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

Subject ID Label: _____

Site: _____

Today's Date: |__|_| - |__|_| - 20 |__|_|

Date Client Enrolled: |__|_| - |__|_| - 20 |__|_|

Data Collector: _____

Interview: 1 Baseline 2 Follow-up

Respondent: 1 Sickle Cell Client 2 Other 3 Both

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 DATABASE, **AND/OR** (3) THE CLIENT'S MEDICAL RECORDS.

Baseline Interview Only [FOR FOLLOW-UP → BEGIN WITH QUESTION 5]

1. What is (your/the client's) date of birth?

|__|_| - |__|_| - |__|_|
 Month Day Year

Q.1 →

- 1 Self report
- 2 Database
- 3 Medical record

2. (Are you/Is the client): 1 Male 2 Female

Q.2 →

- 1 Self report
- 2 Database
- 3 Medical record

3. What is (your/the client's) ethnic background?

1 Hispanic 2 Non-Hispanic

Q.3 →

- 1 Self report

4. What is (your/the client's) race? (MARK ALL THAT APPLY)

1 Black/African American 4 Asian
 2 White 5 American Indian or Alaska Native
 3 Native Hawaiian or Other Pacific Islander

Q.4 →

- 1 Self report

5. Including (yourself/the client), how many people live in the household?

□□□

Q.5 →

- 1 Self report
- 2 Database
- 3 Medical record

6. What is the highest grade of school that (you/the client) completed?

- | | |
|--|--|
| 0 <input type="checkbox"/> Not school age | 6 <input type="checkbox"/> Post-High School Training other than College (Vocational, Technical, etc) |
| 1 <input type="checkbox"/> Currently in Grade School | 7 <input type="checkbox"/> Some College |
| 2 <input type="checkbox"/> Currently in Middle School | 8 <input type="checkbox"/> Graduated from College |
| 3 <input type="checkbox"/> Currently in High School | 9 <input type="checkbox"/> Post-Graduate |
| 4 <input type="checkbox"/> Less than High School Graduate or GED | |
| 5 <input type="checkbox"/> High School Graduate or GED | |

Q.6 →

- 1 Self report
- 2 Database
- 3 Medical record

7. What type(s) of medical insurance (do you/does the client) have? (CHECK ALL THAT APPLY)

- | | |
|--|---|
| 1 <input type="checkbox"/> Medicaid | 5 <input type="checkbox"/> Medicare HMO |
| 2 <input type="checkbox"/> State Children's Health Insurance Plan (CHIP) | 6 <input type="checkbox"/> Private |
| 3 <input type="checkbox"/> Medicaid HMO | 7 <input type="checkbox"/> No insurance |
| 4 <input type="checkbox"/> Medicare | 8 <input type="checkbox"/> Other ↓ |
| -8 <input type="checkbox"/> DON'T KNOW | |
- 7a. Specify: _____

Q.7 →

- 1 Self report
- 2 Database
- 3 Medical record

8. Please use this card (GIVE INCOME CARD) and tell me the number 1 through 11 that best represents your household yearly income from January 1st through December 31st of last calendar year, (SAY APPROPRIATE YEAR). Please include all sources of income.

- | | |
|--|---|
| 1 <input type="checkbox"/> Less than \$5,000 | 8 <input type="checkbox"/> \$50,000 - \$59,999 |
| 2 <input type="checkbox"/> \$5,000 - \$9,999 | 9 <input type="checkbox"/> \$60,000 - \$79,999 |
| 3 <input type="checkbox"/> \$10,000 - \$14,999 | 10 <input type="checkbox"/> \$80,000 - \$94,999 |
| 4 <input type="checkbox"/> \$15,000 - \$19,999 | 11 <input type="checkbox"/> \$95,000 and over |
| 5 <input type="checkbox"/> \$20,000 - \$29,999 | -8 <input type="checkbox"/> DON'T KNOW |
| 6 <input type="checkbox"/> \$30,000 - \$39,999 | -9 <input type="checkbox"/> REFUSED |
| 7 <input type="checkbox"/> \$40,000 - \$49,999 | |

Q.8 →

- 1 Self report
- 2 Database
- 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. <u>Self-Report</u> | b. <u>Database/Medical Record</u> |
|---------------------------------------|-----------------------------|-----------------------------------|
| 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"/> |
| Other → 9c. Specify: _____ | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| DON'T KNOW | -8 <input type="checkbox"/> | -8 <input type="checkbox"/> |

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

- 1 NEWBORN SCREENING 2 OTHER → 10a. Specify Age: year(s) old
 -8 DON'T KNOW
 -9 REFUSED

Q.10 →

- 1 Self report
 2 Database
 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.

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?
 b. Non Sickle cell-related problems?

Qs.11a, b →

- 1 Self report
 2 Database
 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 Database
 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 Database
 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 Database
 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

Qs.15, a →

- 1 Self report
 2 Database
 3 Medical record

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

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 →

- 1 Self report
 2 Database
 3 Medical record

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

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

____|____|

Q.17 →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> 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

Qs.18, a-c →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

For each hospitalization, please tell me the number of nights and the reason) you were/ the client was) in the hospital. (LIST ADDITIONAL STAYS ON BACK OF PAGE)

18a. Hospital Stay 18b. # of nights 18c. Reason

#1	____ ____	_____

#2	____ ____	_____

#3	____ ____	_____

#4	____ ____	_____

#5	____ ____	_____

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

1 Yes → SKIP TO Q.21 2 No

Q.19 →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> 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 →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

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

a. Self-Report

____|____|.____|

-8 DON'T KNOW

b. Database/Medical Record

____|____|.____|

-9 NO ACCESS TO DATABASE/MEDICAL RECORD

22. **BASELINE:** (Have you/Has the client) ever 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"/>
f. Kidney damage	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
g. Leg ulcers	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
h. Sickle eye damage	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
i. Gall bladder attack	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
j. Priapism	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/> -7 <input type="checkbox"/> N/A
k. Hand-foot syndrome	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
l. Spleen problems	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
m. Seizures	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
n. Other	1 <input type="checkbox"/> ↓	2 <input type="checkbox"/>	-8 <input type="checkbox"/>

Qs.22a-n →

1 <input type="checkbox"/> Self report
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> Medical record

Please Specify: _____

23. **BASELINE:** (Have you/Has the client) ever been given regularly scheduled blood transfusions?

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

1 Yes 2 No

Q.23 →

1 <input type="checkbox"/> Self report
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> 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?

	<u>Yes</u>	<u>No</u>	<u>DON'T KNOW</u>
a. SCD complications	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
b. Inheritance of SCD	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>

Qs.24a, b →

1 <input type="checkbox"/> Self report
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> 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.26 2 No

Qs.25, a →

- 1 Self report
- 2 Database
- 3 Medical record

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

SKIP TO Q.27

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

| 1 weeks 2 months 3 years -8 DON'T KNOW

Qs.26, a →

- 1 Self report
- 2 Database
- 3 Medical record

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

- 1 2 times per day
- 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</u> <u>KNOW</u>	<u>NOT</u> <u>APPLICABLE</u>
<u>For children only:</u>				
a. Developmental screening to monitor infant/ 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"/>
<u>For all participants:</u>				
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 screening in the last year?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
d. Vision screening in the last year?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
e. Diabetes screening in the last year?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
f. Blood pressure check in the last year?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
g. TCD (Transcranial Doppler)?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
<u>For adults only:</u>				
h. A mammogram in the in last 2 years?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
i. A pap smear in the last 3 years?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
j. Colon screening in the last 10 years?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
k. A PSA Test?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>

Qs.27a-j

- 1 Self report
- 2 Database
- 3 Medical record

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

FOR CLIENTS AGED 6 YEARS AND YOUNGER:

28a. INDICATE WHETHER OR NOT THE CLIENT IS UP-TO-DATE WITH THE FOLLOWING VACCINATIONS:

	<u>YES</u>	<u>NO</u>	<u>UNKNOWN</u>	<u>NOT APPLICABLE</u>	
(1) Diphtheria, Tetanus, Pertussis (DTaP)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	Q.28a →
(2) Meningococcal (MCV4 or MPSV4)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(3) Pneumococcal Conjugate Vaccine	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(4) Pneumococcal Polysaccharide Vaccine	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(5) Influenza	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(6) Hepatitis A (Hep A)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(7) Hepatitis B (Hep B)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(8) Inactivated Poliovirus (IPV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(9) Measles, Mumps, Rubella (MMR)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(10) Varicella	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(11) Rotavirus (Rota)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(12) Haemophilus influenzae type b (Hib).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	

1 <input type="checkbox"/> Vaccination Card
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> Medical record

FOR CLIENTS AGED 7 TO 18 YEARS:

28b. INDICATE WHETHER OR NOT THE CLIENT IS UP-TO-DATE WITH THE FOLLOWING VACCINATIONS:

	<u>YES</u>	<u>NO</u>	<u>UNKNOWN</u>	<u>NOT APPLICABLE</u>	
(1) Diphtheria, Tetanus, Pertussis (Tdap)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	Q.28b →
(2) Meningococcal (MCV4 or MPSV4)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(3) Pneumococcal Polysaccharide Vaccine.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(4) Influenza	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(5) Hepatitis A (Hep A).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(6) Hepatitis B (Hep B).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(7) Inactivated Poliovirus (IPV).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(8) Measles, Mumps, Rubella (MMR).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(9) Varicella	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(10) Human Papillomavirus (HPV)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	

1 <input type="checkbox"/> Vaccination Card
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> Medical record

FOR CLIENTS AGED 19 YEARS AND OLDER:

28c. INDICATE WHETHER OR NOT THE CLIENT IS UP-TO-DATE WITH THE FOLLOWING VACCINATIONS:

	<u>YES</u>	<u>NO</u>	<u>UNKNOWN</u>	<u>NOT APPLICABLE</u>	
(1) Diphtheria, Tetanus, Pertussis (Td/Tdap) ..	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	Q.28c →
(2) Meningococcal (MCV4 or MPSV4).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(3) Pneumococcal Polysaccharide Vaccine.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(4) Influenza	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(5) Hepatitis A (Hep A)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(6) Hepatitis B (Hep B)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(7) Measles, Mumps, Rubella (MMR)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(8) Varicella.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(9) Human Papillomavirus (HPV).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(10) Zoster.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	

1 <input type="checkbox"/> Vaccination Card
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> Medical record