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SEARCH STUDY

QUALITY OF CARE 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.

Public reporting burden of this collection of information is estimated to average 13 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).

This survey asks questions about your experiences with health care and how you and your child take care of diabetes on your own. There are no right or wrong answers and all of the information you provide will be kept confidential. Your answers will help us learn more about the quality of health care patients and their families receive for diabetes.

HEALTH INSURANCE

1. Has your child had health insurance continuously during the past 12 months?

1 Yes 2 No



If no, for how many months was your child not covered by health insurance? _____ months.

YOUR CHILD'S HEALTH CARE IN THE LAST 12 MONTHS

The next questions ask about your child's health care in general. Do not include care your child got when he or she stayed overnight in a hospital. Do not include the times your child went for dental care visits.

2. In the last 12 months, how much of a problem, if any, was it to get the care, tests, or treatment you or a doctor believed necessary?

1 A big problem

2 A small problem

3 Not a problem

3. In the last 12 months, has there been a time when you thought your child should get care but did not receive it?

1 Yes

2 No

4. How much of a problem is the cost of your child's health care for you (including paying for health insurance premiums and co-payments for doctor's office visits, medications, and medical supplies)?

- ¹ A big problem
² A small problem
³ Not a problem

PRESCRIPTION MEDICATIONS

5. In the last 12 months, how much of a problem, if any, was it to get your child's prescription medicine and medical supplies?

- ¹ A big problem
² A small problem
³ Not a problem

EXPERIENCES WITH CARE

6. In the last 12 months, did your child's doctors or other health providers talk with you about how your child is feeling, growing or behaving?

- ¹ Yes
² No

7. Do your child's doctors or other health providers understand how your child's medical, behavioral or other health conditions affect your child's day-to-day life?

- ¹ Yes
² No

8. Do your child's doctors or other health providers understand how your child's medical, behavioral or other health conditions affect your family's day-to-day life?

- ¹ Yes
² No

9. In the last 12 months, how often did your child’s doctors or health providers:

	Never	Sometimes	Usually	Always
9a. Listen carefully to you?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
9b. Explain things in a way you could understand?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
9c. Show respect for what you had to say?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
9d. Spend enough time with your child?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

10. In the last 12 months, did you have any questions or concerns about your child’s health or health care?

- 1 Yes
- 2 No → (If No, go to Question 14)

11. In the last 12 months, how often did your child’s doctors or other health providers make it easy for you to discuss your questions or concerns?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

12. In the last 12 months, how often did you have your questions answered by your child’s doctors or other health providers?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

13. In the last 12 months, how often did you get the specific information you needed from your child’s doctors or other health providers?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

14. In the last 12 months, how often did you have a hard time speaking with or understanding your child's doctors or other health providers because they spoke different languages?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

15. An interpreter is someone who repeats or signs what one person says in a language used by another person.

In the last 12 months, did you need an interpreter to help you speak with your child's doctors or other health providers?

- 1 Yes
- 2 No → (If No, go to Question 17)

16. In the last 12 months, when you needed an interpreter to help you speak with your child's doctors or other health providers, how often did you get one?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

HEALTH CARE DECISIONS

We want to know how you, your child's doctors and other health providers make decisions about your child's health care.

17. In the last 12 months, were any decisions made about your child's health care?

- 1 Yes
- 2 No → (If No, go to Question 19)

18. When decisions were made in the last 12 months, how often did your child's doctors or other health providers:

	Never	Sometimes	Usually	Always
18a. <u>Offer you choices</u> about your child's health care?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
18b. <u>Discuss</u> with you the good and bad things about each of the different choices for your child's health care?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
18c. <u>Ask you</u> to tell them what choices <u>you</u> prefer?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
18d. <u>Involve you</u> as much as you wanted?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

YOUR CHILD'S PERSONAL DOCTOR OR NURSE

19. A personal doctor or nurse is the health provider who knows your child best. This can be a general doctor, a specialist doctor, a nurse practitioner, or a physician assistant.

Do you have one person you think of as your child's personal doctor or nurse? If your child has more than one personal doctor or nurse, choose the person your child sees most often.

¹ Yes

² No → (If No, go to Question 21)

20. Using any number from 0 to 10 where 0 is the worst personal doctor or nurse possible and 10 is the best personal doctor or nurse possible, what number would you use to rate your child's personal doctor or nurse?

0 1 2 3 4 5 6 7 8 9 10

Worst
personal
doctor or
nurse
possible

Best
personal
doctor or
nurse
possible

21. Using any number from 0 to 10 where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate all your child's health care in the last 12 months?

- 0 1 2 3 4 5 6 7 8 9 10

Worst
health
care
possible

Best
health
care
possible

22. In general, how would you rate your child's overall health now?

- ¹ Excellent
² Very Good
³ Good
⁴ Fair
⁵ Poor

Transition from Pediatric to Adult Care

The next questions are about preparing for your child's health care needs as he/she becomes an adult.

23. Is your child 12 yrs. of age or older?

- Yes
 No (*skip to question 32*)

24. Which of the following best describes your child's current diabetes provider?

- He/She is a pediatric provider, who treats mainly children
 He/She is an adult provider who treats mainly adults, except for a few children –
(*skip to question 32*)
 He/She is an adult and pediatric provider, who treats patients of all ages -
(*skip to question 32*)
 Not sure how to describe my child's current diabetes provider

- 25. Have they talked with you about having your child eventually see doctors or other health care providers who treat adults?**
- Yes *(skip to question 27)*
 - No
 - Not sure
- 26. Would a discussion about doctors who treat adults have been helpful to you?**
- Yes
 - No
 - Not sure
- 27. Have your doctors or other health care providers talked with you about your child's health care needs as your child becomes an adult?**
- Yes *(skip to question 29)*
 - No
 - Not sure
- 28. Would a discussion about your child's health care needs have been helpful?**
- Yes
 - No
 - Not sure
- 29. Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how to obtain or keep some type of health insurance coverage for your child as he/she becomes an adult?**
- Yes *(skip to question 31)*
 - No
 - Not sure
- 30. Would a discussion about health insurance have been helpful to you?**
- Yes
 - No
 - Not sure

31. How often do your doctors or other health care providers encourage your child to take responsibility for his/her health care needs, such as taking medication, checking blood sugars, understanding his/her health, or following medical advice?

- Never
- Sometimes
- Usually
- Always
- Don't know

HEALTH CARE FOR DIABETES

32. For the next set of items, please indicate if your doctor or other health provider has talked to you/your child, about the following:

a. What to do for low blood sugar?	¹ <input type="checkbox"/> Yes	² <input type="checkbox"/> No	³ <input type="checkbox"/> Unsure
b. What to do for high blood sugar?	¹ <input type="checkbox"/> Yes	² <input type="checkbox"/> No	³ <input type="checkbox"/> Unsure
c. Appropriate physical activity for your child?	¹ <input type="checkbox"/> Yes	² <input type="checkbox"/> No	³ <input type="checkbox"/> Unsure
d. Dietary guidelines for diabetes?	¹ <input type="checkbox"/> Yes	² <input type="checkbox"/> No	³ <input type="checkbox"/> Unsure
e. What a target blood sugar is for your child?	¹ <input type="checkbox"/> Yes	² <input type="checkbox"/> No	³ <input type="checkbox"/> Unsure
f. How to adjust your child's insulin or diabetes medication when he/she is sick?	¹ <input type="checkbox"/> Yes	² <input type="checkbox"/> No	³ <input type="checkbox"/> Unsure/ no diabetes medications prescribed
g. Psychological issues your child and your family may face with regard to having diabetes?	¹ <input type="checkbox"/> Yes	² <input type="checkbox"/> No	³ <input type="checkbox"/> Unsure
h. Who you can go to for general information about diabetes?	¹ <input type="checkbox"/> Yes	² <input type="checkbox"/> No	³ <input type="checkbox"/> Unsure

33. A test for hemoglobin A1C ("A one C") measures the average level of blood sugar over the past three months. About how many times in the past 12 months has a doctor or other health provider checked your child's hemoglobin A1C?

- ¹ None
- ² Once
- ³ Twice
- ⁴ Three or more times
- ⁵ Don't know/ Not sure

34. What A1C do you want your child to have?

_____ (write in number)

Don't know/ Not sure

35. During the past 12 months, how often has your child's blood pressure been checked during visits to your doctor's office?

1 Every visit

2 Most visits

3 At least once

4 Never

5 Don't know/ Not sure

36. When was the last time your child had an eye exam by an eye specialist in which his/her pupils were dilated (drops in his/her eyes that make eyes temporarily sensitive to bright light) or a diabetes eye exam?

1 In the past year

2 More than a year but less than 2 years

3 2 – 5 years

4 More than 5 years

5 Never

6 Don't know/Not sure

37. When was the last time your child had a urine test at the doctor's office to check on his/her kidney functioning?

1 In the past year

2 More than a year but less than 2 years

3 2 – 5 years

4 More than 5 years

5 Never

6 Don't know/Not sure

38. When was the last time your doctor took a sample of your child's blood to test for cholesterol or the amount of fat in your child's blood?

- 1 In the past year
- 2 More than a year but less than 2 years
- 3 2 – 5 years
- 4 More than 5 years
- 5 Never
- 6 Don't know/Not sure

39. When was the last time your child took off his/her shoes and socks in your doctor's office to have your child's feet examined to check the feeling in his/her feet?

- 1 In the past year
- 2 More than a year but less than 2 years
- 3 2 – 5 years
- 4 More than 5 years
- 5 Never
- 6 Don't know/Not sure

DIABETES SELF-CARE

The following questions ask about what you and your family usually do to take care of your child's diabetes. There are no right or wrong answers. Please think about the past 3 months and select the answer that comes closest to what your child has done.

40. Does your child wear or carry anything that identifies him/her as having diabetes, like a card or bracelet?

- 1 Wears necklace, bracelet or charm
- 2 Carries billfold identification card only
- 3 Has identification but does not wear or carry it
- 4 Does not have identification about diabetes

HYPOGLYCEMIA

Please think about what you or your child usually did about low blood sugar reactions in the past 3 months.

41. Does your child keep something with her/him to eat in case his/her blood sugar gets too low?

- 1 Yes
- 2 No
- 3 Does not have low blood sugars/no prescribed diabetes medications → (Go to Question 44)

42. If you/your child think he/she has a low blood sugar, how often do you or your child test before treating?

- 1 Always
- 2 More than half the time
- 3 Half the time
- 4 Less than half the time
- 5 Never
- 6 Does not have low blood sugars/no prescribed diabetes medications

43. If you/your child think he/she has a low blood sugar, does he/she eat until feeling better?

- 1 Yes → 43a. If Yes, do you give or does your child take extra insulin for the food eaten while feeling low?
 - 1 No
 - 2 Yes - Always
 - 3 Yes – If more that 15 grams of carbohydrates eaten
 - 4 Yes – If more than 30 grams of carbohydrates eaten
- 2 No
- 3 Does not have low blood sugars/no prescribed diabetes medications

EATING

44. Children with diabetes receive different dietary recommendations, depending on their own individual needs. Please indicate below which of the dietary recommendations you have received for your child from health care providers, and how frequently each method is currently used.

<i>Dietary Recommendations</i>	Have you ever received this recommendation for your child?			How frequently do you or your child currently use this method?		
	Yes	No	Don't know	Often	Sometimes	Never
keep track of calories						
count carbohydrates						
choose low glycemic index foods						
use dietary exchanges						
keep track of fat grams						
limit sweets						
limit high fat foods						
drink more milk						
eat more fruits and vegetables						
eat more fiber and whole grains						

45. Have you or your child been taught about how to adjust your child's insulin depending on how much or what kinds of food your child eats?

1 Yes → 45a. If YES, how often do you or your child adjust insulin based on what he/she has eaten?

1 Often

2 Sometimes

3 Never

2 No

3 Does not apply - insulin not prescribed for child

BLOOD SUGAR TESTING

The following questions have to do with your child's habits when it comes to testing blood sugar. Please think about the past 3 months and choose the answer that is closest to what you or your child has done.

46. In the past 3 months, how often have you or your child tested his/her blood sugar?

- 1 6 or more times daily
- 2 4 or 5 times daily
- 3 2 or 3 times daily
- 4 At least once daily
- 5 Does not test, or tests less than once a day
- 6 Don't know

47. How often has your child's diabetes care provider suggested that your child's blood sugar be tested?

- 1 6 or more times daily
- 2 At least 4 or 5 times daily
- 3 At least 2 or 3 times daily
- 4 At least once daily
- 5 Don't know

Thank you for completing this survey. We appreciate your participation in this important study!

FOR STUDY USE ONLY					
Date Completed	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 40px; height: 20px;" type="text"/>	Completer Code	<input style="width: 40px; height: 20px;" type="text"/>
	Month	Day	Year		
Date Reviewed	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 40px; height: 20px;" type="text"/>	Reviewer Code	<input style="width: 40px; height: 20px;" type="text"/>
	Month	Day	Year		
Date Entered	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 40px; height: 20px;" type="text"/>	Data Entry Code	<input style="width: 40px; height: 20px;" type="text"/>
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