Improving Care of Patients with Sickle Cell Disease and Sickle Cell Trait: The Hemoglobinopathy Learning Collaborative Series

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This month JCOM launches a series calling attention to 5 teams working to improve care for individuals with sickle cell disease and sickle cell trait in the Hemoglobinopathy Learning Collaborative (—Ed.)

Sickle cell disease affects close to 100,000 people in United States [1]. This condition is characterized by chronic anemia and unpredictable pain episodes beginning in early childhood and leading to changes in functioning, diminished health-related quality of life, end-organ damage, increased health care use, and in some cases early mortality [2–5]. Sickle cell disease is identified through universal newborn screening [6] and is found in one in 2474 newborn Americans [7], with Americans of African ancestry most frequently affected. It is estimated that over 2 million Americans are genetic carriers of the sickle cell gene.

Although there have been major advancements in sickle cell care within the past several decades, there still exist significant variations in care and mortality [8–14]. Ongoing strategies to improve patient access to efficacious treatments are essential to improve outcomes for individuals with sickle cell disease.

Recognizing the compelling need for a focused national effort to improve care for this population and the relative lack of private resources committed to it [15], Congress established 2 federal programs to enhance newborn screening and improve follow-up and care and outcomes for this population: the Sickle Cell Disease Newborn Screening Program in 2002 [16] and the Sickle Cell Disease Treatment Demonstration Program in 2004 [17]. The programs are funded by the Health Resources and Services Administration and administered by the National Initiative for Children's Healthcare Quality (NICHQ)'s *Working to Improve Sickle Cell Healthcare* (WISCH) program [2]. NICHQ became the coordinating center for the programs in 2011 and 2010, respectively. Diverse grantees are now working together in a Hemoglobinopathy Learning Collaborative, coordinated and facilitated by NICHQ and its partners Boston Medical Center and the Sickle Cell Disease Association of America. The current rounds of funding continue through 2014 for the Sickle Cell Disease Treatment Demonstration Program and 2015 for the Sickle Cell Disease Newborn Screening Program.

The Hemoglobinopathy Learning Collaborative grantees are developing strategies that will result in more coordinated and appropriate care in order that individuals with sickle cell disease experience fewer complications, acute care visits, and hospitalizations; enhanced quality of life; and more compassionate and respectful treatment from the health care system. Processes are also being developed to ensure that individuals screened for sickle cell disease and sickle cell trait receive genetic counseling, education and appropriate follow-up care for their condition. The aims of the collaborative are aligned with the national quality strategy of the Triple Aim—better care, better health, and lower overall health care costs [18]. The strategies and approaches developed and tested by the teams will be disseminated to the broader sickle cell community for use in the treatment and management of individuals with sickle cell disease.

The Hemoglobinopathy Learning Collaborative's approach is based on the structure of the Breakthrough Series Learning Collaborative [19–21], a model championed by the Institute for Healthcare Improvement that brings together health care organizations that share a

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commitment to making major, rapid changes in order to produce breakthrough improvements in quality. Using a process known as the Model for Improvement [22], the teams develop ideas for changes, test small-scale changes using Plan-Do-Study-Act (PDSA) cycles, and measure to determine if the changes are leading to improvement. This method can quickly identify promising ideas and adapt and develop them to into robust, reliable standard processes [2].

There are 15 improvement teams working on quality improvement projects focused on improving acute care management, provision of recommended care, transition, self-management, provider education, and screening, counseling, and education for individuals with SCD and SCT. The 5 articles in this special series span these major content areas, from improving outcomes in the emergency department using standardized order sets to assessing the readiness of adolescents to transition to adult care, to using health information technology to improve care coordination, to developing a home pain management plan, and to using patient navigators to help coordinate care and resources. The series begins with the article by Treadwell et al in this issue and will continue for the next several months. The WISCH teams will serve as leaders for sustainable and positive change for treatment of individuals with sickle cell disease and sickle cell trait in the United States. Their work is an important step towards transforming care for people with sickle cell disease, so that each person with sickle cell disease will receive the highest quality of care throughout their lifespan.

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