**Public Burden Statement**: An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.  The OMB control number for this project is 0915-0344.  Public reporting burden for this collection of information is estimated to average 45 minutes per respondent annually, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information.  Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 14-33, Rockville, Maryland, 20857.

**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**

Age of client at time of interview:\_\_\_\_\_\_ years \_\_\_\_\_\_ months 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: ­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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 12 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 12 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/13 Valent (i.e. Prevnar as part of childhood immunizations)  23 Valent (i.e. Pneumovax)

Both 7/13 Valent and 23 Valent Pneumococcal vaccine  Not Applicable  Don’t Know

Did Not Answer

1. In the last 12 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? |\_\_|\_\_|

|  |  |
| --- | --- |
| **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 Applicable  What, if any, is the secondary spoken language? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_   1. What language is the client/caregiver most comfortable reading?   Client: .  Don’t Know  Not Applicable  Caregiver: .   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 Applicable  What, 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. | |
| 38.Are you (your child) Hispanic or Latino?  No, not Hispanic or Latino  Yes, Hispanic or Latino  39.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 | |