



Initial Participant Survey - Parent/Guardian version

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

This survey is to be completed by the PARENT or LEGAL Guardian. We want to learn more about children and young people who have diabetes. You can help us to do that by filling out these questions. In this survey, we will use the term CHILD to refer to YOUR child or the child that you are the LEGAL GUARDIAN for.

Thank you for filling out these questions.

1. What is today's date? $\frac{\quad}{\text{Month}} / \frac{\quad}{\text{Day}} / \frac{\quad}{\text{Year}}$

For example, if today is May 1, 2002, write in: 05/01/2002

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

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

1 Yes → Continue to question 4.

1 No → **STOP. Please turn to page 9 and complete this information.**



Please mail the survey to us in the stamped envelope.

THANK YOU FOR ANSWERING THESE QUESTIONS!

.....

We would like to ask you some questions about your child's birthday, when your child first got diabetes, and how you or your child takes care of his/her diabetes. Please answer the questions as best you can. If you do not know the answer to a question, leave it blank.

4. What is your child's birthdate? $\frac{\quad}{\text{Month}} / \frac{\quad}{\text{Day}} / \frac{\quad}{\text{Year}}$

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

$\frac{\quad}{\text{Month}} / \frac{\quad}{\text{Day}} / \frac{\quad}{\text{Year}}$

6. How did you first find out that your child had diabetes? (check yes or no for each question)



1 Yes 2 No My child was thirsty, had to pee a lot, or got sick very quickly

1 Yes 2 No I found out that my child had diabetes when he/she had a school physical or at a regular check-up.

1 Yes 2 No I found out that my child had diabetes when his/her blood sugar was checked at a health fair or at school.

1 Yes 2 No I found out that my child had diabetes when she was pregnant and the diabetes did not go away after the pregnancy.

1 Yes 2 No I found out my child had diabetes when she was pregnant but the diabetes went 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:

7. What type of diabetes did the doctor or nurse tell you or your child that he/she has? (please check one box)

1 type 1 diabetes, IDDM, juvenile diabetes

2 type 2 diabetes NDDM

3 maturity onset diabetes of youth (MODY)

4 other type of diabetes, please specify _____

5 I don't know

8. Has a doctor or nurse told you or your child that his/her diabetes was caused by: (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. Has your child ever taken insulin? 1 Yes 2 No (if no, skip to question 11)

↓
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 use: (check yes or no for each

10a. Diabetes tablets (pills)? 1 Yes 2 No

10b. Diet (meal plan)? 1 Yes 2 No

10c. Exercise? 1 Yes 2 No

10d. Any treatments other than insulin, pills, diet, or exercise (what?): _____

11. 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 Am., Chicano
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino - *Print group.*



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12. 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.*



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- Asian Indian
- Japanese
- Native Hawaiian
- Chinese
- Korean
- Guamanian or Chamorro
- Filipino
- Vietnamese
- Samoan
- Other Asian – *Print race.*
- Other Pacific Islander – *Print race.*



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- Some other race – *Print race.*



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13. When your child **first** got diabetes, where did he/she live?

CITY STATE ZIP CODE COUNTY

14. When your child **first** got diabetes, was he/she in the Army, Navy, Air Force, Marines, or Coast Guard?



1 Yes 2 No 3 Don't know



Now we have some questions about your child's current height and weight.

15. What is your child's **current** weight? _____ Pounds; or _____ Kilograms; Don't know

16. What is your child's **current** height? _____ Feet _____ Inches; or _____ Centimeters; Don't know

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.

17. Does the child's biological mother have diabetes? 1 Yes 2 No 3 Don't know



17a. If yes, how old was she when she was diagnosed with diabetes?

___ ___ years 1 Don't know

18. Did the 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

19. Does the child's biological father have diabetes? 1 Yes 2 No 3 Don't know



19a. If yes, how old was he when he was diagnosed with diabetes?

___ ___ years 1 Don't know

20. Does the child have any full or half brothers? 1 Yes 2 No 3 Don't know *(if no, or don't know, skip to question 21)*



20a. If yes, how many full or half brothers does your child have? ___ ___ brothers

20b. If yes, how many of the full or half brothers have diabetes? ___ ___ brothers

21. Does the child have any full or half sisters? 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 sisters does your child have? ___ ___ sisters

21b. If yes, how many of the full or half sisters have diabetes? ___ ___ sisters

Now we would like to learn a bit about your child's health insurance and the health care services.

22. What kind of health insurance plan does your child have <u>now</u> ? (Answer yes or no for each question).		
a. Medicaid/Medicare/State-funded/ other Federally-funded	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
b. Private insurance, through employer	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
c. Private insurance, purchased on your own	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
d. Military	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
e. School-based insurance	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
f. Tribe/Indian Health Service	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
g. Any other or type unknown	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
h. None	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No

23. What kind of health insurance plan did your child have when he/she was diagnosed with diabetes? (Answer yes or no for each question).		
a. Medicaid/Medicare/State-funded/ other Federally-funded	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
b. Private insurance, through employer	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
c. Private insurance, purchased on your own	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
d. Military	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
e. School-based insurance	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
f. Tribe/Indian Health Service	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
g. Any other or type unknown	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No
h. None	1 <input type="checkbox"/> Yes	2 <input type="checkbox"/> No

24. Who does your child usually go to 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 professional (nurse, nurse practitioner, physician assistant, certified diabetes educator, or other)
- 7 Unsure

The next few questions are related to the education and household income of your family.

25. What is the highest degree or level of school that your child's mother/guardian and father/guardian have completed?		
	Mother/guardian	Father/guardian
25a. Any education less than a high school graduate, no diploma or GED	1 <input type="checkbox"/>	1 <input type="checkbox"/>
25b. High school graduate (high school diploma) or equivalent (for example: GED)	2 <input type="checkbox"/>	2 <input type="checkbox"/>
25c. Business/technical school, associate degree (AA, AS), or some college	3 <input type="checkbox"/>	3 <input type="checkbox"/>
25d. Bachelor degree (for example, BA, AB, BS) (4-year)	4 <input type="checkbox"/>	4 <input type="checkbox"/>
25e. Master degree (for example, MA, MS, MEng, Med, MSW)	5 <input type="checkbox"/>	5 <input type="checkbox"/>
25f. Professional or doctorate degree (for example: MD, DDS, JD, PhD, EdD)	6 <input type="checkbox"/>	6 <input type="checkbox"/>
25g. Don't know	7 <input type="checkbox"/>	7 <input type="checkbox"/>

26. 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? *(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

27. How many people are living in the parent/Guardian's household?

a. Total number of people _____

b. Number of children (less than 18) _____

c. Number of adults _____ Of the number of adults, how many bring income into the household? _____

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

1 Yes (*If Yes, go to question 29*)

2 No **➔** 28a. In what country was your child born? _____
(*write in country of birth*)

28b. In what year did your child come to the United States to live? _____
(*write in year*)

3 Don't know/prefer not to say

29. Was the child's mother born in the United States?

1 Yes (*If Yes, go to question 30*)

2 No **➔** 29a. In what country was the child's mother born? _____
(*write in country of birth*)

Don't know country

29b. In what year did the child's mother come to the United States to live? _____
(*write in year*)

Don't know year

3 Don't know/prefer not to say

30. Was the child's father born in the United States?

1 Yes (*If Yes, go to the next page*)

2 No **➔** 30a. In what country was the child's father born? _____
(*write in country of birth*)

Don't know country

30b. In what year did the child's father come to the United States to live? _____
(*write in year*)

Don't know year

3 Don't know/prefer not to say

Contact Information

We would like to be able to reach you and your child to let you know about other parts of the SEARCH study. To do this, we would like to have the best address and phone number where we can reach you and your child.

A. What is your child's name?

_____/_____/_____
 First Middle Last

Are there any other names that he/she uses?

 Other first name(s)

 Other last name(s)

Joe Mary

B. What are your child's parent/guardians' names?

_____/_____/_____
 First Middle Last

_____/_____/_____
 First Middle Last

C. What is the **best** address and phone number to send mail or call?



_____/_____/_____
 P.O. Box Street Apt. #

_____/_____/_____
 City State Zip Code

Email Address _____

Phone # (best) _____ - _____
 (area code) (extension)

Is this: Home Work Cellular phone Other

Phone # (other) _____ - _____
 (area code) (extension)

Is this: Home Work Cellular phone Other

Phone # (other) _____ - _____
 (area code) (extension)

Is this: Home Work Cellular phone Other



What is the best time to call? morning afternoon evening

May we contact you over the weekend? Yes No

May we contact you at work? Yes No

Who lives at this address (*on the previous page*)? (*check yes or no for each one*)

My child does 1 Yes 2 No

Child's Father 1 Yes 2 No

Child's Mother 1 Yes 2 No

Child's Spouse 1 Yes 2 No

Other 1 Yes 2 No



Does your child usually speak:

1 English

2 Spanish

3 Some other language *Specify:* _____

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 email addresses of two people who could contact you if your address or phone number changes.

Contact #1:

_____/_____/_____
First Name Middle Name Last Name

Relationship

_____/_____/_____
P.O. Box Street Apt. #

_____/_____/_____
City State Zip Code

Email Address _____

Phone # (best) ____/____-_____
(area code) (extension)

Phone # (other) ____/____-_____
(area code) (extension)

Phone # (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 # (best) ____/____-_____
(area code) (extension)

Phone # (other) ____/____-_____
(area code) (extension)

Phone # (other) ____/____-_____
(area code) (extension)

THANK YOU FOR FILLING OUT THIS SURVEY.

PLEASE MAIL IT TO US IN THE STAMPED PRE-ADDRESSED ENVELOPE.

If you have lost the envelope, please send it to the address below.

FOR STUDY USE ONLY

Patient ID
Number

Site	Sub-site	Sequential ID				

Date
Completed

Month	Day	Year				

Completed by

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Mode of Administration

1 In-Person 1 Telephone 1 Mailed CATI

Date Reviewed

Month	Day	Year				

Reviewer Code

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Date Entered

Month	Day	Year				

Data Entry Code

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