Billing Code 4165-15

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Agency Information Collection Activities: Proposed Collection: Public Comment Request

AGENCY: Health Resources and Services Administration, HHS.

ACTION: Notice.

SUMMARY: In compliance with the requirement for opportunity for public comment on proposed data collection projects (Section 3506(c)(2)(A) of the Paperwork Reduction Act of 1995), the Health Resources and Services Administration (HRSA) announces plans to submit an Information Collection Request (ICR), described below, to the Office of Management and Budget (OMB). Prior to submitting the ICR to OMB, HRSA seeks comments from the public regarding the burden estimate, below, or any other aspect of the ICR.

DATES: Comments on this Information Collection Request must be received no later than **[INSERT DATE 60 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER]**.

ADDRESSES: Submit your comments to *paperwork@hrsa.gov* or mail the HRSA Information Collection Clearance Officer, Room 10C-24, Parklawn Building, 5600 Fishers Lane, Rockville, MD 20857.

FOR FURTHER INFORMATION CONTACT: To request more information on the proposed project or to obtain a copy of the data collection plans and draft instruments, email *paperwork@hrsa.gov* or call the HRSA Information Collection Clearance Officer at (301) 443-1984.

SUPPLEMENTARY INFORMATION: When submitting comments or requesting information, please include the information request collection title for reference.

Information Collection Request Title: Sickle Cell Disease Treatment Demonstration Program—Quality Improvement Data Collection

OMB No. 0915-xxxx – New

Abstract: In response to the growing need for resources devoted to sickle cell disease and other hemoglobinopathies, the United States Congress, under Section 712 of the American Jobs Creation Act of 2004 (Pub. L. 108–357) (42 U.S.C. 300b-1 note), authorized a demonstration program for the prevention and treatment of sickle cell disease (SCD) to be administered by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) in the U.S. Department of Health and Human Services. The program is known as the Sickle Cell Disease Treatment Demonstration Program (SCDTDP). The SCDTDP is designed to improve access to services for individuals with sickle cell disease, improve and expand patient and provider education, and improve and expand the continuity and coordination of service delivery for individuals with sickle cell disease and sickle cell trait. The specific aims for the program are threefold: 1) increase the number of providers treating persons with sickle

cell disease, 2) increase the number of providers prescribing hydroxyurea, and 3) increase the number of providers knowledgeable about treating sickle cell disease as well as increase the number of sickle cell patients that are seen by providers knowledgeable about sickle cell disease.

To achieve the goals and objectives of the program, the SCDTDP uses quality improvement (QI) methods in a collective impact model which supports cross-sector collaboration for achieving measurable effects on major social issues. The collective impact model requires shared measurement which facilitates tracking progress in a standardized method in order to promote learning and enhance continuous improvement.

Need and Proposed Use of the Information: The purpose of the proposed data collection strategy is to implement a system to monitor the progress of MCHB-funded activities in improving care and health outcomes for individuals living with sickle cell disease/trait and meeting the goals of the SCDTDP. Each regional grantee site will be asked to report on a core set of evidence-based measures related to healthcare utilization among individuals with sickle cell disease and the quality of care of the SCD population.

The data collected for the Sickle Cell Disease Treatment Demonstration Program will consist of administrative medical claims data collected from State Medicaid Programs and Medicaid Manage Care Organizations that administer Medicaid on behalf of states. The data is collected either for or by State Medicaid offices for delivery of services subject to Medicaid reimbursement.

The data collection strategy will provide an effective and efficient mechanism to do the following: (1) assess the improvements in access to care for sickle cell patients provided by activities in the SCDTDP; (2) collect, coordinate, and distribute data, best practices, and findings from regional grantee sites to drive improvement on quality measures; (3) refine a common model protocol regarding the prevention and treatment of sickle cell disease; (4) examine/address barriers that individuals and families living with sickle cell disease face when accessing quality health care and health education; (5) evaluate the grantees' performance in meeting the objectives of the SCDTDP; and (6) provide HRSA and Congress with information on the overall progress of the program.

Likely Respondents: Four regional grantee sites funded by HRSA under the SCDTDP will be the respondents for this data collection activity and submit responses gathered from State Medicaid Offices and State Medicaid Managed Care Organizations (MCOs).

Burden Statement: Burden in this context means the time expended by persons to generate, maintain, retain, disclose or provide the information requested. This includes the time needed to review instructions; to develop, acquire, install and utilize technology and systems for the purpose of collecting, validating and verifying information, processing and maintaining information, and disclosing and providing information; to train personnel and to be able to respond to a collection of information; to search data sources; to complete and review the collection of information; and to transmit or otherwise disclose the information. The total annual

burden hours estimated for this Information Collection Request are summarized in the table below.

Total Estimated Annualized burden hours:

Form Name	Number of Respondents	Number of Responses per Respondent	Total Responses	Average Burden per Response (in hours)	Total Burden Hours
SCDTDP Data form	4	Range: 16-80	Range: 64 - 320	Range: 4-6	Range: 256-1920
Total	4	Range: 16-80	Range: 64 - 320	Range: 4-6	Range: 256-1920

HRSA specifically requests comments on (1) the necessity and utility of the proposed information collection for the proper performance of the agency's functions, (2) the accuracy of the estimated burden, (3) ways to enhance the quality, utility, and clarity of the information to be collected, and (4) the use of automated collection techniques or other forms of information technology to minimize the information collection burden.

Jackie Painter,

Director, Division of the Executive Secretariat.

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