



# Prevalence of Diabetes in U.S. Youth in 2009: The SEARCH for Diabetes in Youth Study

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## OBJECTIVE

To estimate the prevalence of diabetes in U.S. youth aged <20 years in 2009 and to estimate the total number of youth with diabetes in the U.S. by age, race/ethnicity, and diabetes type.

## RESEARCH DESIGN AND METHODS

To address one of its primary aims, the SEARCH for Diabetes in Youth Study identified youth aged <20 years on 31 December 2009 with physician-diagnosed diabetes in selected areas of Colorado, Ohio, South Carolina, and Washington, among health plan members of Kaiser Permanente Southern California and among American Indians living on reservations in Arizona and New Mexico. Diabetes was classified as type 1, type 2, or other. Race/ethnicity was by self-report.

## RESULTS

From a population of 3,458,974 youth aged <20 years, 7,695 youth with diabetes were identified (2.22/1,000): 6,668 with type 1 diabetes (1.93/1,000), 837 with type 2 diabetes (0.24/1,000), and 190 (0.05/1,000) with other diabetes types. Prevalence increased with age, was slightly higher in females than males, and was most prevalent in non-Hispanic White and least prevalent in Asian/Pacific Islanders, with Native American and black youth having the highest prevalence of type 2 diabetes. An estimated 191,986 U.S. youth aged <20 years have diabetes; 166,984 type 1 diabetes, 20,262 type 2 diabetes, and 4,740 other types.

## CONCLUSIONS

Diabetes, one of the leading chronic diseases in childhood, affects >190,000 (1 of 433) youth aged <20 years in the U.S., with racial and ethnic disparities seen in diabetes prevalence, overall and by diabetes type.

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Diabetes is the third most common chronic disease of childhood (1), and its incidence has been increasing worldwide (2,3). Diabetes in children and adolescents is a set of complex disorders with heterogeneity in etiology, pathogenesis, clinical presentation, and outcomes. Type 1 diabetes is caused by immune-mediated  $\beta$ -cell destruction, leading to insulin deficiency and a lifelong insulin requirement, while type 2 diabetes is characterized by insulin resistance in skeletal muscle, liver, and

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adipose tissues with a failure of  $\beta$ -cell compensation and a relative insulin deficiency (4). The occurrence of type 2 diabetes in youth has been documented in several studies over the past decade (5–7) and is thought to be secondary to coincident increases in obesity in the general population. In addition, there are multiple less common types of diabetes in youth such as monogenic forms, including maturity-onset diabetes in the young, neonatal diabetes, and other known genetic disorders (8,9).

There are few recent studies of the prevalence of diabetes in youth in the U.S. by diabetes type. Most of the prior registries active in the U.S. were initially focused on type 1 diabetes (10,11) and have only recently begun to include type 2 diabetes (12,13). The SEARCH for Diabetes in Youth Study (SEARCH), with centers located in multiple states across the U.S. (14), was developed to assess the prevalence and incidence of diabetes in youth, overall and by type. Surveillance of youth with diabetes began in 2001 and is ongoing for incident case ascertainment, while prevalence surveillance was conducted for calendar years 2001, which was published previously (15), and 2009. The purposes of this article are to report the prevalence of diabetes in 2009, overall and by diabetes type, age, sex, and race/ethnicity, and to apply these estimates to U.S. census data for youth aged <20 years to estimate the total burden (absolute number) of youth with diabetes in the U.S. in 2009.

## RESEARCH DESIGN AND METHODS

A detailed description of SEARCH was published previously (14). Physician-diagnosed diabetes was identified in five SEARCH sites in California, Colorado, Ohio, South Carolina, and Washington. Four of these sites were geographically based; Colorado (14 counties), Ohio (8 counties), South Carolina (4 counties), and Washington (5 counties). The California site comprised health plan enrollees in Kaiser Permanente Southern California (KPSC; seven counties). Coordinated by the Colorado site, SEARCH also collected data from American Indians on selected reservations in Arizona and New

Mexico. All centers had active surveillance by endocrinologists (pediatric and adult), other health care providers, hospitals, community health centers, health plan databases, and previously established diabetes databases. The Indian Health Service (IHS) beneficiary roll was used to identify the reservation-based American Indian youth. Two-source capture-recapture in the geographically based centers was used to estimate the completeness of case identification (16,17). Capture-recapture was not conducted for the membership-based center because the data sources used to ascertain case subjects within the membership-based center were not independent.

SEARCH study participants or their parent/guardian completed a survey that recorded age, date of diagnosis, sex, self-reported race/ethnicity, and place of residence. The study was reviewed and approved by the institutional review board(s) at each center and complied with the privacy rules established by the Health Insurance Portability and Accountability Act. Because this registry attempts to identify 100% of case subjects, case subject identification was conducted with an approved Health Insurance Portability and Accountability Act consent waiver in most study locations.

Sources of case reports included physician reports, medical record review, or self-report. Case subjects were considered valid if the medical record indicated a physician diagnosis, the diagnosis was verified directly by a physician, the participant was referred directly from a physician, or the case was included in a diabetes database that had required physician verification, while eligibility was based on age and area of residence. Clinical diabetes type was determined by the physician and categorized by the study as type 1 diabetes (type 1, type 1a, or type 1b), type 2 diabetes, or other diabetes (including other, hybrid, monogenic diabetes, secondary diabetes, unknown, and missing type). Cases of gestational diabetes mellitus were not included in the study. All case subjects were registered anonymously with the coordinating center at Wake Forest

University and included in this report if they were registered by 31 October 2011.

The numerator for this analysis included all case subjects prevalent in 2009 who were aged <20 years on 31 December 2009, lived in one of the included geographic areas or were a member of the KPSC Health Plan or included on the IHS rolls, and not on active military duty or living in an institution. Race/ethnicity, which was by self-report or extracted from the medical record for 97.3% and estimated using geocoding for 2.7% (18,19), was classified as non-Hispanic White (NHW), non-Hispanic black (black), Hispanic, Asian/Pacific Islander (ASPI), or American Indian/Alaskan Native (AIAN).

The denominator included youth <20 years of age on 31 December 2009 who were noninstitutionalized civilian residents of the study areas covered by the geographic centers or who were members of KPSC residing in seven counties or who were enrolled IHS members in 2009. Derivation of the appropriate denominators was a multistep process taking into account racial/ethnicity categorization and the civilian nature of the study population (15).

For the four geographic centers, age-, sex-, and race/ethnicity-specific denominators were determined using the 2009 bridged-race intercensal population estimates released in October 2012 by the National Center for Health Statistics (18) and pooled across centers. The five racial/ethnic groups listed above were used. The race-bridging methods developed by the National Center for Health Statistics were applied to determine the probability that a multiracial youth belongs to each of the four remaining racial/ethnic groups after excluding the Hispanics (19). For the KPSC population, addresses of all members eligible for inclusion in the study based on age and geographic location were geocoded to the census block level. For each geocoded address, the number of residents of each group living in that block was estimated using Census file SF1 Table P8. The race- and ethnic-specific proportions were then applied

to the sex-specific denominator estimates in 1-year age increments to estimate the racial and ethnic composition of youth by age and sex. As with the geographic-based centers, race-bridging methods were used. For AIAN, denominators were based on the IHS user population, defined as at least one IHS visit in the previous 3 years.

To derive civilian population denominators for the geographic centers, denominators for the youth aged 17–19 years were adjusted by subtracting the age-, sex-, racial/ethnic-, and county-specific number of active-duty military personnel derived from the information from the Military Family Resource Center (<http://www.mfrc.org>) and the Census Bureau. Racial/ethnic-specific denominator estimates were subsequently pooled across all SEARCH centers.

### Statistical Methods

The prevalence of diabetes was expressed per 1,000 youth using data pooled across all SEARCH centers. The 95% CIs were calculated using the skew-corrected inverted score test assuming a binomial distribution (20,21). To obtain an estimate of the total number of youth <20 years of age with physician-diagnosed diabetes in the U.S. population, age-, sex-, and racial/ethnic-specific U.S. prevalence estimates derived from SEARCH were applied to the age-, sex-, and racial/ethnic-specific U.S. population on the basis of 2009 census population estimates. For the purposes of

presentation, the standardized rates by race/ethnicity and four age groups are shown.

### RESULTS

A total of 7,695 youth aged <20 years with diabetes of all types was identified from a population of 3,458,974 youth (Table 1) for a crude prevalence of 2.22 case subjects/1,000 (95% CI 2.18–2.27). Total diabetes prevalence increased with age group from 0.30/1,000 (0.26–0.33) in those aged <5 years to 4.03/1,000 (3.90–4.16) among those aged 15–19 years. Prevalence was highest in NHW youth (2.70 case subjects/1,000 [95% CI 2.62–2.77]) and lowest in ASPI youth (0.80 case subjects/1,000 [0.70–0.92]). Females had a slightly higher prevalence (2.30 case subjects/1,000 [2.23–2.37]) than males (2.16 case subjects/1,000 [2.09–2.23]). Of the 7,695 youth with diabetes, 7,505 (97.5%) were identified as having either type 1 or type 2 diabetes. Of the remaining 190 case subjects (2.5%), 127 had secondary diabetes, and 63 had other or unknown type. These case subjects with a type other than type 1 or type 2 diabetes or with missing information on type represented a prevalence of 0.05 case subjects/1,000 (0.05–0.06) (data not shown) and are excluded from results that follow.

Table 2 shows the prevalence for type 1 and type 2 diabetes overall and by race/ethnicity. The prevalence of type 1 diabetes was 1.93 case subjects/1,000 (1.88–1.97) and of type 2 diabetes was

0.24 case subjects/1,000 (0.23–0.26). Type 1 diabetes prevalence was highest in NHW youth and lowest in AIAN. Conversely, type 2 diabetes prevalence was higher in youth from minority race/ethnic groups than in NHW youth. Among the 15–19-year-old AIAN, type 2 diabetes accounted for 80.0% of all case subjects (Fig. 1). Fig. 2 shows the age-specific prevalence by race/ethnicity and type. Prevalence rose with increasing age in all race/ethnic groups and was highest in the oldest age groups, except that in AIAN, the prevalence of type 1 diabetes was highest at age 10–14 years. The mean age of onset was 8.1 years for type 1 diabetes and 13.7 years for type 2 diabetes among youth diagnosed with diabetes before 20 years of age.

The completeness of case ascertainment for type 1 diabetes in the four geographic centers was 99.3% (99.2–99.5%) and was similar by race/ethnicity and by age group. For type 2 diabetes, in which capture-recapture was restricted to ages 10–19 years due to small numbers under the age of 10 years, completeness was slightly lower at 96.1% (94.6–97.6%) and similar by race/ethnicity except for Hispanic youth, in whom it was 90.0% (88.0–92.0%).

Based on SEARCH-derived prevalence, ~191,986 youth with diabetes aged <20 years lived in the U.S. in 2009, including 166,984 with type 1 diabetes and 20,262 with type 2 diabetes (Table 3). There were ~4,740 secondary, other, and unknown type of diabetes in the U.S. in 2009, or 2.5% of all case subjects identified.

### CONCLUSIONS

Based on data from SEARCH, the largest, most comprehensive surveillance study of diabetes in U.S. youth to date, >190,000 youth in the U.S. were estimated to have physician-diagnosed diabetes in 2009. This represents ~1 of every 433 of the ~3.3 million youth aged <20 years. This represents an overall increase in the number of estimated cases of diabetes of 37,617 between our previously published estimates for 2001 (15) and 2009. The increase in the number of case subjects was primarily driven by an increase in

**Table 1—Prevalence of diabetes (all types) in SEARCH by age, race/ethnicity, and sex, 2009**

	Number of case subjects	Denominator	Prevalence/1,000 (95% CI)
Total	7,695	3,458,974	2.22 (2.18–2.27)
Age group			
0–4 years	246	832,791	0.30 (0.26–0.33)
5–9 years	1,184	844,923	1.40 (1.32–1.48)
10–14 years	2,580	867,403	2.97 (2.86–3.09)
15–19 years	3,685	913,857	4.03 (3.90–4.16)
Race/ethnicity			
NHW	5,085	1,885,451	2.70 (2.62–2.77)
Black	872	383,198	2.28 (2.13–2.43)
Hispanic	1,403	809,267	1.73 (1.65–1.83)
ASPI	210	260,846	0.80 (0.70–0.92)
AIAN	126	120,212	1.05 (0.88–1.24)
Sex			
Female	3,886	1,692,112	2.30 (2.23–2.37)
Male	3,809	1,766,862	2.16 (2.09–2.23)

**Table 2—Estimates of prevalence in SEARCH/1,000 of diabetes according to diabetes type and race/ethnicity, 2009**

Race/ethnicity	Denominator	Type 1			Type 2		
		Number of case subjects	Prevalence (/1,000)	95% CI	Number of case subjects	Prevalence (/1,000)	95% CI
NHW	1,885,451	4,804	2.55	2.48–2.62	176	0.09	0.08–0.11
Black	383,198	626	1.63	1.51–1.77	214	0.56	0.49–0.64
Hispanic	809,267	1,040	1.29	1.21–1.37	323	0.40	0.36–0.45
ASPI	260,846	156	0.60	0.51–0.70	49	0.19	0.14–0.25
AIAN	120,212	42	0.35	0.26–0.47	75	0.63	0.50–0.79
Total	3,458,974	6,668	1.93	1.88–1.97	837	0.24	0.23–0.26

There were 190 secondary, other, unknown case subjects excluded from Table 2 that are included in Table 1.

type 1 diabetes, which increased among all race/ethnic groups.

Diabetes is one of the leading chronic diseases in youth—by our estimate, affecting 2.22/1,000 youth aged <20 years. Diabetes has a major impact on public health in this country, costing ~\$245 billion in 2012 and shortening life expectancy for those affected at young ages (22). The highest net value of future lost earnings due to premature death are for youth <18 years of age and for young adults between 18 and 34 years of age. The development of complications is related to the duration of diabetes, and youth with onset of diabetes early in life represent a population at high risk for developing these complications (23).

Comparisons of prevalence data may be subject to considerable bias, since prevalence is determined not only by disease incidence, but also by case survival, which may vary across populations. Prevalence data, however, are useful in determining the public health impact of diabetes. In 2011 and 2012, data from the National Survey of Children’s Health (24), based on parental self-report, estimated the

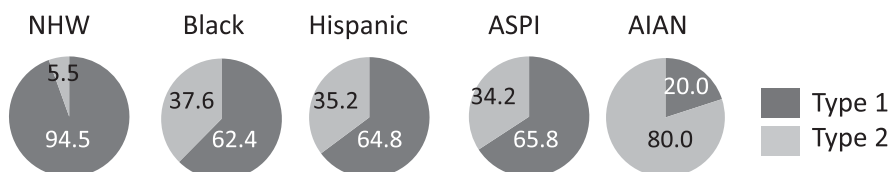
prevalence of all types of diabetes among NHW youth aged <18 years to be 4.0 case subjects/1,000, 2.0/1,000 for Hispanics, 4.0/1,000 for blacks, and 1.0/1,000 for other race/ethnic groups. This is similar to our estimate for Hispanics (1.73/1,000), but is higher than our estimate for NHW (2.70/1,000) and black youth (2.28/1,000). However, those data are based on self-report and likely to be less reliable than the validated SEARCH data. A recent Canadian report on data from 2008 and 2009 suggests somewhat higher prevalence of diabetes in Canada at 2.0/1,000 for ages 1–9 years and 5.0/1,000 for ages 10–19 years (25).

Estimates of the prevalence of diabetes by type have also been reported from the U.S. state of South Carolina (26) and the Canadian province of Manitoba (27). In 1999, type 1 diabetes prevalence in South Carolina NHWs was 1.1/1,000 at ages 0–9 years and 2.5/1,000 among 10–19 year olds, somewhat lower than our results. In Manitoba from 1985–1993, prevalence of type 1 diabetes among NHW youth was 0.2/1,000 (age 0–4 years), 1.1/1,000 (age 5–9 years), and 2.4/1,000 (age 10–14 years), also

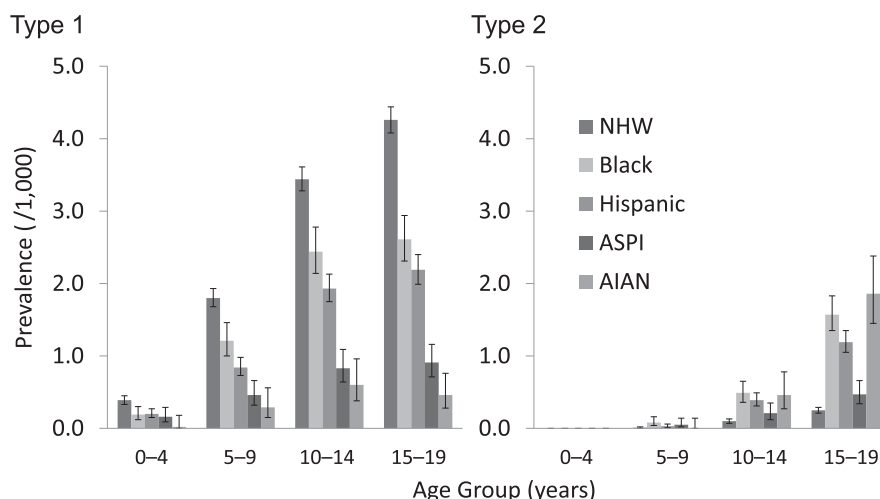
lower than we report, likely due to rising rates of type 1 diabetes.

Type 2 diabetes occurred in youth from all race/ethnic groups in the SEARCH cohort. The proportion of type 2 diabetes was lowest in NHW but still represented 3.5% of all cases of diabetes in NHW youth. Studies of largely Caucasian youth in Germany, France, and the U.K. (28–30) indicate that type 2 diabetes remains rare. The overall burden of diabetes due to type 2 diabetes in SEARCH increased with age group in all race/ethnic groups, and, among 15–19 year olds, type 2 diabetes was more common than type 1 diabetes among AIAN youth. These prevalence figures, while estimating the current burden of diabetes by type, do not reflect any changes in proportion of diabetes types, which can only be estimated from incidence rates.

The prevalence of type 2 diabetes has been reported in other studies largely in minority populations. In Puerto Rican Hispanics, prevalence was 0.2/1,000 from age 10–19 years (31). The differentiation between type 1 and type 2 diabetes was based only on the use of insulin, likely underestimating



**Figure 1**—Proportion of type 1 and type 2 diabetes among 15–19 year olds in SEARCH by race/ethnicity. Diabetes type other/unknown not included in figure.



**Figure 2**—Prevalence of diabetes in SEARCH/1,000 by type, age group, and race/ethnicity. Diabetes type other/secondary/unknown not included in figure. Error bars represent 95% CI.

the type 2 diabetes prevalence, as many youth with type 2 diabetes are also treated with insulin (32). The total prevalence of diabetes (any type) was 0.05/1,000 among >4,000 adolescents completing self-report information; 44% of these cases were classified as type 2 diabetes, implying a prevalence of 0.02/1,000, much lower than the 0.24/1,000 that we report. Possible factors contributing to differences in prevalence between studies include methods of ascertainment and ancestral region of the Hispanic population. In SEARCH, the majority of Hispanic participants' families are of Mexican ancestry, rather than Caribbean (33), which would be likely in a sample from Puerto Rico.

There are several reports of type 2 diabetes prevalence in American Indian or First Nations, Canadian populations. Prevalence in American Indians residing

in Montana, assessed using medical record review, was 3.5/1,000 (age 10–14 years) but only 0.8/1,000 in youth aged 15–19 years (34). In First Nations youth in Canada aged 5–14 years, prevalence was 7.7/1,000 (35), and was 13.0/1,000 among Oklahoma Cherokees aged 10–19 years who underwent screening (36). Among Pima Indians, who have undergone systematic oral glucose tolerance testing for many years, the prevalence in 1987–1996 was 38/1,000 among males aged 15–19 years and 53/1,000 among females (37), rates much higher than observed in the American Indian populations in SEARCH and the highest in the world. AIAN youth have the highest prevalence of type 2 diabetes of any race/ethnic group.

There are some limitations to this study. SEARCH relies on physician diagnosis of diabetes, identifying only clinically recognized case subjects reported to or

directly identified by SEARCH sites, so undiagnosed case subjects are not included in these prevalence estimates. For type 1 diabetes, the number of undiagnosed case subjects is likely very small, but type 2 diabetes, at least in adults, can exist for an extended period of time prior to diagnosis. However, there is very little undiagnosed diabetes in youth (38). Some older youth diagnosed with type 2 diabetes might not be seeing a physician who is aware of the SEARCH study, therefore leading to an underestimation of prevalence in the older age group. However, this is likely to have only slight impact based on our capture-recapture estimates. Denominator estimates were based on U.S. Census estimates of the population in 2009 but corrected for 2010 census results; however, race/ethnicity was geocoded for 2.7% of case subjects using 2010 census data, likely resulting

**Table 3**—Estimated number of youth with diabetes in the U.S. by age group, race/ethnicity, and diabetes type, 2009

Race/ethnicity	Age 0–4 years		Age 5–9 years		Age 10–14 years		Age 15–19 years		Total		Total
	Type 1	Type 2	Type 1	Type 2	Type 1	Type 2	Type 1	Type 2	Type 1	Type 2	
NHW	4,192	0	20,317	85	40,866	1,152	54,812	3,187	119,387	4,364	123,751
Black	582	0	3,633	232	7,725	1,542	9,271	5,585	20,887	7,152	28,039
Hispanic	1,028	0	3,917	125	8,517	1,733	9,740	5,289	23,915	7,427	31,342
ASPI	168	0	481	49	832	205	973	506	2,493	779	3,271
AIAN	5	0	59	1	128	97	110	438	303	540	843
<b>Total</b>	<b>5,975</b>	<b>0</b>	<b>28,408</b>	<b>491</b>	<b>58,069</b>	<b>4,729</b>	<b>74,905</b>	<b>15,006</b>	<b>166,984</b>	<b>20,262</b>	<b>187,246</b>

There were ~4,740 secondary, other, and unknown type of diabetes in the U.S. in 2009, or 2.5% of all case subjects identified, resulting in an estimate of 191,986 persons with diabetes of all types in 2009.

in some race/ethnicity misclassifications. Also, the number of AIAN youth was small, was primarily from IHS rolls in the Southwest, and may not be representative of AIAN youth from other parts of the country or those not using the IHS. In-person study visits were not conducted on 2009 prevalent case subjects, so presence of diabetes autoantibodies and details of medication use, obesity, and other risk factors are not available. However, previous SEARCH data demonstrated that provider assessment of diabetes type is a valid assessment of etiologic diabetes type (39). The number of participating sites in SEARCH has changed since 2001 when the first comprehensive prevalence survey was conducted (15). A detailed comparison of changes in prevalence, by diabetes type, between 2001 and 2009 taking into account the reduced number of sites will be published separately. Also, as case ascertainment was based on site/regional networks, some youth may not have been identified, particularly those who are older. Thus, the estimated prevalence presented in this article is more likely to be an underestimate in the upper age group, and this may explain the difference between these data and the higher prevalence observed in older Canadian youth.

This study also has important strengths. The population under surveillance by the SEARCH sites (~3.5 million) has a similar distribution of important sociodemographic factors (e.g., race/ethnicity, parental education, and income) to the U.S. population as a whole, suggesting that SEARCH is a representative sample of U.S. youth at risk for diabetes (Supplementary Table 1). Thus, these prevalence estimates should be an accurate representation of the true number of diagnosed case subjects in the study areas. This is also the largest such study of diabetes in youth in the U.S., making the estimates for the numbers of case subjects reasonably precise. The paucity of data on the prevalence of type 1 diabetes in contemporary cohorts of youth make the contribution of the SEARCH study particularly valuable.

In conclusion, the burden of diabetes in U.S. youth <20 years of age in 2009 is estimated to be 191,986. Of these,

166,984 have type 1 diabetes, and 20,262 have type 2 diabetes. The burden of type 1 diabetes is highest among NHW youth and is highest for type 2 diabetes in minority youth, especially AIAN youth. Efforts are needed both to provide care for youth living with either type 1 or type 2 diabetes and to reduce the risk for development of diabetes and diabetes-related complications in high-risk populations.

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edited the manuscript. D.A.S. contributed to discussion, edited the manuscript, and collected data. D.J.P. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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