

Initial Participant Survey

Parent / Guardian Version

This survey is to be filled out by a Parent or legal Guardian of the child age less than 18 years old who has diabetes.

Your answers will be kept confidential and will be used for study purposes only.

Public reporting burden of this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC Reports Clearance Officer, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-0904)

Privacy Act Statement

The information you are being asked to provide is authorized to be collected under Section 301 of The Public Health Service Act (42 USC 241). Providing this information is voluntary. CDC will use this information in its study, SEARCH for Diabetes in Youth, in order to: (1) Assess the incidence and prevalence of diabetes among youth in the U.S. by diabetes type, and by demographics including age, sex, and race/ethnicity; and (2) Assess temporal trends in diabetes incidence in major US racial/ethnic groups, including African Americans, Hispanics, American Indian Tribes, Asian Americans, Pacific Islanders, by age, sex, and diabetes type. This information will be shared with third party clinical entities with whom CDC has entered into an Agreement to assist with carrying out this Study.



We want to learn more about children and young adults who have diabetes, and how diabetes affects their lives. You can help us learn more by answering the following questions. In this survey, we will use the term CHILD to refer to YOUR CHILD that has diabetes..

1. What is **TODAY'S** date? _____ / _____ / _____
Month Day Year

For example, if today is May 1, 2016, write in 05/01/2016

2. What is your child's sex? 1 Female 2 Male

3. What is your CHILD'S **BIRTHDATE**? _____ / _____ / _____
Month Day Year

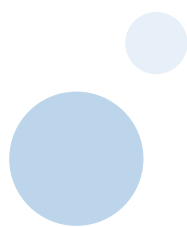
4. Has a doctor or nurse ever told you or your child that your child has diabetes?

1 **YES.** Please go to the next page.

2 **NO. STOP.** Please turn to **page 9** and complete this information.

Please mail the survey to us in the stamped envelope.

Thank You
for filling out these questions.



5. When did a doctor or nurse first tell you that your child had diabetes?
This means when your child was told about his/her diabetes diagnosis.

____ / ____ / ____
Month Day Year

6. Please list all the places your child lived during the year he/she was diagnosed with diabetes. For example if your child was diagnosed in April 2016, list everywhere he/she lived from January 2016 through December 2016.

City State Zip Code County

City State Zip Code County

City State Zip Code County

We are going to ask you some questions about when your child first got diabetes, and how your child's diabetes is treated. Please answer the questions as best as you can. If you do not know the answer to a question, leave it blank.

7. How did you first find out that your child had diabetes?
(Check Yes or No for each question)

Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that my child had diabetes because my child was thirsty, had to pee a lot, or got sick very quickly.
Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that my child had diabetes at a yearly physical or check-up with his/her regular doctor.
Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that my child had diabetes when his/her blood sugar was checked at a health fair or by a school nurse.
Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that my child had diabetes when she was pregnant and the diabetes did not go away after the pregnancy.

If none of the above apply to you, please write on the lines below how you first found out your child had diabetes.



8. Has a doctor or nurse told you or your child that his/her diabetes was caused by:
(please check Yes or No for each question)

8a. Cystic fibrosis? 1 Yes 2 No

8b. Cancer or medicine to treat cancer? 1 Yes 2 No

8c. Another medicine? 1 Yes 2 No

If Yes, what was the medicine? _____

9. Since being diagnosed with diabetes, has your child ever taken insulin?

1 Yes 2 No (If No, skip to question 10)

9a. Was he/she taking insulin two weeks after diagnosis? 1 Yes 2 No

9b. Is he/she taking insulin now? 1 Yes 2 No

10. How else does your child take care of his/her diabetes **now**?

Does he/she: (please check Yes or No for each question)

10a. Take prescribed tablets (pills) for diabetes? 1 Yes 2 No

10b. Follow a diet/meal plan (for example, carbohydrate counting)? 1 Yes 2 No

10c. Follow an exercise program? 1 Yes 2 No

10d. Any treatments other than insulin, pills, diet, or exercise: (If yes, please list below.)

11. Who does your child usually see for **most** of his/her care related to diabetes?
(Please check only one response).

1. Pediatrician

2. Family practice or internal medicine physician

3. Pediatric endocrinologist/diabetologist (diabetes specialist)

4. Adult endocrinologist/diabetologist (diabetes specialist)

5. Another type of physician

6. Other health care provider (nurse, nurse practitioner, physician assistant,
certified diabetes educator, or other)

7. Unsure

8. No current health care provider



Now we would like to learn a bit about your child's health insurance

12. What kind of health insurance plan did your child have when he/she was **DIAGNOSED** with diabetes? And what kind of health insurance plan does your child have **NOW**?
(Please answer Yes or No for each question for insurance at time of DIAGNOSIS and NOW)

HEALTH INSURANCE TYPE	Health Insurance at TIME OF DIAGNOSIS		Health Insurance NOW	
	YES	NO	YES	NO
12a. Medicaid/Medicare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
12b. Private insurance, through employer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
12c. Private insurance, purchased on your own	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
12d. Private insurance, purchased through the health insurance exchange or marketplace	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
12e. Military	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
12f. School or college-based insurance	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
12g. Tribe/Indian Health Service	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
12h. Any other or type unknown	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
12i. No health insurance	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>

13. Is your child Spanish/Hispanic/Latino? (Mark X in the "No" box if **not** Spanish/Hispanic/Latino)

- No, not Spanish/Hispanic/Latino
- Yes, Puerto Rican
- Yes, Mexican, Mexican American, Chicano
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino - Print group in the space below:

14. What is your child's race? Mark one or more races to indicate what your child considers himself/herself to be.

- White
 Black, African American
 American Indian or Alaska Native; Print name of enrolled or principal tribe below:

 Asian Indian
 Japanese
 Native Hawaiian
 Chinese
 Korean
 Guamanian or Chamorro
 Filipino
 Vietnamese
 Samoan
 Other Asian; Print race: _____
 Other Pacific Islander; Print race: _____

15. What is the highest degree or level of school that your child's parent/guardian #1 and parent/guardian #2 have completed?

	Parent / Guardian #1	Parent / Guardian #2
15a. Any education less than a high school graduate, no diploma or GED	1 <input type="checkbox"/>	1 <input type="checkbox"/>
15b. High school graduate, (high school diploma) or equivalent (for example, GED)	2 <input type="checkbox"/>	2 <input type="checkbox"/>
15c. Business/technical school, associate degree (AA, AS) or some college	3 <input type="checkbox"/>	3 <input type="checkbox"/>
15d. Bachelor degree (for example, BA, AB, BS) (4-year)	4 <input type="checkbox"/>	4 <input type="checkbox"/>
15e. Master degree (for example MA, MS, MEng, Med., MSW)	5 <input type="checkbox"/>	5 <input type="checkbox"/>
15f. Professional or doctorate degree (for example, MD, DDS, JD, PhD, EdD)	6 <input type="checkbox"/>	6 <input type="checkbox"/>
15g. Don't know	7 <input type="checkbox"/>	7 <input type="checkbox"/>

16. Which of these categories best describes the **total** income of all persons living in the Parent's/ Guardian's household for the past 12 months? (Income could be from salaries, social security, retirement, Medicaid, disability, alimony, child support, etc.)
Check only one category:
- 1. Less than \$5,000
 - 2. \$5,000 through \$11,999
 - 3. \$12,000 through \$15,999
 - 4. \$16,000 through \$24,999
 - 5. \$25,000 through \$34,999
 - 6. \$35,000 through \$49,999
 - 7. \$50,000 through \$74,999
 - 8. \$75,000 through \$99,999
 - 9. \$100,000 and greater
 - 10. Don't know

17. How many people are currently living in the Parent's/Guardian's household?

17a. Total number of people _____

17b. Number of children (less than 18 years) _____

17c. Number of adults _____

17d. Please mark which adults live in the household

	YES	NO
Child's mother	<input type="checkbox"/>	<input type="checkbox"/>
Child's father	<input type="checkbox"/>	<input type="checkbox"/>
Child's guardian	<input type="checkbox"/>	<input type="checkbox"/>
Other adult(s)	<input type="checkbox"/>	<input type="checkbox"/>

Now we would like to ask you a few questions about whether or not other people in your child's family have diabetes.

Please provide information about the child's mother, father, brothers, and sisters. This refers to the child's biological or natural parents (not step-parents or adoptive parents) and the child's full or half brothers and sisters, not those who were adopted or step brothers or step sisters.

Please include information for relatives who are living and those who are deceased.

18. Does your child's biological mother have diabetes?

1 Yes 2 No 3 Don't know

18a. If Yes, how old was she when she was diagnosed with diabetes?

_____ years Don't know

19. Did your child's biological mother have any form of diabetes when she was pregnant with the child? This includes Type 1 diabetes, Type 2 diabetes, gestational diabetes, or other types of diabetes.

1 Yes 2 No 3 Don't know

20. Does your child's biological father have diabetes?

1 Yes 2 No 3 Don't know

20a. If Yes, how old was he when he was diagnosed with diabetes?

_____ years Don't know

21. Does your child have any full or half brothers?

1 Yes 2 No 3 Don't know

(If No or Don't know, skip to question 22)

21a. If Yes, how many full or half brothers does your child have?

_____ brothers

21b. If Yes, how many full or half brothers have diabetes?

_____ brothers

22. Does your child have any full or half sisters?

1 Yes 2 No 3 Don't know

(If No or Don't know, skip to question 23)

22a. If Yes, how many full or half sisters does your child have?

_____ sisters

22b. If Yes, how many full or half sisters have diabetes?

_____ sisters

23. Was your **child with diabetes** born in the United States?

1 Yes (If Yes, go to question 24)

2 No

23a. If no, in what country was your child born? Write in country of birth.

23b. In what year did your child come to the United States to live? Write in year. _____

3 Don't know; prefer not to say



24. Was your **child's mother** born in the United States?

1 Yes (If Yes, go to question 25)

2 No

24a. If no, in what country was the child's mother born? Write in country of birth.

Don't know country

24b. In what year did the child's mother come to the United States? Write in year. _____

Don't know year

Did not come to the United States

3 Don't know; prefer not to say

25. Was your **child's father** born in the United States?

1 Yes (If Yes, go to next page)

2 No

25a. If no, in what country was the child's father born? Write in country of birth.

Don't know country

25b. In what year did the child's father come to the United States? Write in year. _____

Don't know year

Did not come to the United States

3 Don't know; prefer not to say

26. During the year 2017, list all the places where your child lived.

CITY

STATE

ZIP CODE

COUNTY



Contact Information

We would like to be able to reach you in the future to provide information about the SEARCH study. Please provide the best contact information below.

A. Name of person filling out this form

First Name

Middle Name

Last Name

B. Relationship to child: _____

C. What is your child's name?

First Name

Middle Name

Last Name

Are there any other names that he / she uses?

Other first names

Other last names

D. Full Name of Parent or Guardian #1 of child **(Please note if Parent or Guardian.)**

First Name

Middle Name

Last Name

Parent Guardian #1

E. Full Name of Parent or Guardian #2 of child (Please note if Parent or Guardian.)

First Name

Middle Name

Last Name

Parent Guardian #2

F. Provide your current address, email and phone number for future contact.?

P.O. Box

Street

Apt#

City

State

Zip Code

Email address

Phone number (best)

area code

extension

Is this: Home Work Cellular Phone Other

Phone number (other)

area code

extension

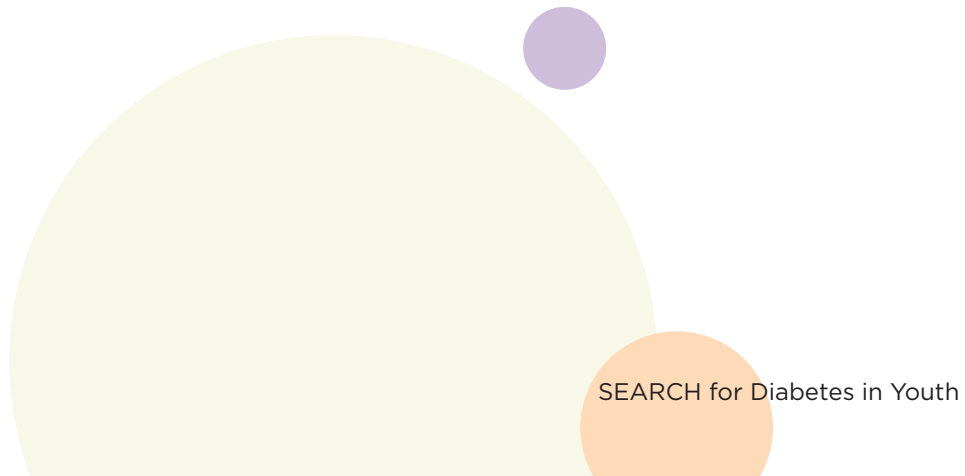
Is this: Home Work Cellular Phone Other

Phone number (other)

area code

extension

Is this: Home Work Cellular Phone Other



Alternate Contact Information

As a part of this study, we may be contacting you in the future. Please provide us with the names, addresses, phone numbers and/or email addresses of a relative or friend, someone who would know how to contact you if your address or phone number changes.

Contact #1:

First Name

Middle Name

Last Name

Relationship to child

P.O. Box

Street

Apt#

City

State

Zip Code

Email address

Phone number (best)

area code

extension

Phone number (other)

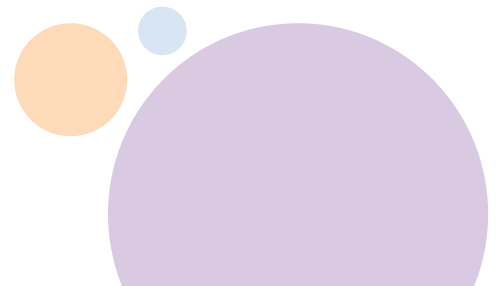
area code

extension

Phone number (other)

area code

extension



FOR STUDY USE ONLY

Patient ID Number
Site Sub-site Sequential ID

Date Completed
Month Day Year Completed by

Mode of Administration In Person Telephone Mailed CATI

Date Reviewed
Month Day Year Reviewer Code

Date Entered
Month Day Year Data Entry Code



