Form Approved OMB No. 0920-0904 Exp. Date 11/30/2014



		(affix labe	el here)
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

	CO-MORBIDITIES/C	OMPLICATIONS		
1. Has your child ever been tested for any genes related to diabetes?				
₁□ Yes →	1a. Results:			
	1☐ Don't know			
	1b. When was the test done?	Month Year		
	1c. Where was this test done?			
2 <b>□</b> No				
₃☐ Don't know				
Has a doctor ever this/her blood?	told you or your child that he/she	has high cholesterol or an abnormal amount of fat in		
₁☐ Yes →	2a. If yes, has a doctor ever pre	escribed medicine for high cholesterol or high fat?		
	1 Yes 2 No	3☐ Don't know		
	2b. Is your child now taking pre	scribed medicine for high cholesterol or high fat?		
	1  Yes 2  No	₃☐ Don't know		
	2c. Has a doctor ever recommen	nded changes in your child's diet to lower cholesterol?		
	1☐ Yes 2☐ No	3☐ Don't know		
2 <b>□</b> No				
₃☐ Don't know				

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3.	Has a doctor eve	er told you or yo	ur child that he/s	she has high blood pressure?
	₁☐ Yes ——	→ 3a. If yes, h	as a doctor ever	prescribed any medicine for high blood pressure?
		₁☐ Yes	2☐ No	3☐ Don't know
		3b. Is your	child now taking	any medicine for high blood pressure?
		₁☐ Yes	2☐ No	3☐ Don't know
	2☐ No			
	3☐ Don't kno	W		
4.	Has a doctor eve	er told you or yo	ur child that he/s	she had any of the following?
	₁☐ Yes	2 <b>□</b> No	Addison's Disea	se
	₁☐ Yes	2☐ No	Asthma	
	₁☐ Yes	2☐ No	Celiac disease	
	₁☐ Yes	2☐ No	Hyperthyroidism	n (high thyroid)
	₁☐ Yes	2 <b>□</b> No	Hypothyroidism	(low thyroid)
	₁☐ Yes	2☐ No	Vitiligo (white s	kin patches)
5.	Has a doctor sai	d that diabetes I	nas affected your	child's kidneys?
	₁☐ Yes			
	2☐ No			
	3☐ Don't kno	W		
6.	Has a doctor sai	d that diabetes I	nas damaged the	e back of your child's eyes, that is, the retina?
	₁□ Yes →	6a. If yes, did t	his require laser	treatment of the retina?
		₁☐ Yes		
		2☐ No		
	2☐ No			
	₃☐ Don't kno	w		

7. Has your child h	ad any other major illness or medical conditions that we have not asked about?
₁☐ Yes —	▶ If yes, please describe:
2☐ No	
Questions 8 and	9 are for FEMALES only.
8. Has your child ali	ready had her first period?
₁□ Yes →	8a. If yes, how old was your child when she had her first period? years old
	1☐ Don't know
2 <b>□</b> No	
₃☐ Don't kno	w
	r told you or your child that your child has polycystic ovaries (PCO, PCOS)?
1☐ Yes	
2☐ No	
₃☐ Don′t kno	w
	Medical History
◆ The next few	questions are about emergency room and hospital visits your child may have had.
10. In the last 6 m	onths, has your child been to the emergency room for any reason?
1 <b>□</b> Yes →	10a. How many times was your child in the emergency room? # of times
2 <b>□</b> No	

11. In the last 6 months, has your child had one or more night's hospital stay for any reason?				
1☐ Yes —→	11a. How many times was your child in the hospital for one or more nights?	# of times		
2 <b>□</b> No				
	onths, has your child had any severe hypoglycemia, that m/her to get help?	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 <b>□</b> No				
	onths, has your child had ketoacidosis (often called DKA nd shortness of breath)?	, frequently with high blood sugar,		
1 <b>□</b> 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				

### **MEDICATION INVENTORY**

## Insulin Use

14. Was your child ever treated with insulin (shots/pumps) since he/she was diagnosed?			
1 ☐ No (skip to question 20)			
2☐ Yes			
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 months after diagnosis			
5 ☐ 1 year or more after diagnosis			
16. Did your child ever stop taking insulin?			
1 No (skip to question 20)			
2☐ Yes			
17. If yes, did that happen			
1☐ Less than 1 <sup>st</sup> month after diagnosis			
2☐ 1-6 months after diagnosis			
3 ☐ 6-12 months after diagnosis			
4 ☐ 1 year or more after diagnosis			
18. How long was your child off insulin?			
1☐ Less than 1 month			
2☐ 1-6 months			
3 ☐ 6-12 months			
4☐ 1 year or more			

19. Did your child ever have any episodes	of ketoacido	sis (DKA) wher	n insulin w	as stopped?	
₁☐ Yes					
2 <b>□</b> No					
3☐ Don't know					
20. How does your child currently treat his	s/her diabete	s? Does your c	hild use:	(check yes or	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 child is not currently taking insulin, g			ke insulin	each day on a	average? <i>(if your</i>
$_1$ ☐ 1 time a day $_4$ ☐ More than	n 3 times a d	ay			
2 2 times a day 5 ☐ Insulin pu	ımp				
3 ☐ 3 times a day					
22. How does your child take insulin?					
1 ☐ 22a. With a syringe (needle)					
2☐ 22b. With an insulin pump	2 22b. With an insulin pump				
3 ☐ 22c. With an insulin pen					
23. What was the dose of insulin (number				Works	heet
took yesterday. <i>(If your child uses a the bolus amounts in 23a – 23e, and basal dose in 23f. This may require l</i>	record the to filling out a vi	otal 24-hour worksheet of	23a.	Breakfast	
hourly basal rates to determine the to	otal basal do	se.)	23b.	Lunch	
			23c.	Dinner	
			23d.	Bedtime	
			23e.	Other	
			23f.	Pump	
			Total in	sulin:	

ls v	our child under t	en vears o	f age?  \( \square \text{Yes, co} \)	ontinue to Question 24)		
13 y	our orma under t	on yours o		ip to question 26)		
24.	How often did y	our child r	niss his/her diabetes medic	cine including insulin?		
	Doesn't take diabetes medicine (skip to question 26)					
	2☐ Never (skip to question 26)					
	3 ☐ 1-3 times a month					
	4 <b>□</b> 1-5 times	a week				
	5 ☐ 1 time a d	ay				
	6☐ More than	1 time a c	lav			
25.	Check Yes, No,	or Not app	olicable. When your child n	nisses 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 <b>□</b> 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 <b>□</b> 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 (specify)		

<b>Prescribed Medication</b>	S			
26. Is your child taking prescribed medication(s) including insulin?				
1☐ Yes ( <i>If Yes, document types or preparat</i>	t up to 10 medications below. If you tions.)	ur child is t	aking insulii	n, be certain to include all
2☐ No (if No, skip to ques	stion 27)			
1.				
2.				
3.				
4				
5				
6.				
7				
8				
9				
10.				
<b>Diabetes Education</b>				
◆ The next few question	ns are about what you have bee	en taught	about diak	petes.
27. In the past 12 months nurse or diabetes educ	have you met with a diabetes cator?	₁☐ Yes	2☐ No	3☐ Don't know
28. In the past 12 months your child's diet?	have you met with a dietician or nu	tritionist, oi	r talked to s	someone in detail about
1 <b>□</b> 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 child's doctor's office or health care plan? (C)			nation hav	e you rece	ived from your
	1☐ Information about diabetes camp					
	1☐ Information about diabetes support grou	ps				
	1☐ Written materials about diabetes such as	pamphlets o	r newslette	ers		
	1☐ Videos or audio tapes					
	1 ☐ Reminder about upcoming appointments					
	1 ☐ A copy or explanation of diabetes laborate	tory or test re	esults			
	1☐ Diabetes information or advice by telepho	one				
	1☐ Diabetes information or advice in person					
	1 ☐ How to get diabetes information on the i	nternet				
	1☐ Information about diabetes research stud	dies other tha	n this stud	ly		
1						
	Below are some questions about your child's dany other health care provider such as a nurse		and diabe	tes contro	I. "Doctor	", is a doctor or
30.	How would you rate your child's diabetes care	overall: Wo	uld you say	<b>/</b> :		
	1☐ Excellent					
	2 ☐ Good 3 ☐ Fair					
	4☐ Poor					
31.	How would you rate: (check the appropriate a	boxes)				
	(	<u>Excellent</u>	Good	<u>Fair</u>	<u>Poor</u>	Not applicable
	Diabetes care from the doctor	1	2	<b>3</b>	4	5
	Getting answers to your diabetes questions	1	2	<b>3</b>	4	5
	Access during emergencies	1	2	3 <b></b>	4	5
	Getting explanation of lab results	1	$_2$	3 <b></b>	4	5
	Courtesy/personal communication style of your doctor	1	2	3	4	5

32. How would you rate your child's diabetes	s control: Wou	uld you say:
1☐ Excellent		
2☐ Good		
3☐ Fair		
4 Needs much work		
The recess mach work		
Home Diabetes Care		
♦ Here are some questions about your	child's diabe	etes care outside of the doctor's office.
are separated, this would include spend	ing the weeker	n a regular basis? For example, if the child's parents and with the child's other parent. It would also ay with on a regular basis (at least once per month).
1☐ Yes → 33a. If yes, does he/she	e live in:	
1 ☐ 2 households		
2☐ 3 or more hou	useholds	
3☐ Don't know		
2☐ No, live in one household		
34. How much of your child's diabetes care of	does your child	d do for him/herself? Would you say: (check one)
1☐ None		
2☐ Less than 25%		
3 ☐ 25-75%		
4  More than 75%		
5 All (skip to question 36)		
35. Who helps your child with his/her diabet	es care?	
,		
35a. Parent/step parent/guardian	₁☐ Yes	2☐ No
35b. Grandparent	₁☐ Yes	2 <b>□</b> No
35c. Brother/sister	₁☐ Yes	2☐ No
35d. Another person	₁☐ Yes	2 <b>□</b> 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)	1 Less than once a week 2 Less than once a day 3 □ 1-2 times a day 4 □ 3 times a day 5 □ 4-6 times a day				
	6 ☐ 7 or more times a day 7 ☐ Only when you are sick				
	36b. Does your child use a continuous glucose monitor (CGM) to measure his/her glucose?  1 Yes 2 No (if no go to 36c)				
	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  1 □ 1 time  he/she used it? → 2 □ 2 or more times  3 □ Don't know/not sure  2 □ My child has a CGM for use at home				
	How often does your child use it?				
	Rarely/never (0-19% of the time)  Cocasionally (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 1 ☐ Yes 2 ☐ No				
	36c(3). Talk to his/her diabetes doctor at the next visit 1 ☐ Yes 2 ☐ No				

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	◆ These questions are about the doctors or health care providers that your child sees.					
37. Who do	37. Who does your child usually see for his/her diabetes care? (Check only one response)					
1	Pediatric endocrinologist/diabetologist (diabetes specialist)					
$_{2}\square$	Pediatrician					
3 <b></b>	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 (specify) →					
12	Don't know/unsure of what kind of doctor					
13	None/no source of medical care					
20 Who do	es your child usually see for his/her medical needs not related to diabetes? (Check only one response)					
36. WHO GO	es your crinic usually see for fils/filer medical fleeus flot related to diabetes: (Check offly one response)					
1	Pediatric endocrinologist/diabetologist (diabetes specialist)					
$_2$	Pediatrician					
3 <b></b>	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 (specify) →					
12	Don't know/unsure of what kind of doctor					
13	None/no source of medical care					

<b>♦</b> F	♦ Here are questions regarding how often your child sees various medical providers.						
39.	39. Who provides medical care for your child? <i>(For each provider checked, indicate the number of visits your child had with this provider in the past 6 months)</i>						
	39a.	₁☐ Yes	2☐ No	Pediatric endocrinologist/ diabetologist (diabetes specialist)		# of visits in the last 6 months	
	39b.	₁☐ Yes	2☐ No	Pediatrician		# of visits in the last 6 months	
	39c.	₁☐ Yes	2☐ No	Family practice doctor		# of visits in the last 6 months	
	39d.	₁☐ Yes	2☐ No	General practice doctor		# of visits in the last 6 months	
	39e.	₁☐ Yes	2☐ No	Adult endocrinologist/ diabetologist (diabetes specialist)		# of visits in the last 6 months	
	39f.	₁☐ Yes	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☐ Yes	2☐ No	Traditional medicine man, healer, or curandero/curandera		# of visits in the last 6 months	
	39j.	₁☐ Yes	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☐ Yes	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 care plan does your child have? (check yes, no or don't know for each one)					
	40a. Medicaid/Medicare/State-funded/ ot	₁☐ Yes	2☐ No			
	40b. Private insurance, through employer	₁☐ Yes	2☐ No			
	40c. Private insurance, purchased on you	r own		₁☐ Yes	2☐ No	
	40d. Military			₁☐ Yes	2☐ No	
	40e. School-based insurance			₁☐ Yes	2☐ No	
	40f. Tribe/Indian Health Service			₁☐ Yes	2☐ No	
	40g. Any other or type unknown			₁☐ Yes	2☐ No	
	40h. None (if none, go to question 42)			₁☐ Yes	2☐ No	
41.	Does your child's health insurance or heal 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 <b>□</b> No	3 ☐ Don't know	N	
	41b. Syringes/pens/needles	₁☐ Yes	2☐ No	3☐ Don't know	N	
	41c. Insulin pump and supplies	₁☐ Yes	2☐ No	3☐ Don't know	N	
	41d. Home glucose monitor	₁☐ Yes	2☐ No	3☐ Don't know	N	
	41e. Monitor strips and related supplies	₁☐ Yes	2☐ No	3☐ Don't know	N	
	41f. Diabetes education	₁☐ Yes	2☐ No	3☐ Don't know	N	
	41g.   Not applicable					
42.	About how much do you spend, on average does not include costs that are covered	, , , , , , , , , , , , , , , , , , , ,				
	1 □ \$0 (none)					
	2 <b>□</b> \$1 - \$19					
	<b>3 □</b> \$20 - \$49					
	<b>4 □</b> \$50 - \$99					
	5 \$100 - \$199					
	6 <b>□</b> \$200 or more					
	7☐ Don't know					

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 ☐ Other (specify) →
	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 No (if no, go to question 46)
	3 Don't know
	4 ☐ Don't want to answer

45a	What were the reasons your child had a change in diabetes provider? (check all that apply)					
	1☐ No longer covered by health plan					
	1☐ Too difficult to get care					
	1 ☐ Not satisfied with care					
	1 ☐ Moved					
	1☐ Other (specify) →					
	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 <b>you</b> have COMPLETED?					
	<ul> <li>No schooling completed</li> <li>Nursery school to 4<sup>th</sup> grade</li> </ul>					
	3 ☐ 5 <sup>th</sup> grade or 6 <sup>th</sup> grade					
	3 ☐ 5° grade or 6° grade 4 ☐ 7 <sup>th</sup> grade or 8 <sup>th</sup> grade					
	5☐ 9 <sup>th</sup> grade					
	6 ☐ 10 <sup>th</sup> grade					
	7 11 <sup>th</sup> grade					
	8☐ 12 <sup>th</sup> grade, NO DIPLOMA					
	9☐ 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 $\square$ Professional or doctorate degree (for example: MD, DDS, JD, PhD, EdD)					
	17 ☐ Don't know					

47.	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 <sup>th</sup> grade					
	3 ☐ 5 <sup>th</sup> grade or 6 <sup>th</sup> grade	3 ☐ 5 <sup>th</sup> grade or 6 <sup>th</sup> grade				
	4 ☐ 7 <sup>th</sup> grade or 8 <sup>th</sup> grade					
	5 ☐ 9 <sup>th</sup> grade					
	6 ☐ 10 <sup>th</sup> grade					
	7☐ 11 <sup>th</sup> grade					
	8☐ 12 <sup>th</sup> grade, NO DIPLOMA					
	9☐ High school graduate (high school diploma) o	r 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, MEn	g, MEd, MSW)				
	16☐ Professional or doctorate degree (for examp	le: MD, DDS, JD, PhD, EdD)				
	17 Don't know					
	18☐ Not applicable (no current spouse/partner)					
48.	18. Which of these categories best describes the total income of all persons living in your household for the past 12 months? (Check only one category.)					
	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 <b>□</b> \$75,000 through \$99,999				
	4☐ \$16,000 through \$24,999	9 <b>□</b> \$100,000 and greater				
	5☐ \$25,000 through \$34,999	10 ☐ Don't know				
		11☐ Prefer not to answer				

49. How many people live in your child'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 adults, how many bring income into the household?
50. Is your child participating in another research study?
1☐ Yes 50a. If yes, what study? —▶
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.

FOR STUDY USE ONLY						
Date Completed	Month	Day	Year	Completed by		
Date Reviewed	Month	Day	Year	Reviewer Code		
Date Entered	Month	Day	Year	Data Entry Code		