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

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 30 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.

<u>Sickle Cell Disease Newborn Screening Program (SCDNBSP)</u> <u>Minimum Database Project (MDP)</u>

Sickle Cell Trait (SCT) Questionnaire

Section A: SITE IDENTIFYING INFORMATION

Today's Date (mn	n/dd/yyyy): - - 20 _			
Date of Client Vis	it/Interview (mm/dd/yyyy): _ - - 20			
Data Entry Personnel: Site ID: State ID:				
	Section B: CLIENT IDENTIFYING INFORMATION			
Client ID: _				
	Cooking Cooking INFORMATION			
Section C: CLIENT INFORMATION				

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

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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: FAMI	ILY INFORMATION				
4. How is the client related to the child with Scheck all that apply) Mother Maternal Grand Father Paternal Grand Maternal Uncle Paternal Uncle Other	dmother Paternal Grandfather e Paternal Aunt				
 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) 					

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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				

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11. Have any of the client's family members been tested for SCD/SCT or other hemoglobin trait? (Please check one)				
☐ Y€	es No Don't Know			
12. If	no, give reason why (Add NA if no re	eason provided or 'don't know' is checked):		
	Section F: CLIE	INT FAMILY COMMUNICATION		
13. For Ca	aregivers of clients under age 18	13. 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.)		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?		A. What is the primary spoken language in the client's home?	1e	
do	English is not your primary language you require a translator for medical rvices/medical information? Yes No Not Applicable	B. If English is not your primary language do you require a translator for medical services/medical information? Yes No Not Applicable		
W	hat, if any, is the secondary spoken	What, if any, is the secondary spoken language?	-	
lar C. W	hat language is the client/caregiver ost comfortable reading?	C. What language are you most comfortable reading?		
Cl	ient: Don't Know Not Applicable	D. What is the highest level of education you attained?	ı	

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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				