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Patient ID Number	Site	Sub-site	Sequential ID

SEARCH Health Questionnaire – Young Adult Version (age 18 and older)

- **The purpose of this questionnaire is to learn more about young adults who have diabetes.**
- **In the questionnaire, the term "doctor" refers to the doctor or other health care provider, such as a nurse.**

CO-MORBIDITIES/COMPLICATIONS

1. Have you 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❑ No
   3❑ Don't know

2. Has a doctor ever told you that you have high cholesterol or an abnormal amount of fat in your blood?

   1❑ Yes →
   - 2a. If yes, has a doctor ever prescribed medicine for high cholesterol or high fat?
     1❑ Yes 2❑ No 3❑ Don't know
   - 2b. Are you now taking prescribed medicine for high cholesterol or high fat?
     1❑ Yes 2❑ No 3❑ Don't know
   - 2c. Has a doctor ever recommended changes in your diet to lower cholesterol?
     1❑ Yes 2❑ No 3❑ Don't know

   2❑ No
   3❑ Don't know

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3. Has a doctor ever told you that you have high blood pressure?

1❑ Yes → 3a. If yes, has a doctor ever prescribed any medicine for high blood pressure?

1❑ Yes 2❑ No 3❑ Don't know

3b. Are you now taking any medicine for high blood pressure?

1❑ Yes 2❑ No 3❑ Don't know

2❑ No

3❑ Don't know

4. Has a doctor ever told you that you had any of the following? *(check yes or no for each one)*

1❑ Yes 2❑ No Addison's Disease

1❑ Yes 2❑ No Asthma

1❑ Yes 2❑ No Celiac disease

1❑ Yes 2❑ No Hyperthyroidism (high thyroid)

1❑ Yes 2❑ No Hypothyroidism (low thyroid)

1❑ Yes 2❑ No Vitiligo (white skin patches)

5. Has a doctor said that diabetes has affected your kidneys?

1❑ Yes

2❑ No

3❑ Don't know

6. Has a doctor said that diabetes has damaged the back of your eyes, that is, the retina?

1❑ Yes → 6a. If yes, did this require laser treatment of the retina?

1❑ Yes

2❑ No

2❑ No

3❑ Don't know

7. Have you had 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. Have you already had your first period?

1 ❑ Yes → 8a. If yes, how old were you when you had your first period? [ ][ ] years old

1 ❑ Don't know

2 ❑ No

3 ❑ Don't know

9. Has a doctor ever told you that you have polycystic ovaries (PCO, PCOS)?

1 ❑ Yes

2 ❑ No

3 ❑ Don't know

MEDICAL HISTORY

◆ **The next few questions are about emergency room and hospital visits you may have had.**

10. In the last 6 months, have you been to the emergency room for any reason?

1 ❑ Yes → 10a. How many times were you in the emergency room? [ ][ ] # of times

2 ❑ No

11. In the last 6 months, have you had one or more night's hospital stay for any reason?

1❑ Yes → 11a. How many times were you in the hospital for one or more nights? ☐☐ # of times

2❑ No

12. In the past 6 months, have you had any severe hypoglycemia, that is, very low blood sugar that required you to get help?

1❑ Yes →

12a. How many times? ☐☐ # of times

12b. How many times were you 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 you go to an emergency room for hypoglycemia? ☐☐ # of times

12e. How many times did you need to stay overnight at a hospital? ☐☐ # of times

2❑ No

13. In the past 6 months, have you had ketoacidosis (often called DKA, frequently with high blood sugar, vomiting and shortness of breath)?

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

MEDICATION INVENTORY

Insulin Use

14. Were you ever treated with insulin (shots/pumps) since you were 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 you ever stop taking insulin?

1❑ No *(skip to question 20)*

2❑ Yes

17. If yes, did that happen…

1❑ Less than 1st 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 were you off insulin?

1❑ Less than 1 month

2❑ 1-6 months

3❑ 6-12 months

4❑ 1 year or more

19. Did you ever have any episodes of ketoacidosis (DKA) when insulin was stopped?

1☐ Yes
2☐ No
3☐ Don't know

20. How do you currently treat your diabetes? Do you 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 you are currently taking insulin, how often do you take insulin each day on average? *(if you are not currently taking insulin, go to question 24)*

1☐ 1 time a day
2☐ 2 times a day
3☐ 3 times a day
4☐ More than 3 times a day
5☐ Insulin pump

22. How do you take insulin? *(check all that apply)*

1☐ 22a. With a syringe (needle)
2☐ 22b. With an insulin pump
3☐ 22c. With an insulin pen

23. We would like to know the dose of insulin (number of units) that you took yesterday. *(If you use 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 hourly basal rates to determine the total basal dose.)*

Worksheet

23a.	Breakfast	☐☐☐ . ☐
23b.	Lunch	☐☐☐ . ☐
23c.	Dinner	☐☐☐ . ☐
23d.	Bedtime	☐☐☐ . ☐
23e.	Other	☐☐☐ . ☐
23f.	Pump	☐☐☐ . ☐
Total insulin:		

Prescribed Medications

24. Are you taking prescribed medication(s) including insulin?

1❑ Yes *(If Yes, document up to 10 medications below. If you are taking insulin, be certain to include all types or preparations.)*

2❑ No *(if No, skip to question 25)*

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.**

25. In the past 12 months have you met with a diabetes nurse or diabetes educator? 1❑ Yes 2❑ No 3❑ Don't know

26. In the past 12 months have you met with a dietician or nutritionist, or talked to someone in detail about your diet?

1❑ Yes →

26a. When you were staying one or more nights in the hospital	1❑ Yes	2❑ No	3❑ Don't know
26b. As an outpatient	1❑ Yes	2❑ No	3❑ Don't know

2❑ No

27. In the past 12 months, which of the following types of diabetes information have you received from your doctor's office or health care plan? *(check all that apply)*

1❑ Information about diabetes camp

1❑ Information about diabetes support groups

1❑ Written materials about diabetes such as pamphlets or newsletters

1❑ Videos or audio tapes

1❑ Reminder about upcoming appointments

1❑ 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❑ How to get diabetes information on the internet

1❑ Information about diabetes research studies other than this study

28. How would you rate your diabetes control: Would you say:

1❑ Excellent
2❑ Good
3❑ Fair
4❑ Needs much work

Home Diabetes Care

◆ **Here are some questions about your diabetes care outside of the doctor's office.**

29. Do you live or stay in more than one home on a regular basis? For example, if your parents are separated, this would include spending the weekend with your other parent. It would also include other relatives you might live or stay with on a regular basis (at least once per month).

1❑ Yes ⟶ 29a. If yes, do you live in:

1❑ 2 households

2❑ 3 or more households

3❑ Don't know

2❑ No, live in one household

30. How much of your own diabetes care do you do for yourself? Would you say: *(check one response)*

1❑ None
2❑ Less than 25%
3❑ 25-75%
4❑ More than 75%
5❑ All *(skip to question 32)*

31. Who helps you with your diabetes care?

31a. Parent/step parent/guardian	1❑ Yes	2❑ No
31b. Grandparent	1❑ Yes	2❑ No
31c. Brother/sister	1❑ Yes	2❑ No
31d. Another person	1❑ Yes	2❑ No

32. Do you test your blood sugar or glucose at home or any place other than the doctor's office?

1❑ Yes →

32a. How often is your blood sugar checked with a glucose meter (glucometer)? *(check one)*

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

2❑ No *(if no, go to question 33)*

32b. Do you use a continuous glucose monitor (CGM) to measure your glucose?

1❑ Yes
2❑ No *(if no go to 32c)*

32b(1). If yes, how do you use the CGM?

1❑ I have used it through my doctor's office

How often have you used it?
1❑ 1 time
2❑ 2 or more times
3❑ Don't know/not sure

2❑ I have a CGM for use at home

How often do you use it?
1❑ Rarely (0-19% of the time)
2❑ Occasionally (20-39% of the time)
3❑ About half the time (40-59% of the time)
4❑ Usually (60-79% of the time)
5❑ Most of the time (80-99% of the time)
6❑ Always (100% of the time)
7❑ Don't know/not sure

32c. What do you usually do when the blood sugar test results are running too high or too low?

32c(1). Make changes to the diabetes treatment (insulin dose or other medications, diet or exercise	1❑ Yes	2❑ No
32c(2). Call your diabetes doctor	1❑ Yes	2❑ No
32c(3). Talk to your diabetes doctor at the next visit	1❑ Yes	2❑ No

Provider Care

◆ **These questions are about the doctors or health care providers that you see.**

33. Who do you usually see for your diabetes care? *(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 *(specify)* → ____________
- 12❑ Don't know/unsure of what kind of doctor
- 13❑ None/no source of medical care

34. Who do you usually see for your 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 *(specify)* → ____________
- 12❑ Don't know/unsure of what kind of doctor
- 13❑ None/no source of medical care

◆ **Below are some questions about how often you see various medical providers.**

35. Who provides medical care for you? *(For each provider checked, indicate the number of visits you had with this provider in the **past 6 months**.)*

35a.	1❑ Yes	2❑ No	Pediatric endocrinologist/ diabetologist (diabetes specialist)	☐☐	# of visits in the last 6 months
35b.	1❑ Yes	2❑ No	Pediatrician	☐☐	# of visits in the last 6 months
35c.	1❑ Yes	2❑ No	Family practice doctor	☐☐	# of visits in the last 6 months
35d.	1❑ Yes	2❑ No	General practice doctor	☐☐	# of visits in the last 6 months
35e.	1❑ Yes	2❑ No	Adult endocrinologist/ diabetologist (diabetes specialist)	☐☐	# of visits in the last 6 months
35f.	1❑ Yes	2❑ No	Internist	☐☐	# of visits in the last 6 months
35g.	1❑ Yes	2❑ No	Nurse practitioner/physician's assistant	☐☐	# of visits in the last 6 months
35h.	1❑ Yes	2❑ No	Nurse diabetes educator	☐☐	# of visits in the last 6 months
35i.	1❑ Yes	2❑ No	Traditional medicine man, healer, or curandero/curandera	☐☐	# of visits in the last 6 months
35j.	1❑ Yes	2❑ No	Dietician	☐☐	# of visits in the last 6 months
35k.	1❑ Yes	2❑ No	Eye doctor (optometrist, ophthalmologist)	☐☐	# of visits in the last 6 months
35l.	1❑ Yes	2❑ No	Psychiatrist, psychologist, or mental health counselor	☐☐	# of visits in the last 6 months
35m.	1❑ Yes	2❑ No	Other *(specify)* ☐	☐☐	# of visits in the last 6 months

Insurance and Cost of Diabetes Supplies

36. What kind of health insurance or health care plan do you have?

36a. Medicaid/Medicare/State-funded/ other Federally-funded	1❑ Yes	2❑ No
36b. Private insurance, through employer	1❑ Yes	2❑ No
36c. Private insurance, purchased on your own	1❑ Yes	2❑ No
36d. Military	1❑ Yes	2❑ No
36e. School-based insurance	1❑ Yes	2❑ No
36f. Tribe/Indian Health Service	1❑ Yes	2❑ No
36g. Any other or type unknown	1❑ Yes	2❑ No
36h. None *(if none, go to question 38)*	1❑ Yes	2❑ No

37. Does your health insurance or health care plan pay for any of your… *(check yes, no or don't know for each one)*

37a. Diabetes medicine/insulin	1❑ Yes	2❑ No	3❑ Don't know
37b. Syringes/pens/needles	1❑ Yes	2❑ No	3❑ Don't know
37c. Insulin pump and supplies	1❑ Yes	2❑ No	3❑ Don't know
37d. Home glucose monitor	1❑ Yes	2❑ No	3❑ Don't know
37e. Monitor strips and related supplies	1❑ Yes	2❑ No	3❑ Don't know
37f. Diabetes education	1❑ Yes	2❑ No	3❑ Don't know

37g. ❑ Not applicable

38. About how much do you spend, on average, in a typical month on diabetes medicine and supplies? *(This does not include costs that are covered or later reimbursed by your insurance plan.)*

1❑ $0 (none)

2❑ $1 - $19

3❑ $20 - $49

4❑ $50 - $99

5❑ $100 - $199

6❑ $200 or more

7❑ Don't know

39. How satisfied are you with your current insurance coverage? Would you say:

1 ❑ Very satisfied

2 ❑ Satisfied

3 ❑ Somewhat satisfied

4 ❑ Not satisfied

40. Has your main health insurance plan changed in the last 6 months?

1 ❑ Yes *(if yes, go to question 40a)*

2 ❑ No *(if no, go to question 41)*

3 ❑ Don't know

4 ❑ Don't want to answer

40a. What were the reasons your 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

41. Has your main diabetes provider changed in the last six months?

1 ❑ Yes *(if yes, go to question 41a)*

2 ❑ No *(if no, go to question 42)*

3 ❑ Don't know

4 ❑ Don't want to answer

41a. What were the reasons you 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 your parents' education.**

42. What is the highest degree or level of school your **mother/guardian** has COMPLETED?

- 1❑ No schooling completed
- 2❑ Nursery school to 4th grade
- 3❑ 5th grade or 6th grade
- 4❑ 7th grade or 8th grade
- 5❑ 9th grade
- 6❑ 10th grade
- 7❑ 11th grade
- 8❑ 12th 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❑ Professional or doctorate degree (for example: MD, DDS, JD, PhD, EdD)
- 17❑ Don't know

43. What is the highest degree or level of school your **father/guardian** has COMPLETED?

1❑ No schooling completed

2❑ Nursery school to 4th grade

3❑ 5th grade or 6th grade

4❑ 7th grade or 8th grade

5❑ 9th grade

6❑ 10th grade

7❑ 11th grade

8❑ 12th 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❑ Professional or doctorate degree (for example: MD, DDS, JD, PhD, EdD)

17❑ Don't know

44. Which of these categories best describes the total income of all persons living in your household, including yourself 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

11❑ Prefer not to answer

45. How many people are currently living in your household, including yourself?

45a. Total number of people ☐☐

45b. Number of children (less than 18) ☐☐

45c. Number of adults ☐☐

45c(1). Of the number of adults, how many bring income into the household? ☐☐

46. Are you participating in another research study?

1 ❑ Yes 46a. 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	