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**SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROGRAM
INDIVIDUAL UTILIZATION QUESTIONNAIRE**

Client ID #: __ __ __	Site ID #: __ __	Agency ID #: __ __ __
Today's Date: __ __ - __ __ - 20 __ __	Date Client Enrolled in SCDTP: __ __ - __ __ - 20 __ __	
Interviewer: _____		
Interview: 1 <input type="checkbox"/> Baseline	2 <input type="checkbox"/> Follow-up	
Respondent: 1 <input type="checkbox"/> Sickle Cell Client	2 <input type="checkbox"/> Other	

For each question, please indicate whether the information was obtained from (1) self-report by the Sickle Cell client or his/her proxy (e.g., caregiver), (2) a client data base, **and/or** (3) the client's medical records.

Baseline Interview Only

1. What is your (the client's) date of birth?	Q.1 →	1 Self report 2 Data base 3 Medical record
__ __ - __ __ - __ __ __ __ Month Day Year		
2. Are you (Is the client): 1 <input type="checkbox"/> Male 2 <input type="checkbox"/> Female	Q.2 →	1 Self report 2 Data base 3 Medical record
3. What is your (the client's) ethnic background?		
1 <input type="checkbox"/> Hispanic 2 <input type="checkbox"/> Non-Hispanic	Q.3 →	1 Self report 2 Data base 3 Medical record
4. What is your (the client's) race? (MARK ALL THAT APPLY)		
1 <input type="checkbox"/> Black/African American 4 <input type="checkbox"/> Asian 2 <input type="checkbox"/> White 5 <input type="checkbox"/> American Indian or Alaskan Native 3 <input type="checkbox"/> Native Hawaiian or Other Pacific Islander	Q.4 →	1 Self report 2 Data base 3 Medical record
4b. Are you (is the client):		
1 <input type="checkbox"/> Mediterranean 2 <input type="checkbox"/> Middle Eastern -7 <input type="checkbox"/> DOES NOT APPLY	Q.4b →	1 Self report 2 Data base 3 Medical record

5. Including yourself (the client), how many people live in the household?	Q.5 →	1 Self report 2 Data base 3 Medical record
__ __		

6. What is the highest grade of school that you (the client) completed?	Q.6 →	1 Self report 2 Data base 3 Medical record
0 <input type="checkbox"/> Not school age 6 <input type="checkbox"/> Post-High School Training other 1 <input type="checkbox"/> Currently in Grade School than College (Vocational, Technical, etc) 2 <input type="checkbox"/> Currently in Middle School 7 <input type="checkbox"/> Some College 3 <input type="checkbox"/> Currently in High School 8 <input type="checkbox"/> Graduated from College 4 <input type="checkbox"/> Less than High School Graduate or GED 9 <input type="checkbox"/> Post-Graduate 5 <input type="checkbox"/> High School Graduate or GED		

7. What type(s) of medical insurance do you (does the client) have? (CHECK ALL THAT APPLY)	1 Self report 2 Data base 3 Medical record
1 <input type="checkbox"/> Medicaid 5 <input type="checkbox"/> Medicare HMO	

- 2 State Children's Health Insurance Plan (CHIP) 6 Private
 3 Medicaid HMO 7 No insurance **Q.7 →**
 4 Medicare 8 Other ↓
 -8 DON'T KNOW **7a. Specify:** _____

8. What was your household yearly income from January 1, 2007 through December 31, 2007? Please include all sources of income.

- 1 Less than \$5,000 8 \$50,000 - \$59,999 **Q.8 →**
 2 \$5,000 - \$9,999 9 \$60,000 - \$79,999
 3 \$10,000 - \$14,999 10 \$80,000 - \$94,999
 4 \$15,000 - \$19,999 11 \$95,000 and over
 5 \$20,000 - \$29,999 -8 DON'T KNOW
 6 \$30,000 - \$39,999 -9 REFUSED
 7 \$40,000 - \$49,999

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

9. What type of Sickle Cell Disease do you (does the client) have? (COLLECT SELF-REPORT RESPONSE AND VERIFY WITH DATABASE OR MEDICAL RECORD)

- | | a. Self-Report | b. Database/Medical Record | |
|--|-----------------------------|-----------------------------------|---------------|
| Sickle Cell Disease (SS)..... | 1 <input type="checkbox"/> | 1 <input type="checkbox"/> | |
| Sickle-Hemoglobin C Disease (SC)..... | 2 <input type="checkbox"/> | 2 <input type="checkbox"/> | |
| Sickle Beta-Plus Thalassemia..... | 3 <input type="checkbox"/> | 3 <input type="checkbox"/> | |
| Sickle Beta-Zero Thalassemia..... | 4 <input type="checkbox"/> | 4 <input type="checkbox"/> | Q.9b → |
| Other → 9c. Specify: _____..... | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> | |
| DON'T KNOW | -8 <input type="checkbox"/> | -8 <input type="checkbox"/> | |

- | | |
|---|----------------|
| 2 | Data base |
| 3 | Medical record |

10. At what age did you (did the client) first find out that you have (the client has) Sickle Cell Disease or Sickle Cell Trait?

- 1 NEWBORN SCREENING 2 OTHER → **10a. Specify Age:** |__| |__|
 -8 DON'T KNOW **Q.10 →**
 -9 REFUSED

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

We are interested in the health care that you receive from a variety of sources. These next questions ask about visits to a primary health care provider, a sickle cell specialist, other medical specialists, and a hospital emergency department. Let's start by asking about visits to a primary health care provider

11. In the past 12 months, how many times have you (has the client) gone to a primary health care provider for:

- a. Sickle cell-related problems? |__| |__| **Q.11a, b →**
 b. Non Sickle cell-related problems? |__| |__|

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

11c. Is your (client's) primary health care provider also your (his/her) sickle cell specialist?

1 YES → SKIP TO Q.13 2 NO

12. In the past 12 months, how many times have you (has the client) gone to a sickle-cell specialist (if not your primary care physician) for:

a. Sickle cell-related problems? |__|__|

b. Non Sickle cell-related problems? |__|__|

Qs. 12a, b →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

13. In the past 12 months, how many times have you (has the client) gone to another type of specialist for:

a. Sickle cell-related problems? |__|__|

b. Non Sickle cell-related problems? |__|__|

Qs. 13a, b →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

14. In the past 12 months, did you (the client) receive a referral for an eye examination?

1 Yes 2 No

Q.14 →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

15. In the past 12 months, did you (the client) make an appointment for an eye examination?

1 Yes → SKIP TO Q.16 2 No

15a. Why wasn't an appointment made for an eye examination?

Qs. 15, a →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

SKIP TO Q.17

16. Did you (the client) go to the eye appointment?

1 Yes → SKIP TO Q.17 2 No

Qs. 16, a →

16a. Why didn't you (the client) go to the appointment?

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

17. In the past 12 months, how many times did you (the client) receive health care services at a hospital emergency department?

|__|__|

Q. 17 →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

18. In the past 12 months, were you (was the client) admitted to the hospital?

1 Yes 2 No → SKIP TO Q.19

For each hospitalization, please tell me the number of nights and the reason you were (the client was) in the hospital.

18a. Hospital Stay	18b. # of nights	18c. Reason
#1	_ _ _	_____
#2	_ _ _	_____
#3	_ _ _	_____
#4	_ _ _	_____
#5	_ _ _	_____

Qs. 18, a-c →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

19. Are you (is the client) currently taking hydroxyurea therapy?

1 Yes → SKIP TO Q.21 2 No

Q.19 →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

20. In the past 12 months has your (client's) physician discussed hydroxyurea therapy as an option for you (the client)?

1 Yes 2 No

Q.20 →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

21. What is your (client's) baseline hemoglobin level? (COLLECT SELF-REPORT RESPONSE AND VERIFY WITH DATABASE OR MEDICAL RECORD).

SELF-REPORT |_|_|_|. |_| -8 DON'T KNOW
 DATABASE/MEDICAL RECORD |_|_|_|. |_| -9 NO ACCESS TO DATABASE/MEDICAL RECOR

22. **BASELINE:** Have you ever (Has the client) had the following Sickle Cell complications?

FOLLOW-UP: In the past 12 months, have you (has the client) had the following Sickle Cell complications?

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
a. Pain.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
b. Sickling in the lungs.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
c. Fever.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
d. Severe infection.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
e. Stroke.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>

Q.22a-n →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

- f. Kidney damage.....1 2 -8
- g. Leg ulcers.....1 2 -8
- h. Sickle eye damage1 2 -8
- i. Gall bladder attack1 2 -8
- j. Priapism.....1 2 -8
- k. Hand-foot syndrome.....1 2 -8
- l. Spleen problems.....1 2 -8
- m. Seizures1 2 -8
- n. Other1 ↓ 2 -8

Please Specify: _____

23. **BASELINE:** Have you (has the client) ever been given regular, scheduled blood transfusions?

FOLLOW-UP: In the past 12 months, have you (has the client) been given regular, scheduled blood transfusions?

- 1 Yes 2 No

Q. 23 →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

24. **BASELINE:** Have you (has the client) ever been counseled on the following?

FOLLOW-UP: In the past 12 months, have you (has the client) been counseled on the following?

Yes No Don't Know

- a. SCD complications 1 2 -8
- b. Inheritance of SCD 1 2 -8

Q. 24a, b →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

IF CLIENT IS 6 YEARS OR OLDER, SKIP TO Q. 27

25. Is the client taking prophylactic antibiotics (i.e., penicillin)?

- 1 Yes → SKIP TO Q.25 2 No

25a. Why isn't the client taking prophylactic antibiotics?

Qs. 25, a →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

SKIP TO Q.27

26. At what age did the client start taking prophylactic antibiotics?

- |__| |__| 1 weeks 3 years 2 months -8 Don't know

26a. How often is the client taking prophylactic antibiotics?

- 1 2 times per day

Qs. 26, a →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Data base |
| 3 | Medical record |

- 2 1 time per day
- 3 Less than 1 time per day

27. Have you (Has the client) had:

	<u>YES</u>	<u>NO</u>	<u>DON'T KNOW</u>	<u>NOT APPLICABLE</u>
a. Developmental screening to monitor infant's/ child development in areas of communication, motor, social, problem-solving and self-help skills?....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
b. A dental exam in the last year?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
c. Hearing and vision screening in the last year?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
d. Diabetes screening in the last year?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
e. Blood pressure check in the last year?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
f. A mammogram in the in last 2 years?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
g. A pap smear in the last 3 years?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
h. Colon screening in the last 10 years?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
i. A PSA Test?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
j. TCD (Transcranial Doppler)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>

- 1 Self report
- 2 Data base
- 3 Medical record

Qs. 27a-j →

THE FOLLOWING INFORMATION SHOULD BE OBTAINED ONLY FROM A VACCINATION CHART, CLIENT DATA BASE OR CLIENT MEDICAL RECORD.

FOR CLIENTS AGED 6 YEARS AND YOUNGER

28a. Are you (Is the client) up-to-date with the following vaccinations?

	<u>Yes</u>	<u>No</u>	<u>Unknown</u>
(1) Diphtheria, Tetanus, Pertussis (DTaP).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(2) Meningococcal (MCV4 or MPSV4).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(3) Pneumococcal Conjugate Vaccine	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(4) Pneumococcal Polysaccharide Vaccine	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(5) Influenza.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(6) Hepatitis A (Hep A)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(7) Hepatitis B (Hep B)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(8) Inactivated Poliovirus (IPV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(9) Measles, Mumps, Rubella (MMR).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(10) Varicella.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(11) Rotavirus (Rota)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>

- 1 Vaccination Card
- 2 Data base
- 3 Medical record

Q28a →

(12) Haemophilus influenzae type b (Hib).....1 2 -8

FOR CLIENTS AGED 7 TO 18 YEARS

28b. Are you (Is the client) up-to-date with the following vaccinations?

	<u>Yes</u>	<u>No</u>	<u>Unknown</u>
(1) Diphtheria, Tetanus, Pertussis (Tdap).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(2) Meningococcal (MCV4 or MPSV4).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(3) Pneumococcal Polysaccharide Vaccine.....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(4) Influenza.....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(5) Hepatitis A (Hep A).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(6) Hepatitis B (Hep B).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(7) Inactivated Poliovirus (IPV).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(8) Measles, Mumps, Rubella (MMR).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(9) Varicella.....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(10) Human Papillomavirus (HPV).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>

Q28b →

- | | |
|---|------------------|
| 1 | Vaccination Card |
| 2 | Data base |
| 3 | Medical record |

FOR CLIENTS AGED 19 YEARS AND OLDER

28c. Are you (Is the client) up-to-date with the following vaccinations?

	<u>Yes</u>	<u>No</u>	<u>Unknown</u>
(1) Diphtheria, Tetanus, Pertussis (Td/Tdap). 1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(2) Meningococcal (MCV4 or MPSV4).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(3) Pneumococcal Polysaccharide Vaccine.....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(4) Influenza.....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(5) Hepatitis A (Hep A).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(6) Hepatitis B (Hep B).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(7) Measles, Mumps, Rubella (MMR).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(8) Varicella.....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(9) Human Papillomavirus (HPV).....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
(10) Zoster.....1	<input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>

Q28c →

- | | |
|---|------------------|
| 1 | Vaccination Card |
| 2 | Data base |
| 3 | Medical record |