OMB Number: 0915-0320
Expiration Date: 10/31/2010

SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROGRAM

INDIVIDUAL UTILIZATION QUESTIONNAIRE

Subject ID Label:

Site: _____

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

Data Collector: _____

Interview: 1☐ Baseline 2☐ Follow-up

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

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? **Q.1→**

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

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
2☐ White
3☐ Native Hawaiian or Other Pacific Islander
4☐ Asian
5☐ American Indian or Alaska Native

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 ☐ Not school age
1 ☐ Currently in Grade School
2 ☐ Currently in Middle School
3 ☐ Currently in High School
4 ☐ Less than High School Graduate or GED
5 ☐ High School Graduate or GED
6 ☐ Post-High School Training other than College (Vocational, Technical, etc)
7 ☐ Some College **Q.6 →**
8 ☐ Graduated from College
9 ☐ Post-Graduate

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 ☐ Medicaid
2 ☐ State Children's Health Insurance Plan (SCHIP)
3 ☐ Medicaid HMO
4 ☐ Medicare
5 ☐ Medicare HMO
6 ☐ Private
7 ☐ No insurance **Q.7 →**
8 ☐ Other↓
-8 ☐ DON'T KNOW

7a. Specify: _____

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

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. Self-Report	**b. Database/Medical Record**
Sickle Cell Disease (SS)	1 ☐	1 ☐
Sickle-Hemoglobin C Disease (SC)	2 ☐	2 ☐
Sickle Beta-Plus Thalassemia	3 ☐	3 ☐
Sickle Beta-Zero Thalassemia	4 ☐	4 ☐
Other → **9c. Specify**: _____	5 ☐	5 ☐
DON'T KNOW	-8 ☐	-8 ☐

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 **Q.10 →**

-9☐ REFUSED

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? |___|___| **Qs.11a, b →**

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

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? |___|___| **Qs.12a, b →**

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

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? |___|___| **Qs.13a, b →**

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

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? **Q.14 →**

1☐ Yes 2☐ No

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 →**

|___|___|

1 ☐ Self report
2 ☐ Database
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 **Qs.18, a-c →**

1 ☐ Self report
2 ☐ Database
3 ☐ 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 →**

1 ☐ Self report
2 ☐ Database
3 ☐ Medical record

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

1☐ Yes 2☐ No

1 ☐ Self report
2 ☐ Database
3 ☐ 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?**

	Yes	No	DON'T KNOW	
a. Pain	1☐	2☐	-8☐	
b. Sickling in the lungs	1☐	2☐	-8☐	**Qs.22a-n →**
c. Fever	1☐	2☐	-8☐	
d. Severe infection	1☐	2☐	-8☐	
e. Stroke	1☐	2☐	-8☐	
f. Kidney damage	1☐	2☐	-8☐	
g. Leg ulcers	1☐	2☐	-8☐	
h. Sickle eye damage	1☐	2☐	-8☐	
i. Gall bladder attack	1☐	2☐	-8☐	
j. Priapism	1☐	2☐	-8☐	-7☐ N/A
k. Hand-foot syndrome	1☐	2☐	-8☐	
l. Spleen problems	1☐	2☐	-8☐	
m. Seizures	1☐	2☐	-8☐	
n. Other	1☐↓	2☐	-8☐	

1☐ Self report
2☐ Database
3☐ 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?** **Q.23 →**

1☐ Yes 2☐ No

1☐ Self report
2☐ Database
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☐	**Qs.24a, b →**
b. Inheritance of SCD	1☐	2☐	-8☐	

1☐ Self report
2☐ Database
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.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

26a. How often is the client taking prophylactic antibiotics? **Qs.26, a →**

1☐ Self report
2☐ Database
3☐ Medical record

1☐ 2 times per day

2☐ 1 time per day

3☐ Less than 1 time per day

27. (Have you/Has the client) had:

	YES	NO	DON'T KNOW	NOT APPLICABLE
For children only:				
a. Developmental screening to monitor infant/ child development in areas of communication, motor, social, problem-solving and self-help skills?	1☐	2☐	-8☐	-7☐
For all participants:				
b. A dental exam in the last year?	1☐	2☐	-8☐	-7☐
c. Hearing screening in the last year?	1☐	2☐	-8☐	-7☐
d. Vision screening in the last year?	1☐	2☐	-8☐	-7☐
e. Diabetes screening in the last year?	1☐	2☐	-8☐	-7☐
f. Blood pressure check in the last year?	1☐	2☐	-8☐	-7☐
g. TCD (Transcranial Doppler)?	1☐	2☐	-8☐	-7☐
For adults only:				
h. A mammogram in the in last 2 years?	1☐	2☐	-8☐	-7☐
i. A pap smear in the last 3 years?	1☐	2☐	-8☐	-7☐
j. Colon screening in the last 10 years?	1☐	2☐	-8☐	-7☐
k. A PSA Test?	1☐	2☐	-8☐	-7☐

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:

	YES	NO	UNKNOWN	NOT APPLICABLE
(1) Diphtheria, Tetanus, Pertussis (DTaP)	1 ☐	2 ☐	-8 ☐	-7 ☐
(2) Meningococcal (MCV4 or MPSV4)	1 ☐	2 ☐	-8 ☐	-7 ☐
(3) Pneumococcal Conjugate Vaccine	1 ☐	2 ☐	-8 ☐	-7 ☐
(4) Pneumococcal Polysaccharide Vaccine	1 ☐	2 ☐	-8 ☐	-7 ☐
(5) Influenza	1 ☐	2 ☐	-8 ☐	-7 ☐
(6) Hepatitis A (Hep A)	1 ☐	2 ☐	-8 ☐	-7 ☐
(7) Hepatitis B (Hep B)	1 ☐	2 ☐	-8 ☐	-7 ☐
(8) Inactivated Poliovirus (IPV)	1 ☐	2 ☐	-8 ☐	-7 ☐
(9) Measles, Mumps, Rubella (MMR)	1 ☐	2 ☐	-8 ☐	-7 ☐
(10) Varicella	1 ☐	2 ☐	-8 ☐	-7 ☐
(11) Rotavirus (Rota)	1 ☐	2 ☐	-8 ☐	-7 ☐
(12) Haemophilus influenzae type b (Hib)	1 ☐	2 ☐	-8 ☐	-7 ☐

Q.28a →

1 ☐ Vaccination Card
2 ☐ Database
3 ☐ Medical record

FOR CLIENTS AGED 7 TO 18 YEARS:

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

	YES	NO	UNKNOWN	NOT APPLICABLE
(1) Diphtheria, Tetanus, Pertussis (Tdap)	1 ☐	2 ☐	-8 ☐	-7 ☐
(2) Meningococcal (MCV4 or MPSV4)	1 ☐	2 ☐	-8 ☐	-7 ☐
(3) Pneumococcal Polysaccharide Vaccine	1 ☐	2 ☐	-8 ☐	-7 ☐
(4) Influenza	1 ☐	2 ☐	-8 ☐	-7 ☐
(5) Hepatitis A (Hep A)	1 ☐	2 ☐	-8 ☐	-7 ☐
(6) Hepatitis B (Hep B)	1 ☐	2 ☐	-8 ☐	-7 ☐
(7) Inactivated Poliovirus (IPV)	1 ☐	2 ☐	-8 ☐	-7 ☐
(8) Measles, Mumps, Rubella (MMR)	1 ☐	2 ☐	-8 ☐	-7 ☐
(9) Varicella	1 ☐	2 ☐	-8 ☐	-7 ☐
(10) Human Papillomavirus (HPV)	1 ☐	2 ☐	-8 ☐	-7 ☐

Q.28b →

1 ☐ Vaccination Card
2 ☐ Database
3 ☐ Medical record

FOR CLIENTS AGED 19 YEARS AND OLDER:

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

	YES	NO	UNKNOWN	NOT APPLICABLE
(1) Diphtheria, Tetanus, Pertussis (Td/Tdap)	1 ☐	2 ☐	-8 ☐	-7 ☐
(2) Meningococcal (MCV4 or MPSV4)	1 ☐	2 ☐	-8 ☐	-7 ☐
(3) Pneumococcal Polysaccharide Vaccine	1 ☐	2 ☐	-8 ☐	-7 ☐
(4) Influenza	1 ☐	2 ☐	-8 ☐	-7 ☐
(5) Hepatitis A (Hep A)	1 ☐	2 ☐	-8 ☐	-7 ☐
(6) Hepatitis B (Hep B)	1 ☐	2 ☐	-8 ☐	-7 ☐
(7) Measles, Mumps, Rubella (MMR)	1 ☐	2 ☐	-8 ☐	-7 ☐
(8) Varicella	1 ☐	2 ☐	-8 ☐	-7 ☐
(9) Human Papillomavirus (HPV)	1 ☐	2 ☐	-8 ☐	-7 ☐
(10) Zoster	1 ☐	2 ☐	-8 ☐	-7 ☐

Q.28c →

1 ☐ Vaccination Card
2 ☐ Database
3 ☐ Medical record