

Health Resources and Services Administration
Sickle Cell Program Information Collection

Subject: Request for a non-substantive change to an existing agency data collection activity approved by OMB under number 0915-0344

This is a request for a non-material or non-substantive change to a currently approved OMB approval for the Health Resources and Service Administration's Sickle Cell Program Information Collection. The current OMB approval is under OMB No. 0915-0344, which expires 12/31/2014.

The proposed changes are to reduce the number of survey items that grantee teams will collect from individuals served through two programs, Sickle Cell Disease Treatment Demonstration Program (SCDTDP) and the Sickle Cell Disease Newborn Screening Program (SCDNBSP). These are achieved by eliminating duplicated demographic items across instruments, by using validated shorter versions of the same instruments, and by eliminating one instrument that collected information that will be gleaned from other sources (chart review). Below, please find a summary of the minimal changes we seek in order to minimize the burden on the public.

Currently approved Questionnaire	Number of questions	Proposed Questionnaire	Number of Questions
SCDTDP			
Short Form 36 (SF-36) Health Survey (adults over 18 years of age)	36	Short Form 8 (SF-8) Health Survey (adults over 18 years of age)	8
Pediatric Quality of Life Inventory (PedsQL) Version 4.0 for children and adolescents 18 years or younger	23	Pediatric Quality of Life Inventory (PedsQL) Version 4.0 Short Form (SF15) for children and adolescents 18 years or younger	15
Pediatric Quality of Life Inventory (PedsQL) Version 4.0 for parents of children and adolescents age 18 years or younger	23	Pediatric Quality of Life Inventory (PedsQL) Version 4.0 Short Form (SF15) for parents of children and adolescents age 18 years or younger	15
Individual Utilization Questionnaire	28	Individual Utilization Questionnaire*	24
The Medical Home Family Index	25	Deleting The Medical Home Family Index **	0
Hemoglobinopathies Emerging Populations Form	3	Hemoglobinopathies Emerging Populations Form	3
SCDNBSP			
Minimum Database Project Sickle Cell Disease (SCD) Questionnaire	39	Minimum Database Project Sickle Cell Disease (SCD) Questionnaire*	35
Minimum Database Project Sickle Cell Trait (SCT) Questionnaire	15	Minimum Database Project Sickle Cell Trait (SCT) Questionnaire	13
Total number of questions:	192		113

* *What is (your/the client's) date of birth* changed to *Age of client at time of interview* to protect confidentiality.

** This deletion does not change the goals of the data collection strategy. The concept of care within the medical home will be captured through other project activities.

The Individual Utilization Questionnaire, Minimum Database Project Sickle Cell Disease (SCD) Questionnaire and the Minimum Database Project Sickle Cell Trait (SCT) Questionnaire are attached. Questions marked for deletion on these instruments are highlighted in yellow. The Short Form 8 (SF-8) Health Survey and PedsQL Version 4.0 Short Form (SF15) both require a site license, and therefore cannot be attached. However, a crosswalk of the items in the OMB approved instrument and the proposed short versions is attached.

The following table outlines the decrease in burden hours due to the proposed changes.

