Attachment C - The Minimum Database Project (MDP) Sickle Cell Trait (SCT) Questionnaire

OMB Number: xxxx-xxxx
Expiration Date:

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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

Caregiver:
.

D. What is highest level of education attained?
Caregiver:

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?

____

Continue to questions 14 and 15

. ☐ Don't Know ☐ Not Applicable **Continue to questions 14 and 15**	
*<u>***Language categories***</u>: 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