**Attachment B** - The Minimum Database Project (MDP) Sickle Cell Disease (SCD) Questionnaire

 OMB Number: xxxx-xxxx

 Expiration Date:

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 **Sickle Cell Disease Newborn Screening Program (SCDNBSP)**

 **Minimum Database Project (MDP)**

 **Sickle Cell Disease (SCD) Questionnaire Form**

**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**

Date of Birth (mm/dd/yyyy): |\_\_|\_\_| - |\_\_|\_\_| - |\_\_|\_\_|\_\_|\_\_| Client ID: |\_\_|\_\_|\_\_|\_\_|\_\_|

Is this client a newborn? (0-2 months): [ ]  Yes [ ]  No

**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: ­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. What is the sex of the client? (Please click one) [ ]  Male [ ]  Female
2. What is the confirmed diagnosis of the client? (Please click one )

 [ ]  Sickle Cell Disease (SS) [ ]  Sickle C Disease (SC)

 [ ]  Sickle Beta-Plus Thalassemia [ ]  Sickle Beta-Zero Thalassemia [ ]  Other\_\_\_\_\_\_\_\_\_\_

1. How old was the client at the time of confirmatory diagnosis? (Enter date of diagnosis)

Date (mm/dd/yyyy): |\_\_|\_\_| - |\_\_|\_\_| - |\_\_|\_\_|\_\_|\_\_|

1. Enter the source of the confirmatory diagnosis: (Please check one)

 [ ]  Caregiver [ ]  Physician [ ]  Lab [ ]  Other:\_\_\_\_\_\_\_\_\_\_

1. Who is the primary caregiver(s)? (Please click one)

**Section D: FAMILY INFORMATION**

 [ ]  Mother only [ ]  Father Only [ ]  Both Parents [ ]  Foster Parents

 [ ]  Other Family [ ]  Grandparent (s) [ ]  Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. If **mother is the primary caregiver,** does she know about her hemoglobin status (SCD or SCT)? (Please check one) [ ]  Yes [ ]  No [ ]  Not Applicable
2. **If yes**, when did the mother know about her status? (Please check one)

 [ ]  Before pregnancy [ ]  During pregnancy [ ]  After birth of child [ ]  Not Applicable

1. **If no,** has she been asked to be tested? (Please check one) [ ]  Yes [ ]  No [ ]  Not Applicable
2. If **father is the primary caregiver,** does he know about his hemoglobin status (SCD or SCT)? (Please check one) [ ]  Yes [ ]  No [ ]  Not Applicable
3. **If yes**, when did the father know about his status? (Please check one)

 [ ]  Before pregnancy [ ]  During pregnancy [ ]  After birth of child [ ]  Not Applicable

1. **If no,** has he been asked to be tested? (Please check one) [ ]  Yes [ ]  No [ ]  Not Applicable
2. What is the age of the primary caregiver(s)? |\_\_|\_\_| |\_\_|\_\_|
3. Is the client genetically related (mother, father etc) to the primary caregiver(s)? [ ]  Yes [ ]  No
4. How many more children **(< 18 years old)** are there in the client’s home with SCD/SCT? |\_\_|\_\_|
5. What is the diagnosis of other child/children? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
6. How many people are in the client’s household (including the client and caregiver): |\_\_|\_\_|
7. Zip code of primary caregiver(s): |\_\_|\_\_|\_\_|\_\_|\_\_|
8. What is annual household income of the client’s family? (Please check one)

 [ ]  Less than $10,000 [ ]  $10,000 – $19,999 [ ]  $20,000 – $29,999

 [ ]  $30,000 – $39,999 [ ]  $40,000 – $49,999 [ ]  $50,000 – $59,999

 [ ]  $60,000 – $74,999 [ ]  $75,000 and over [ ]  Did not answer

 [ ]  Don’t Know

1. What type of insurance does the caregiver have for the client? (Please click one)

 [ ]  Medicaid [ ]  Medicaid HMO [ ]  Private [ ]  No Insurance [ ]  SCHIP [ ]  Medicare

 [ ]  TRICARE [ ]  Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Section E: CLIENTS RECENT MEDICAL HISTORY**

1. Where does the client go for primary care? (Please click all that apply)

 [ ]  Private Practitioner’s Office [ ]  Hospital ER/ED [ ]  Urgent Care Center

 [ ]  Community Health Center [ ]  Hospital-based Clinic [ ]  Public Health Department

 [ ]  Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Whom does the client see for primary care at the above site? (Please click all that apply)

 [ ]  Pediatrician [ ]  Hematologist [ ]  Internist

 [ ]  Nurse Practitioner [ ]  Family Doctor [ ]  Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Has the client seen a hematologist in the past year? [ ]  Yes [ ]  No
2. In the past 3 months, how many times has the client received healthcare services at an ED? |\_\_|
3. What was/were the reasons(s) for the visit? (Please check all that apply)

[ ]  Fever [ ]  Pain [ ]  Respiratory Problems

[ ]  Jaundice [ ]  Pallor [ ]  Lethargy

[ ]  Enlarged Spleen [ ]  Priapism [ ]  Vomiting/Nausea

[ ]  Swollen Limbs [ ]  Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ [ ]  Not Applicable

1. In the past 3 months, how many times has the client been admitted to the hospital? |\_\_|
2. What was/were the reasons(s) for the visit? (Please check all that apply)

[ ]  Fever [ ]  Pain [ ]  Respiratory Problems

[ ]  Jaundice [ ]  Pallor [ ]  Lethargy

[ ]  Enlarged Spleen [ ]  Priapism [ ]  Vomiting/Nausea

[ ]  Swollen Limbs [ ]  Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ [ ]  Not Applicable

1. Is the client taking prophylactic antibiotics (i.e., penicillin)?

 [ ]  Yes [ ]  No (why): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. If yes, at what age was prophylactic penicillin started? (Please check one)

 [ ]  1 Week [ ]  2 Weeks [ ]  3 Weeks [ ]  4 Weeks [ ]  5 Weeks

 [ ]  6 Weeks [ ]  7 Weeks [ ]  8 Weeks [ ]  3 Months [ ]  4 Months

 [ ]  Greater than 4 Months – 2 Years [ ]  Don’t Know [ ]  Not Applicable

1. How often is the client taking prophylactic antibiotics? (Please click one)

 [ ]  2 times per day [ ]  1 time per day [ ]  Less than 1 time per day

1. Has the client received the pneumococcal vaccine? [ ]  Yes [ ]  No
2. If yes, what type? (Please check one)

 [ ]  7 Valent (i.e. Prevnar as part of childhood immunizations) [ ]  23 Valent (i.e. Pneumovax)

 [ ]  Not Applicable [ ]  Don’t Know [ ]  Did Not Answer

1. In the last 3 months, what treatment(s) has the client received? (Please check all that apply)

 [ ]  Nebulizer/Inhaler [ ]  Transfusions **[ ]** Transcranial Doppler (TCD) [ ]  Chelation Therapy

 [ ]  Hydroxyurea [ ]  None of these services

**Section F: SERVICES CLIENTS FAMILY RECEIVED**

1. During the past 3 months, # of genetic counseling sessions attended? |\_\_|\_\_|
2. During the past 3 months, # of referrals has the client or caregiver received? |\_\_|\_\_|

1. During the past 3 months, # of other services (ex: interpreter, transportation etc.) has the client or caregiver received? |\_\_|\_\_|

|  |
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| **Section G: CLIENT FAMILY COMMUNICATION** |
| **37. For Caregivers of clients under age 18** | **37. For Clients 18 years or older** |
| The following questions pertain to clients under the age of 18 years and their caregivers. ***(Language categories provided below.)***1. What is the primary spoken language in the client’s home? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. If English is not your primary language do you require a translator for medical services/medical information?

[ ]  Yes [ ]  No [ ]  Not ApplicableWhat, if any, is the secondary spoken language? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_1. What language is the client/caregiver most comfortable reading?

Client: . [ ]  Don’t Know [ ]  Not ApplicableCaregiver: . 1. What is highest level of education attained?

Caregiver: .[ ]  Don’t Know [ ]  Not Applicable**Continue to questions** **38 and 39** | The following questions pertain to the client 18 years of age or older. ***(Language categories provided below.)***1. What is the primary spoken language in the client’s home? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. If English is not your primary language do you require a translator for medical services/medical information?

[ ]  Yes [ ]  No [ ]  Not ApplicableWhat, if any, is the secondary spoken language? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_1. What language are you most comfortable reading? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. What is the highest level of education you attained? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Continue to questions 38 and 39** |
| \****Language categories***: American Sign Language, Arabic, Chinese, Haitian Creole, Igbo, Korean, Somali, Spanish, Vietnamese, Yoruba or please provide any other language not listed. |
| 1. Are you (your child) Hispanic or Latino?

[ ]  No, not Hispanic or Latino [ ]  Yes, Hispanic or Latino1. 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 Other Pacific Islander  |