OMB Number: 0915-0344
Expiration Date: 12/31/2014

Sickle Cell Disease Newborn Screening Program (SCDNBSP)
Minimum Database Project (MDP)

Sickle Cell Trait (SCT) Questionnaire

Section A: SITE IDENTIFYING INFORMATION

Today's Date (mm/dd/yyyy): |__|__| - |__|__| - 20|__|__|

Date of Client Visit/Interview (mm/dd/yyyy): |__|__| - |__|__| - 20|__|__|

Data Entry Personnel: _____ Site ID: |__|__|__| State ID: |__|__|

Section B: CLIENT IDENTIFYING INFORMATION

Client ID: |__|__|__|__|__|

Section C: CLIENT INFORMATION

1. Who referred the client? (Please check one)

☐ State Newborn Screening (NBS) Program ☐ Health Department (not a NBS Program)

☐ Physician ☐ Self-Referral

☐ Hospital ☐ Comprehensive Sickle Cell Center

☐ Community-Based Organization ☐ Other: _____

☐ Relative/ Family Member ☐ Don't Know

2. What is the sex of the client? (Please check one) ☐ Male ☐ Female

3. Zip code of client |__|__|__|__|__|

Section D: FAMILY INFORMATION

4. How is the client related to the child with SCT identified by newborn screening? (Please check all that apply)

☐ Mother ☐ Maternal Grandmother ☐ Maternal Grandfather

☐ Father ☐ Paternal Grandmother ☐ Paternal Grandfather

☐ Maternal Aunt ☐ Maternal Uncle ☐ Paternal Aunt

☐ Paternal Uncle ☐ Maternal First Cousin ☐ Paternal First Cousin

☐ Other

5. What is the confirmed sickle cell trait status of the child with SCT identified by newborn screening? (Please check one)

☐ Sickle Cell Trait (FAS) ☐ Hb C carrier (FAC) ☐ Hb E carrier (FAE)

☐ Other Hb variant carrier (FA other)

6. Who provided the information about this child's confirmatory diagnosis? (Please check one)

☐ Client ☐ Child's Parent ☐ Physician ☐ Lab ☐ Other: _____

Section E: SERVICES CLIENT RECEIVED

7. What educational/ counseling services did the client receive? (Please check one)

☐ Face-to face education/counseling session ☐ Telephone education/counseling

☐ None ☐ Not Applicable

8. What educational materials were provided to the client (Please check all that apply)

☐ Print materials ☐ Multimedia materials (e.g. DVD, video, on-line)

☐ Information about materials available on-line ☐ None ☐ Not Applicable

9. Did the client elect to be tested for SCT status? (Please check one)

☐ Yes ☐ No ☐ Don't Know

10. If the client was tested, what were the results? (Please check one)

☐ Sickle Cell Trait (AS) ☐ Hb C carrier (AC) ☐ Hb E carrier (AE)

☐ Other Hb variant carrier (A other) ☐ Sickle Cell Disease (SS)

☐ Other hemoglobinopathy _____ ☐ Don't Know

11. Have any of the client's family members been tested for SCD/SCT or other hemoglobin trait? (Please check one)

☐ Yes ☐ No ☐ Don't Know

12. If no, give reason why (Add NA if no reason provided or 'don't know' is checked):

_____

Section F: CLIENT FAMILY COMMUNICATION

13. For Caregivers of clients under age 18

The following questions pertain to clients under the age of 18 years and their caregivers. ***(Language categories provided below.)***

A. What is the primary spoken language in the client's home?

_____

B. If English is not your primary language do you require a translator for medical services/medical information?
☐ Yes ☐ No ☐ Not Applicable

What, if any, is the secondary spoken language? _____

C. What language is the client/caregiver most comfortable reading?
Client:

☐ Don't Know ☐ Not Applicable

13. For Clients 18 years or older

The following questions pertain to the client 18 years of age or older. ***(Language categories provided below.)***

A. What is the primary spoken language in the client's home?

_____

B. If English is not your primary language do you require a translator for medical services/medical information?
☐ Yes ☐ No ☐ Not Applicable

What, if any, is the secondary spoken language? _____

C. What language are you most comfortable reading?

_____

D. What is the highest level of education you attained?

_____

Caregiver: D. What is highest level of education attained? Caregiver: ☐ Don't Know ☐ Not Applicable **Continue to questions 14 and 15**	**Continue to questions 14 and 15**

*__*Language categories*__: American Sign Language, Arabic, Chinese, Haitian Creole, Igbo, Korean, Somali, Spanish, Vietnamese, Yoruba or please provide any other language not listed.

14. Are you (your child) Hispanic or Latino?

☐ No, not Hispanic or Latino

☐ Yes, Hispanic or Latino

15. What is your (your child's) race? Mark (X) one or more boxes.

☐ White

☐ Black or African American

☐ American Indian or Alaska Native

☐ Asian

☐ Native Hawaiian or Pacific Islander