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## Factors influencing time to case registration for youth with type 1 and type 2 diabetes: SEARCH for Diabetes in Youth Study

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### Abstract

**Purpose**—The development of a sustainable pediatric diabetes surveillance system for the United States requires a better understanding of issues related to case ascertainment.

**Methods**—Using the SEARCH for Diabetes in Youth registry, we examined whether time from diabetes diagnosis to case registration differed by diabetes type, patient demographics, and the type of provider reporting the case to the study. Plots for time from diagnosis to registration were developed, and differences by key variables were examined using the log-rank test.

**Results**—Compared with time to registration for type 1 cases, it took 2.6 (95% confidence interval [CI], 2.5–2.6) times longer to register 50% of type 2 diabetes cases, and 2.3 (95% CI, 2.0–2.5) times longer to register 90% of type 2 cases. For type 1 diabetes cases, a longer time to registration was associated with older age, minority race/ethnicity, and cases, where the referring provider was not an endocrinologist. For type 2 diabetes cases, older age, non-Hispanic white race/

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ethnicity, and cases reported by providers other than an endocrinologist took longer to identify and register.

**Conclusions**—These findings highlight the need for continued childhood diabetes surveillance to identify future trends and influences on changes in prevalence and incidence.

### Keywords

Surveillance; Case ascertainment; Diabetes in youth; Type 1 diabetes; Type 2 diabetes

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## Introduction

Diabetes is one of the leading chronic diseases in youth [1], yet data on burden and trends of type 1 and type 2 diabetes in youth in the United States were scarce until the early 2000s. In the United States, surveillance for diabetes in adults relies predominantly on self-report and laboratory data from national surveys [2]. However, because the prevalence of diabetes in childhood is relatively low (<1%) [3], national surveys do not have a large enough sample size to produce reliable estimates by diabetes type, within demographic groups or at the state level. From 1999 to 2010, the National Health and Nutrition Examination Survey only yielded 58 self-reported cases of diabetes among youth aged 12–19 years [4]. Before year 2000, limited data from North America existed on the incidence of type 1 and type 2 diabetes among individuals less than 20 years and existing data were from populations in limited geographic areas [5–7] or very selected populations (e.g., native populations) [8,9].

The SEARCH for Diabetes in Youth was designed and launched in 2000 as the largest ongoing registry of diabetes in U.S. youth to conduct a comprehensive assessment of the incidence and prevalence of type 1 and type 2 diabetes in youth less than 20 years across all racial/ethnic groups in geographically diverse and defined areas. From 2001 to 2009, SEARCH reported a 21.1% (95% CI, 15.6–27.0) increase in the prevalence of type 1 diabetes and a 30% (95% CI, 17.3%–45.1%) increase in the prevalence of type 2 diabetes in youth, and, from 2002 to 2009, a 2.7% annual increase in the incidence of type 1 diabetes in non-Hispanic white youth [3]. These findings highlight the need for continued childhood diabetes surveillance to identify future trends and influences on changes in prevalence and incidence. Understanding factors influencing time to registration of newly diagnosed cases of pediatric diabetes is essential for efficient and sustainable approaches to surveillance in the future and interpretation of the results. Therefore, we explored potential contributors to a delay in case registration after onset of diabetes including diabetes type, case demographic characteristics, and referring health care provider type.

## Materials and methods

### Study design and data collection

SEARCH is a multicenter epidemiologic surveillance study funded by the Centers for Disease Control and Prevention and the National Institutes for Diabetes and Digestive Kidney Diseases that conducts population-based case ascertainment of youth diagnosed with diabetes (excluding gestational diabetes) with onset before 20 years of age. A detailed description of the SEARCH study has been published elsewhere [10]. In brief, the catchment



## Results

### Type 1 diabetes

A total of 5264 incident cases of type 1 diabetes among youth less than 20 years at diagnosis were registered between 2005 and 2009. The proportion of cases by age group was 16.1% for 0–4 years, 32.6% for 5–9 years, 36.5% for 10–14 years, and 14.8% for 15–19 years. Non-Hispanic white youth comprised 68.4% of the type 1 diabetes cases, and the referring provider was an endocrinologist for 91.3% of cases (Table 1). Figure 1 shows the time from diagnosis to registration for 2005–2009 incident cases by diabetes type. The median time from diagnosis to registration was 2.2 months for type 1 diabetes cases, and the median time to 90% registration was 11.2 months (Fig. 1). Time to registration increased significantly for older age groups ( $P < .0001$ ), as illustrated in Figure 2. Time to registration of 90% of cases was 9.6, 10.1, 10.9, and 16.9 months for cases diagnosed at 0–4, 5–9, 10–14, and 15–19 years, respectively (Fig. 2). Figure 3 shows that the overall time to registration according to race/ethnicity. Time to 90% registration was 11.5 months for racial/ethnic minorities compared to 10.6 months for NHW cases ( $P = .03$ ). Figure 4 shows that the overall time to registration was shorter when the referring provider was an endocrinologist compared to all other provider types (9.1 months compared to 22.5 months to register 90% of the cases,  $P < .0001$ ).

### Type 2 diabetes

A total of 1266 incident cases of type 2 diabetes among youth less than 20 years were registered by SEARCH between 2005 and 2009. Most cases were over the age of 10 years (94.6%) of a minority racial/ethnic group (80.8%) and were referred to the SEARCH study by an endocrinologist (67.4%; Table 1). The median time from diagnosis to case registration was 5.7 months, with 90% of cases registered by 25.3 months. Compared to the type 1 diabetes cases, it took 2.6 times longer to register 50% of the cases (95% CI for the ratio: 3.1–3.3 months) and 2.3 times longer to register 90% (95% CI, 2.5–2.8 months; Fig. 1). Figure 2 shows that the time to registration of type 2 diabetes cases was significantly longer for the older age groups ( $P = .002$ ) with a time to 90% registration of 22.3 months and 26.9 months for age-groups 10–14 and 15–19 years, respectively. Compared to type 1 diabetes cases, it took twice as long to register 90% of the cases diagnosed at ages 10–14 (95% CI, 1.7–2.4) and 1.6 times longer in the 15-to-19-year age group (95% CI, 1.3–1.8; Fig. 2). The overall time to registration was significantly different by race/ethnicity ( $P = .02$ ): the median time to registration for NHW was 4.9 months compared with 5.4 months for other race/ethnic groups, whereas the time to 90% registration was 29.7 months for NHW compared with 22.5 months for other race/ethnic groups. Compared to type 1 diabetes cases, it took longer to register 50% and 90% of the type 2 diabetes cases for both NHW and youth of racial/ethnic minorities (Fig. 3). Overall time to registration was shorter when the referring provider was an endocrinologist compared to all other provider types (3.2 months compared to 21.6 months to register 50% of cases and 11.1 months compared to 28.5 months to register 90% of cases,  $P < .0001$ ). The ratio of time to registration of 90% of cases of type 2 diabetes compared to type 1 diabetes was higher for referral by endocrinologists (2.4; 95% CI, 2.1–2.7 months) than for other provider types (1.1; 95% CI, 1.0–1.3; Fig. 4).

## Discussion

In this study of factors contributing to differences in time to registration by in the SEARCH surveillance system, we found that it took more than twice as long to register type 2 diabetes cases compared to type 1 diabetes cases. These findings highlight the considerably greater effort required to ascertain type 2 cases relative to type 1 diabetes in youth in the SEARCH ascertainment network. The ascertainment patterns observed likely reflect the decentralized nature of the U.S. health delivery system and the different patterns of care, including differences in patterns of referral to specialty care for youth with type 1 diabetes versus type 2 diabetes. The clinical presentation of type 1 diabetes usually manifests acutely with clear signs and symptoms, including sometimes a short and dramatic progression toward ketoacidosis [11], which may lead to a faster diagnosis and referral to specialty care. In contrast, type 2 diabetes in childhood is more likely to have a longer, protracted clinical presentation period in which multiple clinical providers are seen before a final diagnosis is made [12]; youth with type 2 diabetes may not be as likely to be referred to subspecialty care. In addition, youth with type 2 diabetes may have less frequent and more sporadic contact with health care providers as they self-manage at home or in their community.

Older age was a significant factor associated with longer time to registration among both diabetes types. However, it still took twice as long to register 90% of the type 2 versus type 1 diabetes cases in the 10-to-14-year age group and 1.6 times longer in the 15-to-19-year age group. This may well reflect the transitions in care occurring in the older age group, including less frequent care-seeking behavior, transition from pediatric to adult care, transition from high school to college or employment, as well as potential gaps in health insurance for this age group. The difference in registration time was statistically significant but negligible (less than 1 month) for type 1 diabetes cases of minority race/ethnicities compared to NHW cases. However, for type 2 diabetes cases, it took 7.2 months longer to register 90% of the NHW cases compared to minorities. Therefore, the ratio of time to registration of 90% of type 2 versus type 1 diabetes cases was smaller for minorities than for non-Hispanic whites. This interesting finding could reflect a diagnostic suspicion bias among health care providers who are more likely to suspect type 2 diabetes among minority youth, thus referring them more quickly to specialty care.

When the referring provider was not an endocrinologist, it took 16.4 months longer to ascertain 90% of type 1 diabetes cases and 6.9 months longer to register 90% of the type 2 diabetes cases, compared to when the provider referring to SEARCH was an endocrinologist. These findings are likely related in part to the logistics of the case ascertainment and registration approach used by the SEARCH study, where, for cost-efficiency, nonspecialty providers and related data systems are queried less often. However, we also found that even when the referring physician was an endocrinologist, it took 2.4 times longer to ascertain 90% of type 2 compared to 90% of type 1 diabetes cases, whereas no difference in time to registration by diabetes type was seen when the referring provider was not an endocrinologist. These findings suggest, again, different patterns of care and referral to specialty care for youth with type 2 versus type 1 diabetes, with type 2 cases likely to spend a longer period of time in primary care and are only later to be referred to endocrinologists, thus prolonging the time to case registration by the SEARCH network.

There are several limitations to our study. The SEARCH surveillance network identifies incident cases of diabetes diagnosed in childhood based on clinical diagnosis from a network of health care providers, hospitals, community health centers, and health plans in defined geographic areas. Therefore, the fragmented nature of the U.S. health care system may impose several limitations to case ascertainment and therefore time to registration. Although SEARCH operates under a Health Insurance Portability and Accountability Act waiver of consent, access to identifying information necessary to determine eligibility based on residence or age may lead to longer time to registration. A standardized ascertainment approach is used across the SEARCH surveillance network; however, differences in the composition of the health care provider networks at each site may introduce some variation in time to registration across SEARCH participating sites. Time from case identification to registration may also vary over time due to operational issues (e.g., site-specific staffing patterns, other study priorities, and so forth), but this variability is unlikely to differentially impact time to registration by diabetes type, age, race/ethnicity, or type of provider. Our study also has multiple important strengths. We believe that our findings on ascertainment patterns of type 1 and type 2 diabetes among children included the SEARCH registry are reasonably generalizable to the U.S. population with pediatric diabetes. As previously reported [3], the proportional distribution of youth under surveillance in SEARCH was very similar to the U.S. census for 2000 and 2010 in terms of race/ethnicity, age, parental educational attainment, and median household income. The case ascertainment protocol within SEARCH has remained consistent over the study period including a uniform case definition, high case ascertainment rate, and a high level of agreement between physician diagnosed and etiologic diabetes type [13].

## Conclusions

In the United States, active surveillance of diabetes in youth based on a network of primarily pediatric specialty health care providers required more than twice as long to ascertain the vast majority of type 2 diabetes compared to type 1 diabetes cases. Even within the same age-ethnic and racial-ethnic groups, it took 2–3 times longer to identify and register youth with type 2 versus those with type 1 diabetes. Referral to SEARCH by nonspecialty providers and sources was associated with longer time to registration for both diabetes types; however, even when the referring physician was an endocrinologist, it took twice as long to ascertain most patients with type 2 compared to those with type 1 diabetes. Although some of the within-diabetes type differences are a direct reflection of the design of the SEARCH case ascertainment network and the logistics of the approach, our data also suggest that variations in patterns of referral to specialty care by diabetes type are a major contributor to differences in the time to case registration by diabetes type. Surveillance of both major forms of pediatric diabetes through the same network of specialty and nonspecialty providers, hospitals, and community centers is possible, but ascertainment of cases of type 2 diabetes requires more time and effort.

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention and the National Institute of Diabetes and Digestive and Kidney Diseases.

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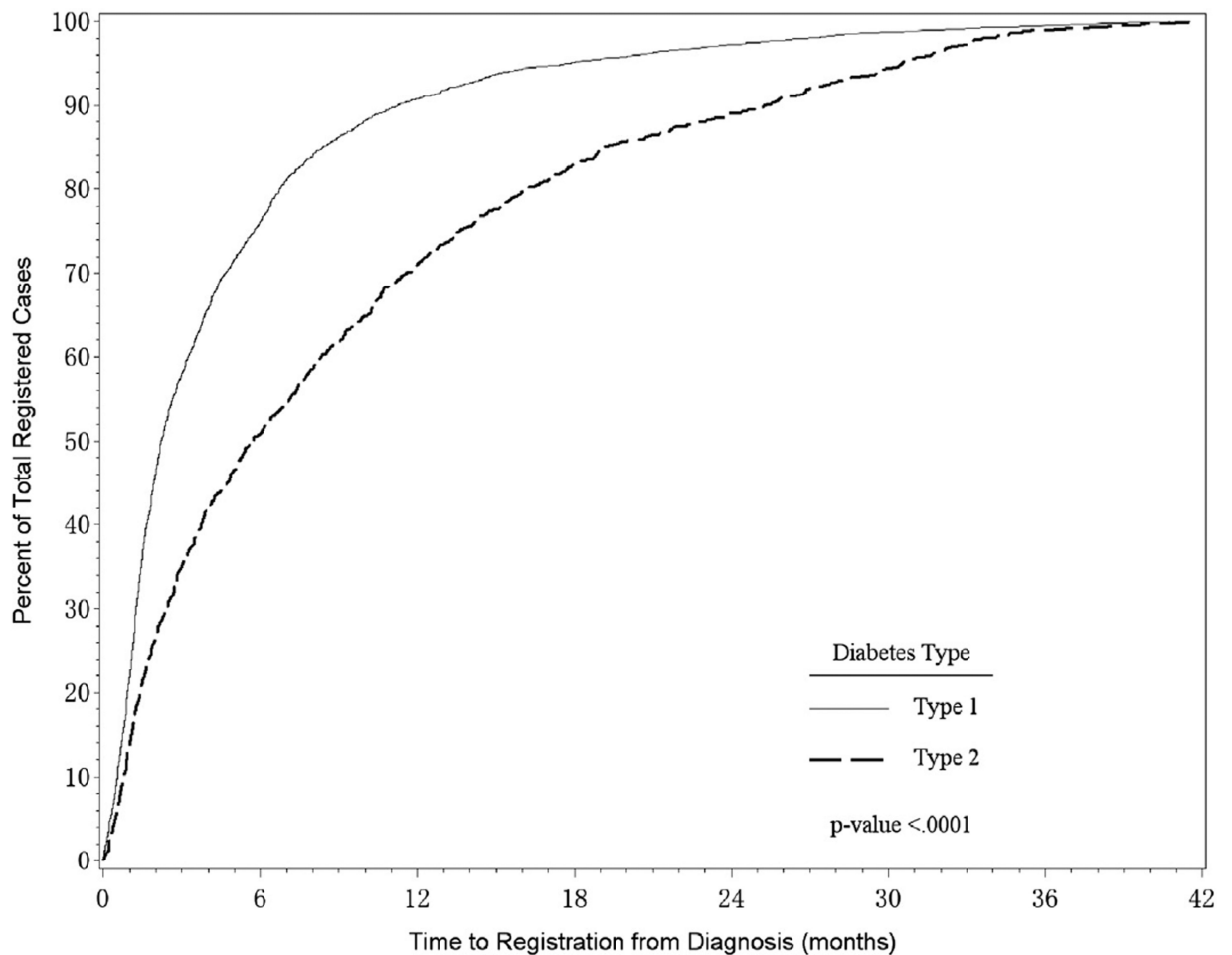
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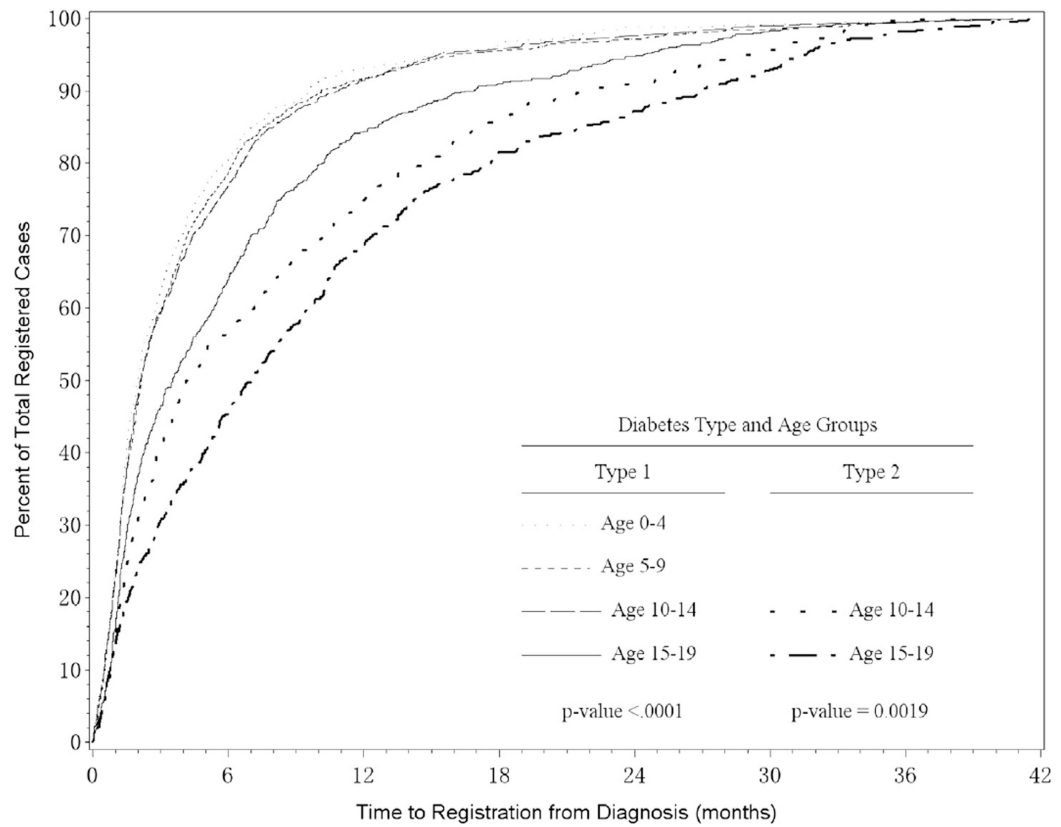




**Time from diagnosis to 50% and 90% case registration for incident cases of type 1 and type 2 diabetes in youth age <20 years, 2005-2009**

	Type 1		Type 2		Ratio of time to registration for type 2 to type 1	CI for the ratio
	Cases observed	Months	Cases observed	Months		
Time to 50% ascertainment	2,635	2.2	632	5.7	2.6	2.5, 2.6
Time to 90% ascertainment	4,738	11.2	1,139	25.3	2.3	2.0, 2.5

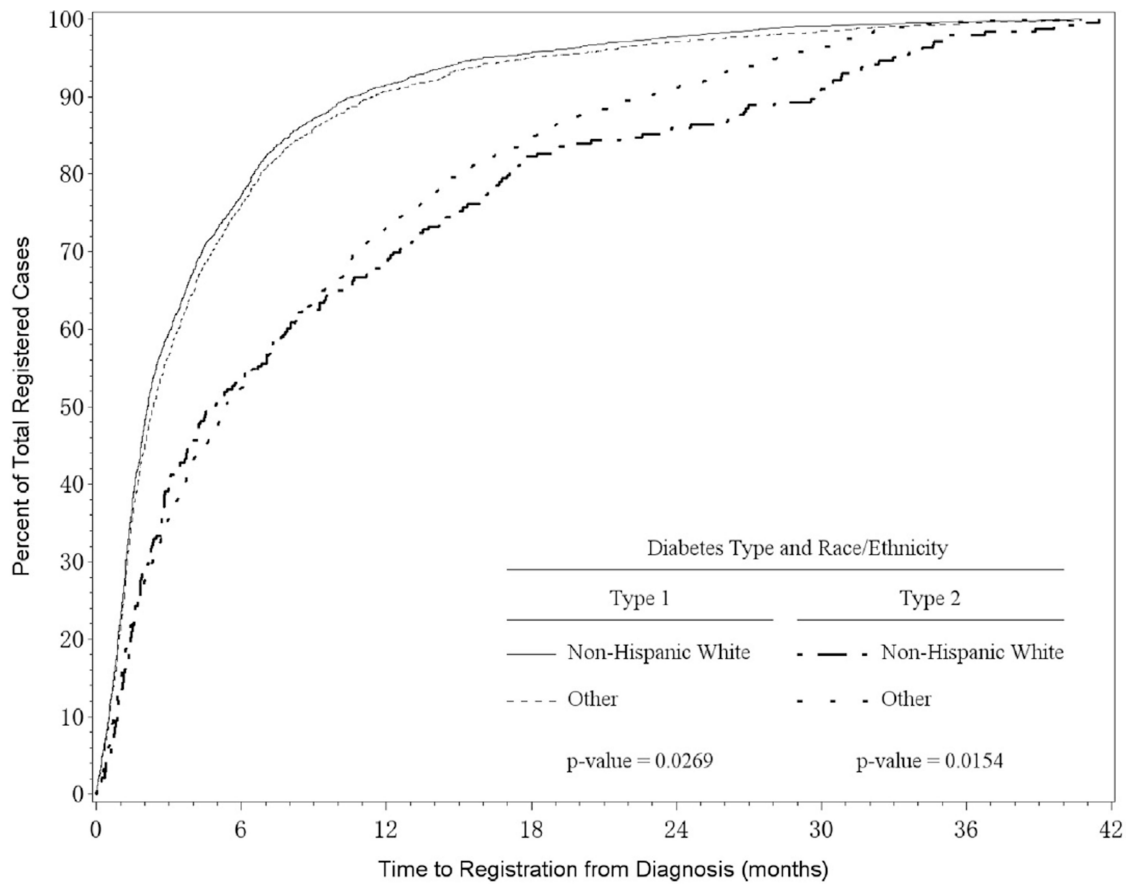
**Fig. 1.**  
Time from diagnosis to case registration for 2005–2009 incident type 1 and type 2 diabetes cases in youth age <20 years.



**Time from diagnosis to 50% and 90% case registration by diabetes type and age group, 2005-2009**

Time to 50% registration	Type 1		Type 2		Ratio of time to registration for type 2 to type 1	CI for the ratio
	Cases observed	Months	Cases observed	Months		
Age 0-4	430	2.0	--	--	--	--
Age 5-9	866	2.2	--	--	--	--
Age 10-14	964	2.1	293	4.2	2.0	1.9, 2.1
Age 15-19	391	3.5	307	7.1	2.0	1.9, 2.1
Time to 90% registration	Type 1		Type 2		Ratio of time to registration for type 2 to type 1	CI for the ratio
	Cases observed	Months	Cases observed	Months		
Age 0-4	766	9.6	--	--	--	--
Age 5-9	1,544	10.1	--	--	--	--
Age 10-14	1,732	10.9	525	22.3	2.0	1.7, 2.4
Age 15-19	700	16.9	551	26.8	1.6	1.3, 1.8

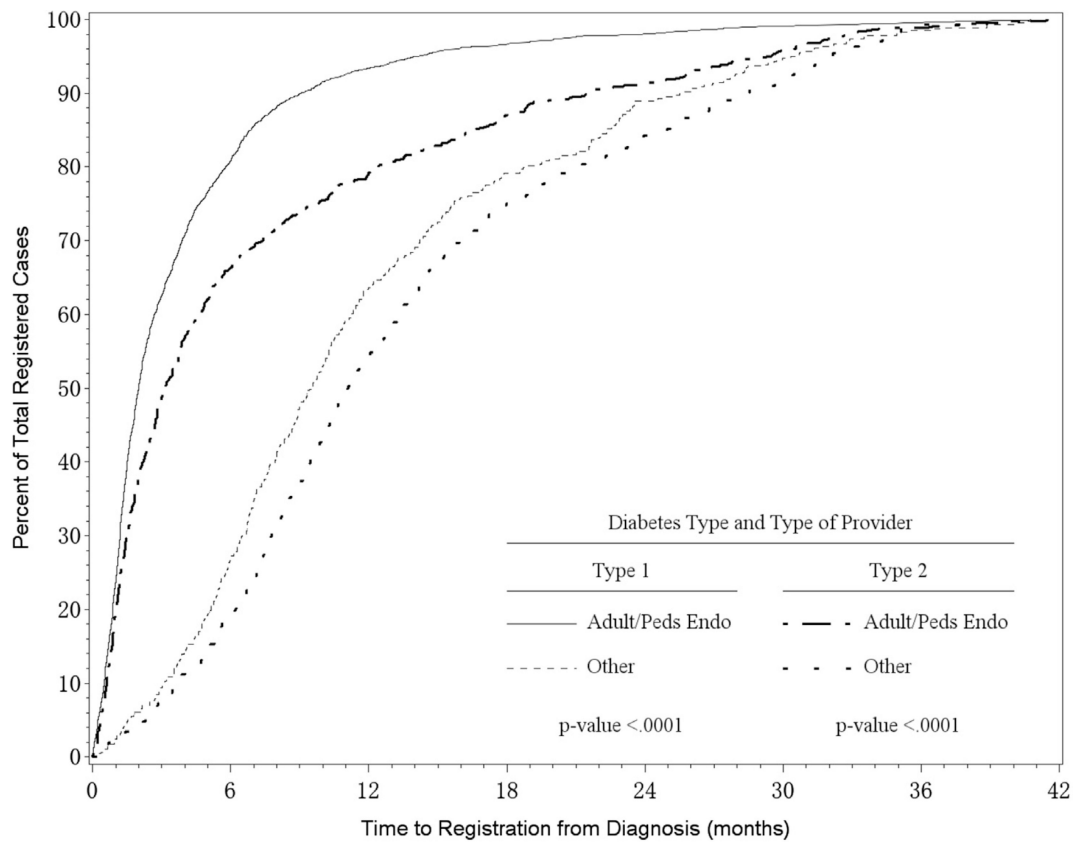
**Fig. 2.**  
Time from diagnosis to case registration by diabetes type and age group, 2005–2009 cases.



**Time from diagnosis to 50% and 90% case registration by diabetes type and race/ethnicity, 2005-2009**

Time to 50% ascertainment	Type 1		Type 2		Ratio of time to registration for type 2 to type 1	CI for the ratio
	Cases observed	Months	Cases observed	Months		
Non-Hispanic White	1,805	2.1	122	4.9	2.3	2.2, 2.5
Other	793	2.4	483	5.4	2.3	2.2, 2.4
Time to 90% ascertainment	Type 1		Type 2		Ratio of time to registration for type 2 to type 1	CI for the ratio
	Cases observed	Months	Cases observed	Months		
Non-Hispanic White	3,244	10.6	219	29.7	2.8	2.4, 3.2
Other	1,415	11.5	869	22.5	2.0	1.7, 2.3

**Fig. 3.** Time from diagnosis to case registration by diabetes type and race/ethnicity, 2005–2009 cases.



**Time from diagnosis to 50% and 90% case registration by diabetes type and provider of type who registered the case, 2005-2009**

Time to 50% ascertainment	Type 1		Type 2		Ratio of time to registration for type 2 to type 1	CI for the ratio
	Cases observed	Months	Cases observed	Months		
Adult/Peds Endo	2,434	2.0	428	3.2	1.6	1.5, 1.7
Other	231	9.5	207	11.1	1.2	1.1, 1.2
Time to 90% ascertainment	Type 1		Type 2		Ratio of time to registration for type 2 to type 1	CI for the ratio
	Cases observed	Months	Cases observed	Months		
Adult/Peds Endo	4,328	9.1	766	21.6	2.4	2.1, 2.7
Other	414	25.5	371	28.5	1.1	1.0, 1.3

**Fig. 4.** Time from diagnosis to case registration by diabetes type and type of referring provider, 2005–2009 cases.

**Table 1**

Total incident cases of type 1 and type 2 diabetes among youth less than 20 years of age in the SEARCH for Diabetes in Youth Study, 2005–2009

	Diabetes type	
	Type 1, <i>n</i> = 5264	Type 2, <i>n</i> = 1266
	N (%)	N (%)
Age at diagnosis (y)		
0–4	849 (16.1)	3 (0.2)
5–9	1715 (32.6)	66 (5.2)
10–14	1923 (36.5)	583 (46.1)
15–19	777 (14.8)	614 (48.5)
Race/ethnicity		
NHW	3603 (68.4)	243 (19.2)
All others	1661 (31.6)	1023 (80.8)
Type of referring provider		
Endocrinologist	4805 (91.3)	852 (67.4)
All others	459 (8.7)	413 (32.6)