10.6 (8.5–13.1)
	2002–2004				13.5 (10.5–17.2)	12.5 (9.3–16.2)
Puerto Rico (95)	1985–1994	0–14	Island-wide registry	18.0 (17.6–18.3)		

CI, confidence interval.

SOURCE: References are listed within the table.

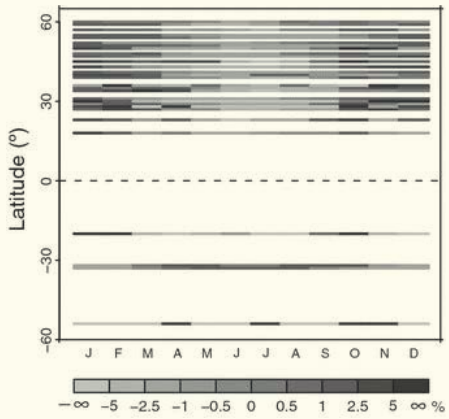
TABLE 2.3. Incidence of Type 1 Diabetes in Non-Hispanic White Youth in the United States and Selected Caucasian Populations

REF.	POPULATION	STUDY/REGION	YEARS	AGE (YEARS)	STUDY METHODS	INCIDENCE CASES/100,000/YEAR (95% CI)		
						Overall	Males	Females
United States								
2	Non-Hispanic white	SEARCH	2008–2009	0–19	Multisite registry	27.6. (26.3–29.0)	28.7. (26.8–30.7)	26.5 (24.6–28.5)
Europe								
14	Finland		2006–2011	0–14	Nationwide registry	62.5 (60.2–64.4)	68.4	55.4
75	Norway		2004–2012	0–14	Nationwide registry	32.7 (32.1–34.0)	33.9	31.4
96	Italy	Sardinia	1989–2009	0–14	Regional registry	44.8 (43.1–46.7)	50.6	38.7
55	Sweden		2005–2007	0–14	Nationwide registry	43.9 (40.7–47.3)	46.7	41.2
71	United Kingdom	Northern Ireland	2004–2008	0–14	Regional registry	33.9		
71	United Kingdom	Yorkshire	2004–2008	0–14	Regional registry	25.5		
71	United Kingdom	Oxford	2004–2008	0–14	Regional registry	25.2		
71	Denmark		2004–2008	0–14	Nationwide registry	25.1		
71	Germany	North Rhine-Westphalia	2004–2008	0–14	Regional registry	23.7		
71	Germany	Saxony	2004–2008	0–14	Regional registry	20.1		
71	Czech Republic		2004–2008	0–14	Nationwide registry	19.3		
71	Luxembourg		2004–2008	0–14	Nationwide registry	19.0		
71	Hungary	18 counties	2004–2008	0–14	Regional registry	18.3		
71	Austria		2004–2008	0–14	Nationwide registry	17.5		
97	Italy		1990–2003	0–14	Multiregional registry	12.3 (11.9–12.6)	13.1	11.4
71	Switzerland		2004–2008	0–14	Nationwide registry	13.1		
71	Spain	Catalonia	2004–2008	0–14	Regional registry	12.1		
71	Croatia	Zagreb	2004–2008	0–14	Regional registry	10.4		
71	Macedonia		2004–2008	0–14	Nationwide registry	5.8		
Other								
58	Australia		2000–2006	0–14	Nationwide registry	21.6 (21.0–22.1)		
72	New Zealand	Auckland	1990–2009	0–14	Regional registry	16.4 (15.3–17.5)		

CI, confidence interval.

SOURCE: References are listed within the table.

FIGURE 2.6. Seasonal Variation of Diagnosis of Type 1 Diabetes in Children Age <15 Years Worldwide, by Latitude, the DIAMOND Project, 1990–1999



The shades of grey reflect the difference between the percentage of annual incident cases estimated to occur in each month and the percentage expected under the completely uniform month distribution, i.e., 100%/12 month=8.33% per month. Darker shades of grey correspond to annual peaks and lighter shades correspond to troughs.

SOURCE: Reference 70, copyright © 2009 John Wiley & Sons, reprinted with permission

a population at risk of 40.5 million with data on 31,091 type 1 diabetes cases. The reasons of these seasonal variations are unknown. The occurrence of acute diseases, usually more frequent in autumn and winter, could accelerate the beta cell failure resulting in hyperglycemia. Future research is needed to understand the underlying etiologic factors responsible for these seasonal patterns.

TEMPORAL TRENDS IN INCIDENCE

In the United States, data from the 1978–1988 Colorado type 1 diabetes registry linked to the 2002–2004 Colorado SEARCH registry have indicated that, in youth age 0–17 years, the overall incidence (per 100,000 per year) increased from 14.8 (95% CI 14.0–15.6) in 1978–1988 to 23.9 (95% CI 22.2–25.6) in 2002–2004 (52). The average annual increase was 2.7% in non-Hispanic whites and 1.6% in Hispanics (Table 2.4). The highest relative increase was observed among children age 0–4 years (3.5% per year, 95% CI 2.1%–4.9%), followed by 2.2% per year (95% CI 1.0%–3.5%) for those age 5–9 years; 1.8% per year (95% CI 1.0%–2.7%) for those age 10–14 years; and 2.1% per year (95% CI 0.5%–3.7%) for those age 15–17 years. Similarly, a hospital-based type 1 diabetes registry in Southeastern Wisconsin reported an increased incidence from 19.1 in 1995 to 41.7 in 2004 and annual increases of 2.4%, 2.3%, 3.0%, and 1.8% per year, respectively, in children ages 0–4, 5–9, 10–14 years, and 15–19 years (53).

Data from SEARCH showed that among non-Hispanic white youth, the age- and sex-adjusted incidence (per 100,000 per year) of type 1 diabetes increased from 24.4 (95% CI 23.9–24.8) in 2002 to 27.4 (95% CI 26.9–27.9) in 2009, a relative increase of 2.7% per year (Figure 2.7) (59). Significant increases were observed among 5–9-year-olds ($p<0.05$), 10–14-year-olds ($p<0.001$), and 15–19-year-olds ($p<0.05$), but not among 0–4-year-olds. Over a 20-year period from 1985–2004, the Philadelphia Pediatric Diabetes Registry reported an average yearly increase of 1.5%. However, in time trend analysis stratified by race, a significant linear increase in incidence was observed only in non-Hispanic black children (2.3% per year over the entire time period) (Table 2.4), while among non-Hispanic white and Hispanic youth, incidence rates were stable from 1985–1989 to 1995–1999, and increased only between the last two time periods from 1995–1999 to 2000–2004 (by 48% in whites and 27% in Hispanics) (34).

During 1990–1999, the DIAMOND project detected a worldwide increase in the incidence of type 1 diabetes, with an average annual increase of 2.8% (31). The greatest relative increase was observed in the 0–4-years age group (4.0% per year) followed by the 5–9-years age group (3.0%), with the lowest in the 10–14-years age group (2.1%). (DIAMOND collects data only in those age <15 years.) This pattern was primarily seen in European populations.

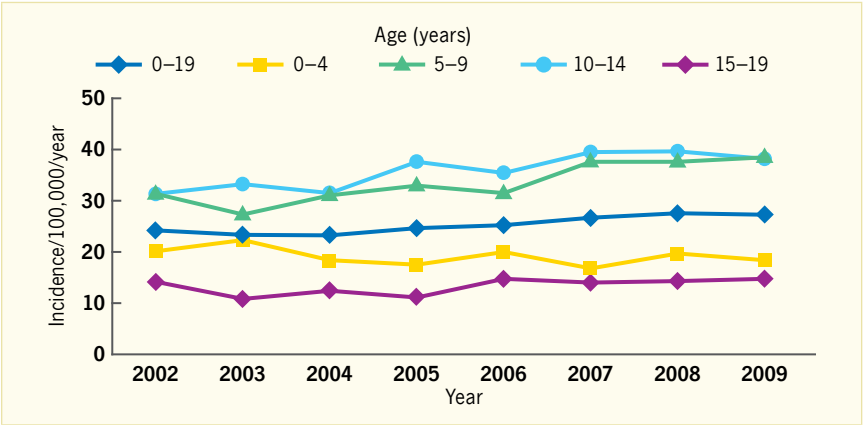
TABLE 2.4. Temporal Trends in Type 1 Diabetes Incidence in U.S. Youth

STUDY/REGION (REF.)	YEARS	AGE (YEARS)	RACE/ETHNICITY	RELATIVE INCREASE PER YEAR (95% CI)
SEARCH (59)	2002–2009	0–19 0–14	Non-Hispanic white Non-Hispanic white	2.7% (1.2%–4.3%) 2.7% (1.1%–4.4%)
Colorado (52)	1978–2004	0–17	Non-Hispanic white Hispanic	2.7% (1.9%–3.6%) 1.6% (0.2%–3.1%)
Philadelphia, Pennsylvania (34)	1985–2004	0–14	Non-Hispanic white Non-Hispanic black Hispanic	No significant linear increase 2.3% No significant linear increase
Chicago, Illinois (36)	1994–2003	0–17	Non-Hispanic white Non-Hispanic black Hispanic	0.47% -1.01% 4.73%
Southeastern Wisconsin (53)	1995–2004	0–19	80% Caucasian	2.39%
United States (31)	1990–1999	0–14	Multiracial	5.5% (3.0%–8.0%)

CI, confidence interval.

SOURCE: References are listed within the table.

FIGURE 2.7. Trends in the Incidence of Type 1 Diabetes in Non-Hispanic White Youth Age <20 Years, Overall and by 5-Year Age Groups, the SEARCH for Diabetes in Youth Study, U.S., 2002–2009



Overall yearly relative increase: 2.7% (95% confidence interval 1.18–4.28, p<0.01), adjusted for sex and age. Sex-adjusted age group p-values <0.05 for all age groups, except 0–4 years.

SOURCE: Reference 59, copyright © 2014 American Diabetes Association, reprinted with permission from the American Diabetes Association

The findings of DIAMOND have been confirmed worldwide by more recent data from population-based registries. The EURODIAB study, a registry of type 1 diabetes with onset at age <15 years in 17 European countries, detected a 3.4% increase per year in 1989–1998 and 3.3% per year in 1999–2008, with increases of 5.4% for children age 0–4 years, 4.3% for those age 5–9 years, and 2.9% for adolescents age 10–14 years (71).

In the Auckland region of New Zealand, in 1990–2009, type 1 diabetes incidence in children age <15 years was 16.4/100,000. Over this time period there was a steady increase in incidence from 10.9 per 100,000 in 1990 to 22.5 per 100,000 in 2009 (72). In contrast to the trends reported in Europe and in Colorado, the greatest increase was among children age 10–14 years (average yearly increase 0.81%) and lowest among children age 0–4 years (0.32% per year). A greater increase of 3.8% per year has been reported in Australia from 2001 to 2008 among adolescents age 10–18 years (73).

Data from Scandinavian countries, where the incidence of type 1 diabetes is highest, indicate that the rise in incidence may be slowing. The Swedish Childhood Diabetes Registry reported 30-year trends in the incidence of type 1 diabetes from 1978 to 2007 in children age <15 years (55). The incidence (per 100,000 per year) increased from 21.6 during 1978–1980 to 43.9 during 2005–2007. Interestingly, in the 2000–2006 birth cohorts, they observed a declining cumulative incidence and a drop in the incidence rate for children age 0–4 years, from a peak of 28.7 per 100,000 in 2002–2004 to 25.2 per 100,000 in 2005–2007. In Finland, among children age 0–14 years, the incidence increased by 3.6% per year from 1980 to 2005 but leveled off from 2005 to 2011 (74). Similarly, in Norway, the incidence increased yearly by 1.8% in 1989–1996 and by 3.4% in 1996–2004 but remained stable during 2004–2012 (75).

These data suggest that the environmental factors leading to type 1 diabetes may be changing and highlight the need for continuous population-based surveillance of childhood diabetes.

PROJECTIONS BY RACE/ETHNICITY

Using a Markov modeling framework, the SEARCH study has estimated the future burden of type 1 diabetes in U.S. youth of major race/ethnicity groups for the period 2010–2050 (76). Two scenarios were considered for type 1 diabetes incidence trends: (1) constant incidence over time at the 2002 rate, as estimated from the SEARCH data; (2) yearly percentage increases of 3.5%, 2.2%, 1.8%, and 2.1% in the age groups 0–4 years, 5–9 years, 10–14 years, and 15–19 years, respectively, as detected by the study in Colorado (52). The model projected that, over the 40-year period, if the incidence remained stable at the 2002 rate, the number of youth with prevalent type 1 diabetes would rise from approximately 166,000 to 203,000, respectively, in 2010 and 2050, an increase of 23%. Under the scenario of increased incidence over time, the number of youth with type 1 diabetes would nearly triple from approximately 179,000 in 2010 to 587,000 in 2050. The prevalence would increase from 2.13 per 1,000 in 2010 to 5.20 per 1,000 in 2050, an increase of +144%. Because the proportion of youth of racial/ethnic minorities was projected to increase in the overall U.S. youth population (77), the increase in the number of youth with type 1 diabetes would be primarily driven by youth of minority race/ethnicity groups.

PREVALENCE AND INCIDENCE OF TYPE 1 DIABETES IN U.S. ADULTS AGE ≥20 YEARS

About half of type 1 diabetes cases occur in adult life (42,44,78,79); however, epidemiologic data on adult-onset type 1 diabetes are very scarce. This is due to a number of factors, including difficulty in distinguishing types of diabetes, fragmented and multiple sources of health care delivery, and increased mobility, making case ascertainment more challenging. Because national surveys do not collect information on type of diabetes nor do they measure type 1 diabetes immune biomarkers, the identification of type 1 diabetes cases in these data sets is usually based on treatment patterns and age at diagnosis.

PREVALENCE

A study estimated the prevalence of type 1 diabetes using data from the NHANES 1999–2010 (18). Type 1 diabetes was defined using two different sets of criteria based on age at diagnosis and insulin use patterns: (1) diagnosed with diabetes at age <30 years, starting insulin within one

year of diabetes diagnosis, and current use of insulin; (2) same as definition 1 except diagnosed with diabetes at age <40 years. Among 59,130 NHANES participants, 123 individuals met the definition 1 criteria and 160 the definition 2 criteria. The overall prevalence (cases/1,000) ranged from 2.6 for definition 1 to 3.4 for definition 2, corresponding to about 740,000 (95% CI 540,000–930,000) and 970,000 (95% CI 740,000–1,190,000) people of the civilian, noninstitutionalized U.S. population (Table 2.5), respectively. Under both definitions, the prevalence increased in young and middle-aged adults and then declined in people age ≥60 years. The prevalence was slightly higher in men than in women (3.0 and 4.0 vs. 2.2 and 2.8, for definitions 1 and 2, respectively), but these differences were not statistically significant. Non-Hispanic whites had significantly higher prevalence than did Hispanics, and their prevalence was similar to that of non-Hispanic blacks. Based on these two definitions, it was estimated that type 1 diabetes represents 4.6% and 6.0% of all diagnosed diabetes cases, respectively.

TABLE 2.5. Prevalence of Type 1 Diabetes, by Age, Sex, and Race/Ethnicity, National Health and Nutrition Examination Surveys, U.S., 1999–2010

CHARACTERISTICS	PERCENT (95% CI)	
	Definition 1*	Definition 2†
Overall‡	0.26 (0.20–0.33)	0.34 (0.27–0.43)
Current age (years)‡		
0–19	0.24 (0.17–0.33)	0.24 (0.17–0.33)
20–39	0.34 (0.22–0.49)	0.42 (0.30–0.57)§
40–59	0.31 (0.16–0.55)	0.49 (0.30–0.75)§
≥60	0.08 (0.02–0.18)§	0.12 (0.05–0.23)§
Sex‡		
Male	0.30 (0.21–0.42)	0.40 (0.29–0.54)
Female	0.22 (0.14–0.32)	0.28 (0.19–0.39)
Race/ethnicity		
Non-Hispanic white	0.30 (0.21–0.42)	0.37 (0.27–0.49)
Non-Hispanic black	0.29 (0.19–0.44)	0.47 (0.32–0.66)
All Hispanic	0.12 (0.06–0.23)‖	0.23 (0.12–0.38)‖
Mexican American¶	0.11 (0.05–0.19)‖	0.18 (0.11–0.27)‖

CI, confidence interval.
* Definition 1: Diagnosis of diabetes before age 30 years, now taking insulin, started taking insulin within one year of diagnosis.
† Definition 2: Diagnosis of diabetes before age 40 years, now taking insulin, started taking insulin within one year of diagnosis.
‡ All participants, including those who self-reported other races, were included.
§ p<0.05 compared to 0–19 years
‖ p<0.05 compared to non-Hispanic white
¶ Insufficient numbers of individuals in other Hispanic groups were available.
SOURCE: Reference 18, copyright © 2013 Wolters Kluwer Health, reprinted with permission

INCIDENCE

There is a paucity of data on the incidence of type 1 diabetes in adults, and differences in case definition and time of ascertainment across studies make comparisons difficult. Table 2.6 summarizes estimates of type 1 diabetes incidence in adults. The majority of data come from European registries. One study conducted among U.S. military personnel assessed the incidence of insulin-requiring diabetes during 1990–2005 in active duty military personnel age 18–44 years (19). The overall age-adjusted incidence of insulin-requiring diabetes was 17.5 per 100,000 person-years in men and 13.6 per 100,000 person-years in women (Table 2.6). In men, the incidence was twice as high in blacks as in whites (31.5 vs. 14.5 per 100,000). A similar pattern was observed in women (21.8 vs. 9.7 per 100,000, respectively, in black and white women). It is possible that the lifetime risk of developing type 1 diabetes is similar for blacks and whites, with blacks more likely to be diagnosed at older ages. Applying these estimates to the U.S. population age 20–44 years, an estimated 16,000 new cases of type 1 diabetes occur each year in this age group.

Diabetes registries in nine European countries in 1996–1997 reported that in young adults age 15–29 years, the incidence varied from 4.8 per 100,000 person years in Slovakia to 13.4 per 100,000 person years in Leicestershire, England (80). In this age group, type 1 diabetes represented 61% of all new diabetes cases. In the oldest age group, 25–29 years, there was an excess risk for men. In Finland, data from 1992–2001 showed that in the population age 15–39 years the overall age-adjusted incidence of type 1 diabetes was 18.0 per 100,000 per year (95% CI 17.4–18.6) (46). These data also confirmed a higher risk among men, with a men:women incidence ratio of 1.7. In the province of Turin, Italy, in the period 1999–2001, the incidence rate of type 1 diabetes among persons age 30–49 years was 7.3 per 100,000 person-years (95% CI 6.2–8.6) (81). Similar to the findings of other European registries, the incidence was higher in men (9.2/100,000, 95% CI 7.5–11.3) than in women (5.4/100,000, 95% CI 4.1–7.1). The proportion of all new diabetes cases due to type 1 diabetes decreased with age, from 30% in the age group 30–34 years to 8% in the age group 45–49 years. A diabetes registry of the county of Kronoberg in Southeastern Sweden assessed the incidence in children age 0–19 years from 1998 to 2001, as well as in adults (age 20–100 years), and defined type 1 diabetes on the basis of the presence of DAA and/or C-peptide concentrations (44). In adults age 40–100 years, the incidence did not differ by sex, but it was as high as that in children (34.0 and 37.8/100,000/year, respectively). Lower incidence was observed in the 20–29-year-olds (19.7/100,000/year) and 30–39-year-olds (11.7/100,000/year). This two-peak pattern was also observed in Rochester, Minnesota, in 1960–1969 (82).

Findings on temporal trends in type 1 diabetes incidence in the adult population have been inconclusive (Table 2.6). Diabetes registries in Finland between 1992 and 2001 (46), Italy from 1984 to 2004 (47), and the United Kingdom from 1991 to 2008 (83) have indicated an increase in incidence. In contrast, in Sweden between 1983 and 2007, the incidence of type 1 diabetes

TABLE 2.6. Incidence of Type 1 Diabetes in Adults in the United States and Selected European Countries

COUNTRY/REGION (REF.)	YEARS	AGE (YEARS)	STUDY METHODS	INCIDENCE CASES/100,000/ YEAR (95% CI)	MEN:WOMEN RATIO	RELATIVE INCREASE PER YEAR (95% CI)*
United States, active duty military service members (19)	1990–2005	18–44	Inpatient, outpatient health records	M: 17.5 (16.4–18.8) W: 13.6 (12.4–14.9)	1.3	
Sweden (44,85)	2011	20–24	Nationwide prescription drug registry	15.6 (12.5–18.6)		
		25–29		15.5 (12.3–18.6)		
		30–34		8.7 (6.3–11.1)		
	1998–2001	40–100	Kronoberg County registry	34.0 (32.8–35.2)	1.0	
Finland (46)	1992–2001	15–39	Nationwide registry	18.0 (17.4–18.6)	1.7	3.9% (2.7%–5.3%)
Italy, Turin (47,81)	1984–2004	15–29	Diabetes registry	M: 8.2 (7.1–9.1) W: 5.9 (5.2–6.6)	1.4	2.8% (1.0%–4.6%)
	1999–2001	30–49		M: 9.2 (7.5–11.3) W: 5.4 (4.1–7.1)	1.7	
Lithuania (98)	1991–2008	15–34	Diabetes registry	M: 10.4 (9.8–11.1) W: 6.1 (5.6–6.6)	1.7	
United Kingdom (83)	1991–2008	15–34	General Practice Research Database	M: 20 (15.5–24.4) W: 10 (6.9–13.2)	2.0	2.8% (1.6%–3.9%)
Belgium, Antwerp (99)	1989–2003	15–39	Diabetes registry	9.0 (8.1–9.9)	1.6	-1.9% (-4.1%–0.2%)
Italy, Sardinia (80)	1996–1997	20–24	Diabetes registry	M: 15.6 (11.8–23.2) W: 9.1 (4.8–15.6)	1.7	
		25–29		M: 14.7 (9.1–22.6) W: 3.6 (1.1–8.4)	4.1	
Romania, Bucharest (80)	1996–1997	20–24	Diabetes registry	M: 5.7 (2.7–10.6) W: 4.4 (1.8–8.6)	1.3	
		25–29		M: 12.6 (7.1–18.6) W: 6.4 (3.5–10.8)	2.0	
Spain, Catalonia (80)	1996–1997	20–24	Diabetes registry	M: 14.7 (11.5–18.3) W: 8.8 (6.1–11.3)	1.7	
		25–29		M: 13.0 (10.1–16.7) W: 7.8 (5.5–10.7)	1.7	
Slovakia (80)	1996–1997	20–24	Diabetes registry	M: 5.9 (3.8–8.6) W: 3.3 (1.8–5.4)	1.8	
		25–29		M: 5.0 (3.0–7.8) W: 1.9 (0.8–4.0)	2.6	

CI, confidence interval; M, men; W, women.
* Data are only reported when available.

SOURCE: References are listed within the table.

increased in children age <15 years, but decreased significantly in young adults age 25–34 (84). This finding was, however, probably due to a very low ascertainment rate in the older age group (85). Long-term population-based surveillance efforts of children and young adults are necessary to establish whether the cumulative incidence of type 1 diabetes is increasing or the observed increase in children is due to a shift to a younger age of onset. The answer to this question will enhance the comprehension of potential environmental exposures involved in the etiology of the disease.

FUTURE FOR SURVEILLANCE OF TYPE 1 DIABETES

There are several potential approaches for type 1 diabetes surveillance in childhood and in adulthood. Systems in which the denominator (i.e., the population under surveillance) is based on geography have the advantage of population representativeness. However, disadvantages from an implementation standpoint include fragmented health care, multiple health care providers and locations, and the requirement for access to multiple care systems for a complete case ascertainment. Registries based on health maintenance organization enrollment have the potential to achieve the surveillance goals of ascertaining registration, follow-up, clinical course, costs, and health care utilization (86); however, they rely on long-term enrollment and suffer from some degree of bias owing to potential changes in enrollment over time and comprising relatively homogenous populations. Nonetheless, they are useful resources for certain surveillance purposes because such plans have large memberships and collect substantial clinical and follow-up data routinely as part of medical care.

In addition, it would be helpful if major national surveys agree, validate, and adopt a common set of questions that could facilitate the identification of the subgroup with overt type 1 diabetes. This would enable a more comprehensive estimate of type 1 diabetes prevalence in the United States than currently possible.

One emerging approach for diabetes surveillance at the population level is the use of health information technology (HIT). The U.S. Health Information Technology for Economic and Clinical Health Act (HITECH Act) of 2009 defined HIT as "hardware, software, integrated technologies or related licenses, intellectual property, upgrades, or packaged solutions sold as services that are designed for or support the use by health care entities or patients for the electronic creation, maintenance, access, or exchange of health information." HIT-based surveillance systems could provide relatively low-cost, efficient, and timely disease surveillance from large and diverse populations. In addition to assessing diabetes prevalence, incidence, and temporal trends, HIT could provide a valid tool for estimating the prevalence and incidence of diabetes complications and mortality, assess quality of care, and also monitor the effect of interventions.

Various kinds of diabetes algorithms and "decision trees" have been developed from administrative data and electronic health record data (39,40,41,45,87,88,89,90). Some of them perform quite well in identifying diabetes cases and differentiating type of diabetes. Also, the adoption and increasing popularity of electronic health records will largely facilitate diabetes surveillance efforts (91,92,93), because they can provide rich clinical information by linking multiple data sources, such as laboratory data and medication records. The transition from paper-based records to electronic health records could dramatically enhance and improve public health surveillance capacity. However, automated algorithms for the identification of diabetes cases by type in children and in adults need to be developed, evaluated, and compared in terms of sensitivity, specificity, and predictive values both within and between health care settings (40,87). With the help of technology and dedication of public health professionals, optimal strategies could be found to inform and even establish a national sustainable surveillance system of type 1 diabetes both in children and adults.

CONCLUSIONS AND FUTURE DIRECTIONS

Clearly, type 1 diabetes, a major disease in terms of the impact on individual and community health, has an increasing prevalence and incidence in the United States. A number of gaps exist in understanding its burden and trends in the U.S. population. First, the lack of standardized common case definitions does not allow comparisons of prevalence and incidence rates across health care systems, population subgroups, and time periods. The adoption of a common set of questions based on the initiation of continuous insulin treatment and age to be used in all national surveys could provide at least a basic, likely minimal, estimate of national prevalence.

Second, it is of great interest to further investigate the higher risk of type 1 diabetes after puberty among males, as well as the apparent absence of a pubertal peak in incidence in non-Hispanic black and Hispanic boys and the documented earlier peak in non-Hispanic white girls. Such studies may provide new insights into the etiopathogenesis of type 1 diabetes with pubertal or adult onset. The finding of a lower incidence of type 1 diabetes in blacks compared to whites at young ages and the higher incidence of insulin-requiring diabetes in black compared to white adults also need to be confirmed and further evaluated, including the question of whether or not lifetime risk differs. Lastly, monitoring on a regular basis the prevalence and incidence of type 1 diabetes both in youth and in adults would facilitate health care delivery planning and the evaluation of secondary prevention efforts. These efforts would benefit from simplified methods to distinguish people with type 1 diabetes from those with type 2 diabetes, especially in adults.

The development and validation of HIT-based relatively low-cost sustainable diabetes surveillance systems could also allow the assessment of the prevalence and incidence of diabetes by age, sex, race/ethnicity, geographic region, and type of diabetes among the U.S. youth and adult populations. Finally, the evaluation of the surveillance systems should include the ability and accuracy of detecting incident cases, characterizing the population under surveillance, and assessing characteristics of the surveillance system including, but not limited to, flexibility, timeliness, and sustainability.

LIST OF ABBREVIATIONS

CDC . . . . . .Centers for Disease Control and Prevention
CI . . . . . .confidence interval
DAA . . . . . .diabetes autoantibodies
DIAMOND . . . .DIAbetes MONDiale project
EURODIAB . . .EUROpe and DIABetes study
HIT. . . . . .health information technology
IHS. . . . . .Indian Health Service
NHANES . . . . .National Health and Nutrition Examination Survey
SEARCH . . . . .SEARCH for Diabetes in Youth study

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DUALITY OF INTEREST

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