Å.			(affix lab	el here))	
-webee	Patient ID Number	Site	Sub-site		Sequential ID	

SEARCH Health Questionnaire – Parent Version

- The purpose of this questionnaire is to learn more about children and adolescents who have diabetes. This questionnaire is to be completed by the parent or legal guardian of the child (under age 18) who has diabetes.
- In the questionnaire, the term "doctor" to refers to the doctor or other health care provider, such as a nurse.

	CO-MORBIDITIES/	COMPLICATIONS
1. Has your child even	r been tested for any genes relat	ed to diabetes?
1 ☐ Yes	1a. Results:	
	1b. When was the test done?	Month Year
	1c. Where was this test done?	
2 🗖 No		
3 🗖 Don't know		
2. Has a doctor ever t his/her blood?	told you or your child that he/sh	e has high cholesterol or an abnormal amount of fat in
1 ☐ Yes →	2a. If yes, has a doctor ever pr	escribed medicine for high cholesterol or high fat?
	1 Yes 2 No	3 Don't know
	2b. Is your child now taking pro	escribed medicine for high cholesterol or high fat?
	1 Yes 2 No	3 Don't know
	2c. Has a doctor ever recomme cholesterol?	nded changes in your child's diet to lower
	1 Yes 2 No	3 Don't know
2 🗖 No		
3 Don't know		

SEARCH 3 Cohort Study -Health Questionnaire - Parent Version - 12-09-10

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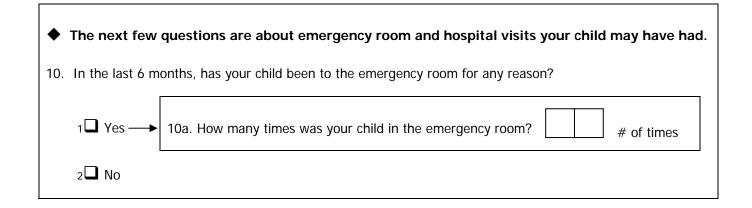
Public reporting burden of this collection of information is estimated to average 15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining data needed, and completing and reviewing the collection of information. An agency may not 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-xxxx)

3. Has a doctor ev	ver told you or your	child that he/sh	he has high blood pressure?
1 🖵 Yes —	➔ 3a. If yes, has	a doctor ever p	rescribed any medicine for high blood pressure?
	1 Yes	2 🗖 No	3 Don't know
	3b. Is your ch	iild now taking a	iny medicine for high blood pressure?
	1 Yes	2 🗖 No	3 Don't know
2 🖵 No			
3 🗖 Don't kno	W		
4. Has a doctor ev	ver told you or your	child that he/sh	he had any of the following?
1 🖵 Yes	2 N O A	ddison's Disease	9
1 🖵 Yes	2 N O A	sthma	
1 Ves	2 🗖 No 🛛 C	celiac disease	
1 🖵 Yes	2 🗖 No 🛛 H	lyperthyroidism	(high thyroid)
1 🖵 Yes	2 🗖 No 🛛 H	lypothyroidism ((low thyroid)
1 Yes	2 🗖 No 🛛 V	'itiligo (white ski	n patches)
5. Has a doctor sa	id that diabetes ha	s affected your o	child's kidneys?
1 Yes			
2 □ No			
3 🗖 Don't kno	0W		
6. Has a doctor sa	id that diabetes ha	s damaged the t	back of your child's eyes, that is, the retina?
1□ Yes →	6a. If yes, did this	s require laser tr	reatment of the retina?
	1 🖵 Yes		
	2 🗖 No		
2 🗖 No			
3 Don't kno)W		
3 🖵 Don't kno	W		

7. Has your child had any other major illness or medical conditions that we have not asked about?
$_{1}$ Yes \longrightarrow If yes, please describe:
2 🗖 No

Questions 8 and 9 are for FEMALES only.
8. Has your child already had her first period?
1 ☐ Yes → 8a. If yes, how old was your child when she had her years old first period?
1 Don't know
2 🗖 No
3 Don't know
9. Has a doctor ever told you or your child that your child has polycystic ovaries (PCO, PCOS)?
1 Yes
2 🗖 No
3 Don't know

MEDICAL HISTORY



11. In the last 6 m	onths, has your child had one or more night's hospital st	ay for any reason?
1 🖵 Yes →	. 11a. How many times was your child in the hospital for one or more nights?	# of times
2 🗖 No		
	oonths, has your child had any severe hypoglycemia, tha m/her to get help?	t is, very low blood sugar that
1□ Yes →	12a. How many times?	# of times
	12b. How many times was your child given an injection of glucagon – for hypoglycemia (low blood sugar)?	# of times
	12c. How many times was "911" or life squad/ paramedics called for hypoglycemia?	# of times
	12d. How many times did your child go to an emergency room for hypoglycemia?	# of times
	12e. How many times did your child need to stay overnight at a hospital?	# of times
2 🗖 No		
	nonths, has your child had ketoacidosis (often called DKA nd shortness of breath)?	A, frequently with high blood sugar,
1□ Yes →	13a. How many times?	# of times
	13b. How many times did this result in an emergency room visit?	# of times
	13c. How many times did this result in one or more night's hospital stay?	# of times
2 🗖 No	L	

MEDICATION INVENTORY

Insulin Use	
14. Was your child ever treat	ted with insulin (shots/pumps) since he/she was diagnosed?
1 No <i>(skip to questic</i>	n 20)
2 Ves	
15. If yes, when were insulin	shots/pump started?
1 At diagnosis	
2 Less than 1 month	after diagnosis
$_{3}$ Within 1-6 months	after diagnosis
4 Within 6-12 month	s after diagnosis
$_{5}$ 1 year or more after	er diagnosis
16. Did your child ever stop	aking insulin?
1 No <i>(skip to questic</i>	n 20)
2 Yes	
17. If yes, did that happen	
1 Less than 1 st mont	h after diagnosis
2 2 1-6 months after d	iagnosis
3 - 6-12 months after	diagnosis
$4\Box$ 1 year or more after	er diagnosis
18. How long was your child	off insulin?
1 Less than 1 month	
$2\Box$ 1-6 months	
3 6-12 months	
4 4 1 year or more	

19. Did your child ever have any episodes of ketoacidosis (DKA) when	า insulin w	as stopped?		
1 Yes				
2 🗖 No				
3 Don't know				
20. How does your child currently treat his/her diabetes? Does your c	hild use:	(check yes or	r no for each)	
20a. Diabetes tablets (pills) 1 Yes 2 No				
20b. Insulin shots, pump, or pen 1 Yes 2 No				
20c. Diet (meal plan) 1 Yes 2 No				
20d. Exercise 1 Yes 2 No				
20e. Other (what?)				
21. If your child is currently taking insulin, how often does he/she taking insulin, go to question 24)	ke insulin	each day on a	average? <i>(if your</i>	
1 1 time a day 4 More than 3 times a day				
2 2 times a day 5 Insulin pump				
3 3 times a day				
22. How does your child take insulin?				
1 22a. With a syringe (needle)				
${}_{2}\Box$ 22b. With an insulin pump				
3 22c. With an insulin pen				
23. What was the dose of insulin (number of units) that your child		Works	sheet	
took yesterday. (If your child uses an insulin pump, record the bolus amounts in 23a – 23e, and record the total 24-hour basal dose in 23f. This may require filling out a worksheet of	23a.	Breakfast		
hourly basal rates to determine the total basal dose.)	23b.	Lunch		
	23c.	Dinner		
	23d.	Bedtime		
	23e.	Other		
	23f.	Pump		
	Total in	sulin		

Is your child under ten years of age? No (If No	es, continue to Question 24) o, skip to question 26)
24. How often did your child miss his/her diabetes m	
1 Doesn't take diabetes medicine <i>(skip to qu</i>	lestion 26)
2 Never (skip to question 26)	
3 1-3 times a month	
$4\Box$ 1-5 times a week	
5	
6 More than 1 time a day	
25. Check Yes, No, or Not applicable. When your ch	nild misses a diabetes medicine is it because:
25a. 1 Yes 2 No 3 Not applicable	Forgot
25b. 1 Yes 2 No 3 Not applicable	Thought it would help to lose weight
25c. 1 Yes 2 No 3 Not applicable	Worried about low blood sugar
25d. 1 Yes 2 No 3 Not applicable	Cannot afford insulin supplies or other medicine
25e. 1 Yes 2 No 3 Not applicable	Don't want to give insulin when others are around
25f. 1 Yes 2 No 3 Not applicable	Tired of shots
25g. 1 Yes 2 No 3 Not applicable	Afraid of needles
25h. 1 Yes 2 No 3 Not applicable	Other reason <i>(specify)</i>

Prescribed Medications	
26. Is your child taking prescribed medication(s) including ins	ulin?
1 Yes (If Yes, document up to 10 medications below. If you types or preparations.)	our child is taking insulin, be certain to include all
2 No (if No, skip to question 27)	
1	-
2	-
3	_
4	-
5	_
6	_
7	-
8	-
9	_
10	_

Diabetes Education

The next few questions are about what you have been taught about diabetes.				
27. In the past 12 months have you met with a diabetes nurse or diabetes educator? 1□ Yes 2□ No 3□ Don't know				
28. In the past 12 mo your child's diet?	onths have you met with a dietician or nu	tritionist, oi	talked to s	someone in detail about
1 ☐ Yes →	28a. When he/she was staying one or more nights in the hospital	1 Yes	2 🗖 No	3 Don't know
	28b. As an outpatient	1 Yes	2 🗖 No	3 Don't know
2 🗖 No				

29.	In the past 12 months, which of the following types of diabetes information have you received from your child's doctor's office or health care plan? <i>(Check all that apply)</i>
	1 Information about diabetes camp
	1 Information about diabetes support groups
	$_1\square$ Written materials about diabetes such as pamphlets or newsletters
	1 Videos or audio tapes
	1 Reminder about upcoming appointments
	$_{1}\square$ A copy or explanation of diabetes laboratory or test results
	1 Diabetes information or advice by telephone
	1 Diabetes information or advice in person
	$1\Box$ How to get diabetes information on the internet
	1 Information about diabetes research studies other than this study

• I	Below are some questions about your child's d any other health care provider such as a nurs		and diabe	tes control	. "Doctor	", is a doctor or
30.	How would you rate your child's diabetes care 1 Excellent 2 Good 3 Fair	overall: Wo	uld you say	<i>I</i> :		
31.	4 Poor How would you rate: (<i>check the appropriate</i>)	boxes)				
		Excellent	<u>Good</u>	<u>Fair</u>	<u>Poor</u>	Not applicable
	Diabetes care from the doctor	1	2	3	4	5
	Getting answers to your diabetes questions	1	2	3	4	5
	Access during emergencies	1	2	3	4	5
	Getting explanation of lab results	1	2	3	4	5
	Courtesy/personal communication style of your doctor	1	2	3	4	5

32. How would you rate your child's diabetes control: Would you say:				
1 Excellent	1 Excellent			
2 Good	2 Good			
3 🗖 Fair				
4 Needs much work				
Home Diabetes Care				
Here are some questions	about your child's diab	petes care outside of the doctor's o	office.	
are separated, this would	include spending the week	on a regular basis? For example, if the kend with the child's other parent. It w tay with on a regular basis (at least on	vould also	
1 □ Yes → 33a. If ye	es, does he/she live in:			
1	2 households			
2	3 or more households			
3	Don't know			
2 No, live in one house	2 No, live in one household			
34. How much of your child's	diabetes care does your chi	ild do for him/herself? Would you say:	(check one)	
1 D None	1 D None			
2 Less than 25%				
3 25-75%				
4 More than 75%				
5 All <i>(skip to question</i>	36)			
35. Who helps your child with	his/her diabetes care?			
35a. Parent/step parent/g	35a. Parent/step parent/guardian 1 Yes 2 No			
35b. Grandparent	35b. Grandparent 1 Yes 2 No			
35c. Brother/sister	35c. Brother/sister 1 Yes 2 No			
35d. Another person	1 Ves	2 🖵 No		

36. Is your child's blood sugar tested at home or any place other than the doctor's office?				
1 □ Yes →	► 36a. How often is your child's blood sugar checked with a glucose meter (glucometer)? (check one)			
2 No (if no, go to question 37)	$2\Box$ Less than once a day			
	36b. Does your child use a continuous glucose monitor (CGM) to measure his/her glucose? 1 Yes 2 No <i>(if no go to 36c)</i> 36b(1). If yes, how does he/she use the CGM?			
	1 He/she has used it through his/her doctor's office			
	How often has he/she used it? \longrightarrow $_2$ \bigcirc 2 or more times $_3$ \bigcirc Don't know/not sure $_2$ \bigcirc My child has a CGM for use <u>at home</u>			
	How often does your child use it?			
	 Rarely/never (0-19% of the time) Occasionally (20-39% of the time) About half the time (40-59% of the time) Usually (60-79% of the time) Most of the time (80-99% of the time) Always (100% of the time) Don't know/not sure 			
	36c. What do you usually do when the blood sugar test results are running too high or too low?			
	36c(1). Make changes to the diabetes treatment (insulin dose 1 Yes 2 No or other medications, diet or exercise			
	36c(2). Call his/her diabetes doctor			
	36c(3). Talk to his/her diabetes doctor at the next visit 1 Yes 2 No			

Provider	Care		
♦ These q	uestions	are about the doctors or health care providers that your child sees.	
37. Who doe	es your ch	nild usually see for his/her diabetes care? (Check only one response)	
1	Pediatric	c endocrinologist/diabetologist (diabetes specialist)	
2	Pediatric	sian	
3	Family p	practice doctor	
4	General	practice doctor	
5	Adult en	ndocrinologist/diabetologist (diabetes specialist)	
6	Internist	t	
7	Nurse p	ractitioner/physician's assistant	
8	Nurse di	iabetes educator	
9	Traditior	nal medicine man, healer, or curandero/curandera	
10	Dieticiar	n/Nutritionist	
11	Other (s	specify)	
12	Don't kn	now/unsure of what kind of doctor	
13	None/nc	o source of medical care	

38. Who do	es your child usually see for his/her medical needs not related to diabetes? (Check only one response)			
1	Pediatric endocrinologist/diabetologist (diabetes specialist)			
2	Pediatrician			
3	Family practice doctor			
4	General practice doctor			
5	Adult endocrinologist/diabetologist (diabetes specialist)			
6	Internist			
7	Nurse practitioner/physician's assistant			
8	Nurse diabetes educator			
9	Traditional medicine man, healer, or curandero/curandera			
10	Dietician/Nutritionist			
11	Other <i>(specify)</i> →			
12	Don't know/unsure of what kind of doctor			
13	None/no source of medical care			

ſ

•			child? <i>(For each provider checked, ind</i> past 6 months)	dicate the nur	mber of visits your
39a.	1 Ves	2 🗖 No	Pediatric endocrinologist/ diabetologist (diabetes specialist)		# of visits in the last 6 months
39b.	1 Ves	2 🗖 No	Pediatrician		# of visits in the last 6 months
39c.	1 Ves	2 🗖 No	Family practice doctor		# of visits in the last 6 months
39d.	1 Ves	2 🗖 No	General practice doctor		# of visits in the last 6 months
3 9 e.	1 Ves	2 🗖 No	Adult endocrinologist/ diabetologist (diabetes specialist)		# of visits in the last 6 months
39f.	1 Ves	2 🗖 No	Internist		# of visits in the last 6 months
39g.	1 Yes	2 🗖 No	Nurse practitioner/physician's assistant		# of visits in the last 6 months
39h.	1 Yes	2 🗖 No	Nurse diabetes educator		# of visits in the last 6 months
39i.	1 Ves	2 🗖 No	Traditional medicine man, healer, or curandero/curandera		# of visits in the last 6 months
39j.	1 Ves	2 🗖 No	Dietician		# of visits in the last 6 months
39k.	1 Yes	2 🗖 No	Eye doctor (optometrist, ophthalmologist)		# of visits in the last 6 months
391.	1 Yes	2 🗖 No	Psychiatrist, psychologist, or mental health counselor		# of visits in the last 6 months
39m.	1 Ves	2 🗖 No	Other (specify)		# of visits in the last 6 months

Insurance and Cost of Diabetes Supplies					
40.	What kind of health insurance or health ca each one)	are plan doe	es your child	I have? (check ye	es, no or don't know for
	40a. Medicaid/Medicare/State-funded/ otl	her Federall	y-funded	1 Yes	2 🗖 No
	40b. Private insurance, through employer			1 Yes	2 🗖 No
	40c. Private insurance, purchased on you	r own		1 Ves	2 🗖 No
	40d. Military			1 Yes	2 🗖 No
	40e. School-based insurance			1 Ves	2 🗖 No
	40f. Tribe/Indian Health Service			1 Ves	2 🗖 No
	40g. Any other or type unknown			1 Ves	2 🗖 No
	40h. None (if none, go to question 42)			1 Yes	2 🗖 No
41.	Does your child's health insurance or health each one)	th care plan	pay for any	y of his/her <i>(ch</i>	eck yes, no or don't know for
	41a. Diabetes medicine/insulin	1 Yes	2 🗖 No	3 Don't knov	N
	41b. Syringes/pens/needles	1 Yes	2 🗖 No	3 Don't knov	N
	41c. Insulin pump and supplies	1 Yes	2 🗖 No	3 Don't knov	N
	41d. Home glucose monitor	1 Yes	2 🗖 No	3 Don't knov	N
	41e. Monitor strips and related supplies	1 Yes	2 🗖 No	3 Don't knov	N
	41f. Diabetes education	1 Yes	2 🗖 No	3 Don't knov	N
	41g. 🗖 Not applicable				
42.	About how much do you spend, on average does not include costs that are covered				
	1 🗖 \$0 (none)				
	2 🖵 \$1 - \$19				
	3 🗖 \$20 - \$49				
	4 🗖 \$50 - \$99				
	5 🗖 \$100 - \$199				
	6 \$ \$200 or more				
	7 Don't know				
1					

43. How satisfied are you with your child's current insurance coverage? Would you say:
1 Very satisfied
2 Satisfied
3 Somewhat satisfied
4 Not satisfied
44. Has your child's main health insurance plan changed in the last 6 months?
1 Yes (if yes, go to question 44a)
2 No (if no, go to question 45)
3 Don't know
4 Don't want to answer
44a. What were the reasons your child's health insurance plan changed? (check all that apply)
1 Employer stopped offering this plan
1 Doctor left this plan
1 Unhappy with benefits/coverage
1 Too difficult to get care
1 Moved
1 Change in jobs
$1\Box$ Other (specify) \longrightarrow
1 Don't know
1 Don't want to answer
45. Has your child's main diabetes provider changed in the last six months?
1 Yes (if yes, go to question 45a)
${}_{2}\square$ No (if no, go to question 46)
3 Don't know
4 Don't want to answer

45a.	What were the reasons your chi	ild had a change in diabetes provider? (check all that apply)
	1 No longer covered by healt	th plan
	1 Too difficult to get care	
	1 Not satisfied with care	
	1 D Moved	
	1 ☐ Other (<i>specify</i>) →	
	1 Don't know	
	1 Don't want to answer	

•	These questions deal with education and household income. Please remember that your answers are confidential.
46.	What is the highest degree or level of school you have COMPLETED?
	1
	3 5 th grade or 6 th grade
	4 7 th grade or 8 th grade
	5 9 th grade
	₀ 🖵 10 th grade
	7 ☐ 11 th grade
	8 □ 12 th grade, NO DIPLOMA
	${}_9 oldsymbol{\Box}$ High school graduate (high school diploma) or equivalent (for example: GED)
	10 Business/technical school
	11 Some college credit but less than 1 year
	12 1 or more years of college, no degree
	13 Associate degree (for example: AA, AS) (2-year)
	14 Bachelor's degree (for example: BA, AB, BS) (4-year)
	15 Master's degree (for example: MA, MS, MEng, MEd, MSW)
	16 Professional or doctorate degree (for example: MD, DDS, JD, PhD, EdD) 17 Don't know

47. What is the highest degree or level of school your current spouse/partner has COMPLETED?				
1 No schooling completed				
2 Nursery school to 4 th grade	2 Nursery school to 4 th grade			
3 5 th grade or 6 th grade	³ ³ 5 th grade or 6 th grade			
$4\Box$ 7 th grade or 8 th grade				
5 9 th grade				
₀☐ 10 th grade				
7 🗖 11 th grade				
8 12 th grade, NO DIPLOMA				
9 High school graduate (high school diploma) \circ	or equivalent (for example: GED)			
10 Business/technical school				
11 \Box Some college credit but less than 1 year				
$_{12}\Box$ 1 or more years of college, no degree				
13 Associate degree (for example: AA, AS) (2-year)				
14 Bachelor's degree (for example: BA, AB, BS) (4-year)			
15 Master's degree (for example: MA, MS, ME	ng, MEd, MSW)			
16 Professional or doctorate degree (for examp	ble: MD, DDS, JD, PhD, EdD)			
17 Don't know				
18 Not applicable (no current spouse/partner)				
48. Which of these categories best describes the total i past 12 months? <i>(Check only one category.)</i>	income of all persons living in your household for the			
1 Less than \$5,000	6 🗖 \$35,000 through \$49,999			
2 🖵 \$5,000 through \$11,999	7 🖵 \$50,000 through \$74,999			
3 🖵 \$12,000 through \$15,999	8 \$75,000 through \$99,999			
4 4 \$16,000 through \$24,999	9 \$100,000 and greater			
5 3 \$25,000 through \$34,999	10 Don't know			
	11 Prefer not to answer			

49.	How many people live in your child	d's main household (including the child and all parents/guardians)?
	49a. Total number of people	
	49b. Number of children (less than 18)	
	49c. Number of adults	
	49c(1). Of the number of a	adults, how many bring income into the household?
50.	Is your child participating in anoth	er research study?
	1	ıdy?
	2 🗖 No	

♦ As a part of the study, we will be contacting you in the future. It would be helpful to us if you could provide us with the names, addresses, and phone numbers of two people who could contact you even if you move.

Name	
Relationship	

Address:			
P.O. Box	Street		Apt. #
City		State	Zip Code
Email Address			

Phone # (best)		
	(area code)	ext.
Phone # (other)		
	(area code)	ext.
Phone # (other)	(area code)	ext.

Name			
Relationship			
Address:			
P.O. Box	Street		Apt. #
City		State	Zip Code
Email Address			
Phone # (best)			
	(area code)		ext.
Phone # (other)	(area code)		ext.
Phone # (other)			
	(area code)		ext.

Thank you for completing this questionnaire.

г

FOR STUDY USE ONLY				
Interview Assessment:				
1. How much difficulty did the Parent/Guardian have in understanding the questions?				
🗅 None 🗖 Slight 🗖 Mo	oderate A Great Deal Don't know			
2. Were there significant problems with the questionnaire?				
Yes J No				
If yes describe:				
Date Completed	Completed by Year			
Mode of Administration 1 In-Person 2 Telephone				
Date Reviewed	Year Reviewer Code			
Date Entered	Data Entry Code			