

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

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Subject ID Label: _____	Site: _____
Today's Date: __ _ - __ _ - 20 __ _	Date Client Enrolled: __ _ - __ _ - 20 __ _
Data Collector: _____	
Interview: 1 <input type="checkbox"/> Baseline 2 <input type="checkbox"/> Follow-up	Respondent: <input type="checkbox"/> Sickle Cell Client 2 <input type="checkbox"/> Other 3 <input type="checkbox"/> 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 data base, **and/or** (3) the client's medical records.

Baseline Interview Only [FOR FOLLOW-UP	BEGIN WITH QUESTION 4
<p>1. Age of client at time of interview: _____ years _____ months</p>	<p>Q.1 →</p> <div style="border: 1px solid black; padding: 5px; width: fit-content;"> 1 Self report 2 Database 3 Medical record </div>
<p>2. Are you/Is the client: 1 <input type="checkbox"/> Male 2 <input type="checkbox"/> Female</p>	<p>Q2. →</p> <div style="border: 1px solid black; padding: 5px; width: fit-content;"> 1 Self report </div>
<p>3. What is (your/the client's) ethnic background? 1 <input type="checkbox"/> Hispanic 2 <input type="checkbox"/> Non-Hispanic</p>	<p>Q.3 →</p> <div style="border: 1px solid black; padding: 5px; width: fit-content;"> 1 Self report </div>
<p>3. What is (your/the client's) race? (MARK ALL THAT APPLY)</p> <p>1 <input type="checkbox"/> Black/African American 4 <input type="checkbox"/> Asian</p> <p>2 <input type="checkbox"/> White 5 <input type="checkbox"/> American Indian or Alaskan Native</p> <p>3 <input type="checkbox"/> Native Hawaiian or Other Pacific Islander</p>	<p>Q.4 →</p> <div style="border: 1px solid black; padding: 5px; width: fit-content;"> 1 Self report </div>

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 | |

Q.7 →

1	Self report
2	Database
3	Medical record

7a. Specify: _____

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. 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"/> |
| Other → 9c. Specify: _____ | 5 <input type="checkbox"/> | 5 <input type="checkbox"/> |

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
-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? ||

Q.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.11 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.14 2 No

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

Qs. 15, a →

- | | |
|---|----------------|
| 1 | Self report |
| 2 | Database |
| 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 →

- | | |
|---|----------------|
| 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

|_|_|

Qs. 17, a →

- | | |
|---|----------------|
| 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)?

1 Yes 2 No

Q.20 →

- | | |
|---|----------------|
| 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?

	<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"/>
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"/>

Q.22a-n →

1	Self report
2	Database
3	Medical record

-7 N/A

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	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?

	<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"/>

Q. 24a, b →

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

21a. Why isn't the client taking prophylactic antibiotics?

SKIP TO Q.23

Qs. 25, a →

- 1 Self report
- 2 Database
- 3 Medical record

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

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

22a. 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

Qs. 26, a →

- 1 Self report
- 2 Database
- 3 Medical record

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

	<u>YES</u>	<u>NO</u>	<u>DON'T KNOW</u>	<u>NOT APPLICABLE</u>
<u>For children only:</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"/>
<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) in the last year?.....	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

For adults only:

e. A mammogram in the in last 2 years?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
f. A pap smear in the last 3 years?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
g. Colon screening in the last 10 years?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
h. A PSA Test?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>

**THE FOLLOWING INFORMATION SHOULD BE OBTAINED ONLY FROM A VACINATION
CHART, CLIENT DATA BASE 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	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(2) Meningococcal (MCV4 or MPSV4)1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(3) Pneumococcal Conjugate Vaccine1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(4) Pneumococcal Polysaccharide Vaccine1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(5) Influenza1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(6) Hepatitis A (Hep A)1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(7) Hepatitis B (Hep B)1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(8) Inactivated Poliovirus (IPV)1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(9) Measles, Mumps, Rubella (MMR).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(10) Varicella.....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(11) Rotavirus (Rotateq)1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(12) Haemophilus influenza type b (Hib)1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>

Q28a →

- | | |
|---|------------------|
| 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	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(2) Meningococcal (MCV4 or MPSV4)1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(3) Pneumococcal Polysaccharide Vaccine1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(4) Influenza1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(5) Hepatitis A (Hep A).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(6) Hepatitis B (Hep B).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(7) Inactivated Poliovirus (IPV).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(8) Measles, Mumps, Rubella (MMR).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(9) Varicella.....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(10) Human Papillomavirus (HPV).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>

Q28b →

- | | |
|---|------------------|
| 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	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(2) Meningococcal (MCV4 or MPSV4)1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(3) Pneumococcal Polysaccharide Vaccine1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(4) Influenza1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(5) Hepatitis A (Hep A).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(6) Hepatitis B (Hep B).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(7) Measles, Mumps, Rubella (MMR).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(8) Varicella.....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(9) Human Papillomavirus (HPV).....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
(10) Zoster.....1	<input type="checkbox"/>	<input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>

Q28c →

- | | |
|---|------------------|
| 1 | Vaccination Card |
| 2 | Database |
| 3 | Medical record |