**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 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. |
| 38.Are you (your child) Hispanic or Latino?[ ]  No, not Hispanic or Latino [ ]  Yes, Hispanic or Latino39.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  |