



**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 <b>TODAY'S</b> da	nte?/	/_		
		Month	Day	Year	
	For example, if today is M	lay 1, 2016, write in C	)5/01/2016		
2.	What is your sex?	1 <b>□</b> Female	2 🗖 Mal	е	
3.	What is your BIRTH[	DATE??		/	_/
			Month	Day	Year

**4.** Has your doctor or nurse ever told you that you have diabetes?

1 ☐ YES.

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



City	State	Zip Code	County	
City	State	Zip Code	County	
City	State	Zip Code	County	

Year



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	No 2 <b></b>	I found out that I had diabetes because I was thirsty, had to pee a lot, or got sick very quickly.
Yes	No 2 <b></b>	I found out that I had diabetes at a yearly physical or check-up with my regular doctor.
Yes	No 2 <b></b>	I found out that I had diabetes when my blood sugar was checked at a health fair or by a school nurse.
Yes	No 2 🗖	I found out that I had diabetes when I 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 you had diabetes.



8.	Has a doctor or nurse told you that your diabetes was caused by: (please check Yes or No for each question)
	<b>8a.</b> Cystic fibrosis? 1 Yes 2 No
	<b>8b.</b> Cancer or medicine to treat cancer? 1 ☐ Yes 2 ☐ No
	<b>8c.</b> 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
	<b>9b.</b> Are you taking insulin now? 1 ☐ Yes 2 ☐ No
10.	How else do you take care of your diabetes <b>now</b> ?  Do you: (please check Yes or No for each question)
	<b>10a.</b> Take prescribed tablets (pills) for diabetes? 1 ☐ Yes 2 ☐ No
	<b>10b.</b> Follow a diet/meal plan (for example, carbohydrate counting)? 1 ☐ Yes 2 ☐ No
	<b>10c.</b> 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 do you usually see for <b>most</b> 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		nsurance OW
	YES	NO	YES	NO
<b>12a.</b> Medicaid/Medicare	1 🗖	2 🗖	1 🔲	2 🗖
<b>12b.</b> Private insurance, through employer	1 🗖	2 🗖	1 🗖	2 🗖
<b>12c.</b> Private insurance, purchased on your own	1 🗖	2 🗖	1 🗖	2 🗖
<b>12d.</b> Private insurance, purchased through the health insurance exchange or marketplace	1 🗖	2 🗖	1 🗖	2 🗖
<b>12e.</b> Military	1 🗖	2 🗖	1 🗖	2 🗖
<b>12f.</b> School or college-based insurance	1 🗖	2 🗖	1 🗖	2 🗖
<b>12g.</b> Tribe/Indian Health Service	1 🗖	2 🗖	1 🗖	2 🗖
<b>12h.</b> Any other or type unknown	1 🗖	2 🗖	1 🗖	2 🗖
<b>12i.</b> No health insurance	1 🔲	2 🗖	1 🔲	2 🗖

13.	Are you Spanish/Hispanic/Latino? (Mark X in the "No" box if <b>not</b> 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 race? Mark on	e or more races to in	dicate what you consider yourself to be.
	■ White	☐ Black, Africar	n American
	☐ American Indian or A	Alaska Native; Print r	name of enrolled or principal tribe below:
	☐ Asian Indian	Japanese	☐ Native Hawaiian
	☐ Chinese	☐ Korean	☐ Guamanian or Chamorro
	☐ Filipino	■ Vietnamese	☐ Samoan
	Other Asian; Print ra	ce:	
	☐ Other Pacific Islande	er; 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 🗖	1 🗖	1 🗖
15b. High school graduate, (high school diploma) or equivalent (for example, GED)	2 🗖	2 🗖	2 🗖
15c. Business/technical school, associate degree (AA, AS) or some college	3 🗖	3 🗖	3 🗖
15d. Bachelor degree (for example, BA, AB, BS) (4-year)	4 🗖	4 🗖	4 🗖
15e. Master degree (for example MA, MS, MEng, Med., MSW)	5 🗖	5 🗖	5 🗖
15f. Professional or doctorate degree (for example, MD, DDS, JD, PhD, EdD)	6 🗖	6 🗖	6 🗖
15g. Don't know	7 🗖	7 🗖	7 🗖

1. Less than \$5,000 6. \$35,000 through \$49,999 2. \$5,000 through \$11,999 3. \$1,2000 through \$15,999 4. \$16,000 through \$24,999 9. \$100,000 and greater 5. \$25,000 through \$34,999 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		or the past 12 months? (Inc. disability, alimony, child sup) Check only one category:	ome could		income of all persons living in your household ry, social security, retirement, Medicaid,
3. \$12,000 through \$15,999 8. \$75,000 through \$99,999 4. \$16,000 through \$24,999 9. \$100,000 and greater 5. \$25,000 through \$34,999 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		1. 🗖 Less than \$5,000	6	S. <b>🔲</b> \$35,000	through \$49,999
4. \$\ \\$16,000 through \\$24,999  9. \$\ \\$100,000 and greater \\ 5. \$\ \\$25,000 through \\$34,999  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 children (less than 18 years)  17c. Number of adults  17d. Please mark which adults live in the household   \qquad     \		2. <b>\( \)</b> \$5,000 through \$11,999	)	7. 🗖 \$50,000	through \$74,999
7. How many people are currently living in your household, including yourself?  17a. Total number of people		3. 🔲 \$12,000 through \$15,999		3. 🔲 \$75,000	through \$99,999
7. How many people are currently living in your household, including yourself?  17a. Total number of people		4. <b>□</b> \$16,000 through \$24,999		9. 🔲 \$100,000	) and greater
17a. Total number of people		5. <b>\( \)</b> \$25,000 through \$34,9	99 10	). 🔲 Don't kn	ow
Mother  Father  Guardian  Roommate/ Friend  Spouse/Partner  Other adult(s)  Ilease provide information about your mother, father, brothers, and sisters. This refeour biological or natural parents (not step-parents or adoptive parents) and your furothers and sisters, not those who were adopted or step brothers or step sisters.  Ilease include information for relatives who are living and those who are deceased.  B. 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  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.	7.	<ul><li>17a. Total number of people</li><li>17b. Number of children (les</li><li>17c. Number of adults</li></ul>	 ss than 18 y	/ears)	
Father			YES	NO	
Guardian		Mother			
Roommate/ Friend		Father			
Spouse/Partner  Other adult(s)  ow we would like to ask you a few questions about whether or not other people in mily have diabetes.  lease provide information about your mother, father, brothers, and sisters. This reference bur biological or natural parents (not step-parents or adoptive parents) and your furthers and sisters, not those who were adopted or step brothers or step sisters.  lease include information for relatives who are living and those who are deceased.  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  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.		Guardian			
Other adult(s)  Other adult(s)  Ow we would like to ask you a few questions about whether or not other people in mily have diabetes.  ease provide information about your mother, father, brothers, and sisters. This reference bur biological or natural parents (not step-parents or adoptive parents) and your furthers and sisters, not those who were adopted or step brothers or step sisters.  ease include information for relatives who are living and those who are deceased.  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  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.		Roommate/ Friend			
ow we would like to ask you a few questions about whether or not other people in mily have diabetes.  ease provide information about your mother, father, brothers, and sisters. This reference but biological or natural parents (not step-parents or adoptive parents) and your furthers and sisters, not those who were adopted or step brothers or step sisters.  ease include information for relatives who are living and those who are deceased.  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  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.		Spouse/Partner			
lease provide information about your mother, father, brothers, and sisters. This reference bur biological or natural parents (not step-parents or adoptive parents) and your furothers and sisters, not those who were adopted or step brothers or step sisters.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.  Lease include information for relatives who are living and those who are deceased.		Other adult(s)			
<ul> <li>18a. ☐ If Yes, how old was she when she was diagnosed with diabetes? years ☐ Don't know</li> <li>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.</li> </ul>	m	ily have diabetes.			
years Don't know  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.	ou ro le	r biological or natural par thers and sisters, not thos ase include information fo	rents (not se who we or relative	t step-parer ere adopted es who are li	its or adoptive parents) and your full or I or step brothers or step sisters.
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.	ro lea	thers and sisters, not those include information for Does your biological mother	rents (not se who we or relative	t step-paren ere adopted es who are li petes?	its or adoptive parents) and your full or I or step brothers or step sisters.
This includes Type 1 diabetes, Type 2 diabetes, gestational diabetes, or other types of diabetes.	ro lea	thers and sisters, not those ase include information for Does your biological mother 1 Yes 2 No 3	rents (not se who we or relative r have diab decided to the control of the contro	t step-paren ere adopted es who are li petes?	its or adoptive parents) and your full or I or step brothers or step sisters. Iving and those who are deceased.
	ou ro le	priological or natural parthers and sisters, not those ase include information for Does your biological mother 1 Yes 2 No 3 18a. If Yes, how old was seen the second secon	rents (not see who we or relative have diable Don't know the see the when see the rent see the when see the whole who we will be a see that when see the whole who we will be a see that who will be a see that who will be a see that when see that who we will be a see that when see that who we will be a see that when see the whole which when see the whole which which we will be a see that which will be a see that which which which we will be a see that which which which we will be a see that which which which we will be a see that which which we will be a see that which which which will be a see that which which which we will be a see that which which which which which which which we will be a see that which which which which we will be a see that which which which which we will be a see that which which which which we will be a see that which which which which we will be a see that which which which which which which we will be a see that which which which which which will be a see that which which which will be a see that which which which which which we will be a see that which which	t step-paren ere adopted es who are li petes?	its or adoptive parents) and your full or I or step brothers or step sisters. I ving and those who are deceased.

20.	Does your biological father have diabetes?
	1 ☐ Yes 2 ☐ No 3 ☐ Don't know
	<b>20a.</b> $\square$ 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.
	<b>23b.</b> In what year did you come to the United States to live? Write in year

24.	vvas your moth	er born in the Officed States?					
	1 <b>□</b> Yes	(If Yes, go to question 25)					
	2 No						
	<b>24a.</b> If no,						
	☐ Don't k						
	<b>24b.</b> In wh	Write in year:					
	☐ Don't k	now year					
	3 🔲 Don't know	r; prefer not to say					
25.	Was your father born in the United States?						
	1 <b>□</b> Yes	(If Yes, go to next page)					
	2 ☐ No						
	<b>25a.</b> If no, in what country was your father born? Write in country of birth.						
	☐ Don't k						
	<b>25b.</b> In wh	Write in year:					
	🗖 Don't k						
	☐ Did not come to the United States						
	3 ☐ Don't know	r; prefer not to say					



## **Contact Information**

We would like to be able to reach you in the future to provide information about the SEARCH study. To do this, please provide the best contact information below.

Α.	What is your name?						
	First Name  Middle Name						
	Last Name						
	Are there any other names that you use?						
	Other first names						
	Other last names						
В.	Full Name of Mother or other adult						
	First Name						
	Middle Name						
	Last Name						
	☐ Mother ☐ Other Adult						
C.	C. Full Name of Father or other adult						
	First Name						
	Middle Name						
	Last Name						
	☐ Father ☐ Other Adult						

P.O.Box	Street	Apt#
City		
State Zip		
Email address		
hone number (best)		
	area code Is this:   Home  Work  Cellular Phone	☐ Other
hone number (other)		
	area code Is this:   Home  Work  Cellular Phone	☐ Other
hone 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:

First Name		
Middle Name		
Last Name		
Relationship		
P.O.Box S	treet	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 S	treet	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**

T

