

# Initial Participant Survey

## Adult Version

This survey is to be filled out by the person (18 years or older) 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 adults who have diabetes, and how diabetes affects their lives. You can help us learn more by answering the following questions. You may ask your Parent or another adult to help you.

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 sex? 1  Female 2  Male

3. What is your **BIRTHDATE**? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Month Day Year

4. Has a doctor or nurse ever told you that you have 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 you had diabetes?  
This means when you were told about your diabetes diagnosis.

\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
Month Day Year

6. Please list all the places you lived during the year you were diagnosed with diabetes. For example if you were diagnosed in April 2016, list everywhere you 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 you first got diabetes, and how your 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 you had diabetes? (Check Yes or No for each question)

Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that I had diabetes because I 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 I had diabetes at a yearly physical or check-up with my regular doctor.
Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that I had diabetes when my 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 I had diabetes when I was pregnant and the diabetes <b>did not</b> go away after the pregnancy.

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

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8. Has a doctor or nurse told you that your 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, have you ever taken insulin?

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

9a. Were you taking insulin two weeks after diagnosis? 1  Yes 2  No

9b. Are you taking insulin now? 1  Yes 2  No

10. How else do you take care of your diabetes **now**?

Do you: (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.)

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11. Who do you usually see for **most** of your 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 ask about your health insurance.**

**12.** What kind of health insurance plan did you have when you were **DIAGNOSED** with diabetes? And what kind of health insurance plan do you 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
<b>12a.</b> Medicaid/Medicare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
<b>12b.</b> Private insurance, through employer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
<b>12c.</b> Private insurance, purchased on your own	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
<b>12d.</b> 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"/>
<b>12e.</b> Military	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
<b>12f.</b> School or college-based insurance	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
<b>12g.</b> Tribe/Indian Health Service	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
<b>12h.</b> Any other or type unknown	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
<b>12i.</b> No health insurance	1 <input type="checkbox"/>	2 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>

**13.** Are you 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:

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14. What is your race? Mark one or more races to indicate what you consider yourself 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 you, your Parent/Guardian #1 and Parent/Guardian #2 have completed?

	Yourself	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"/>	1 <input type="checkbox"/>
15b. High school graduate, (high school diploma) or equivalent (for example, GED)	2 <input type="checkbox"/>	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"/>	3 <input type="checkbox"/>
15d. Bachelor degree (for example, BA, AB, BS) (4-year)	4 <input type="checkbox"/>	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"/>	5 <input type="checkbox"/>
15f. Professional or doctorate degree (for example, MD, DDS, JD, PhD, EdD)	6 <input type="checkbox"/>	6 <input type="checkbox"/>	6 <input type="checkbox"/>
15g. Don't know	7 <input type="checkbox"/>	7 <input type="checkbox"/>	7 <input type="checkbox"/>

- 16.** Which of these categories best describes the **total** income of all persons living in your household for the past 12 months? (Income could be from salary, 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 your household, including yourself?

**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
<b>Mother</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Father</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Guardian</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Roommate/ Friend</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Spouse/Partner</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other adult(s)</b>	<input type="checkbox"/>	<input type="checkbox"/>

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

**Please provide information about your mother, father, brothers, and sisters. This refers to your biological or natural parents (not step-parents or adoptive parents) and your 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 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 biological mother have any form of diabetes when she was pregnant with you? 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 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.** Do you 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 do you have?

\_\_\_\_\_ brothers

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

\_\_\_\_\_ brothers

**22.** Do you 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 do you have?

\_\_\_\_\_ sisters

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

\_\_\_\_\_ sisters

**23.** Were you born in the United States?

1  Yes (If Yes, go to question 24)

2  No

**23a.** If no, in what country were you born? Write in country of birth.

\_\_\_\_\_

**23b.** In what year did you come to the United States to live? Write in year. \_\_\_\_\_

3  Don't know; prefer not to say

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

1  Yes (If Yes, go to question 25)

2  No

**24a.** If no, in what country was your mother born? Write in country of birth.

\_\_\_\_\_

Don't know country

**24b.** In what year did your 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 **father** born in the United States?

1  Yes (If Yes, go to next page)

2  No

**25a.** If no, in what country was your father born? Write in country of birth.

\_\_\_\_\_

Don't know country

**25b.** In what year did your 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 you lived.

CITY

STATE

ZIP CODE

COUNTY

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27. On April 1st 2017, were you in the Army, Navy, Air Force, Marines, or the Coast Guard?

1  Yes 2  No 3  Don't know

28. When you **first** got diabetes, were you in the Army, Navy, Air Force, Marines, or the Coast Guard?

1  Yes 2  No 3  Don't know

## 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. What is your name?

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First Name

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Middle Name

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Last Name

Are there any other names that you use?

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Other first names

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Other last names

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

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First Name

---

Middle Name

---

Last Name

Parent  Guardian #1

C. "Full Name of Parent or Guardian #2 of child **(Please note if Parent or Guardian.)**

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First Name

---

Middle Name

---

Last Name

Parent  Guardian #2

**D.** Provide your current address, email and phone number for future contact.

---

P.O. Box                      Street    Apt#

---

City

---

State                      Zip Code

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Email address

Phone number (best) \_\_\_\_\_

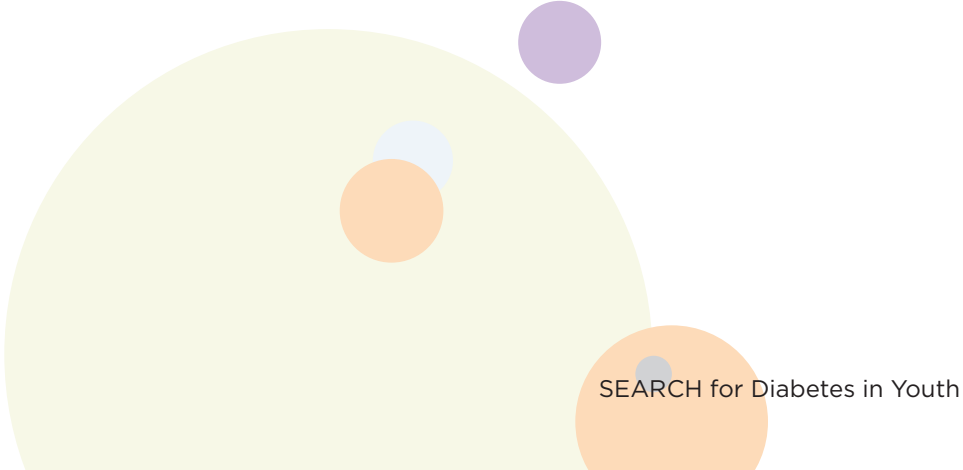
area code  
Is this:  Home  Work  Cellular Phone  Other

Phone number (other) \_\_\_\_\_

area code  
Is this:  Home  Work  Cellular Phone  Other

Phone number (other) \_\_\_\_\_

area code  
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:

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First Name

---

Middle Name

---

Last Name

---

Relationship

---

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

**Contact #2:**

\_\_\_\_\_  
First Name

\_\_\_\_\_  
Middle Name

\_\_\_\_\_  
Last Name

\_\_\_\_\_  
Relationship

\_\_\_\_\_  
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

**Thank You** for filling out this survey.

Please mail it to us in the stamped, pre-addressed envelope.



## 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





