Sickle Cell disease Treatment Demonstration Program
Hemoglobinopathy Learning Collaborative

The Sickle Cell Disease Treatment Demonstration Program enhances the prevention and treatment of sickle cell disease through the coordination of service delivery, genetic counseling and testing, bundling of technical services, training of health professionals, and other related efforts.

The Hemoglobinopathy Learning Collaborative brings together Sickle Cell Disease Treatment Demonstration Program grantee networks and helps them generate and document improved health outcomes for underserved populations, transform clinical practice through models of care, improvement and learning, develop infrastructure, expertise and multi-disciplinary leadership, and build strategic partnership. Hemoglobinopathy describes blood disorders, including sickle cell disease and thalassemia.

The first collaborative session was held in March 2009 and focused on Family/Patient-Center Medical Home Care Model, the model for improvement, and the importance of developing community partnerships. It was followed by an action period, which included follow-up calls, reports, data collection and technical assistance. A second session, emphasizing consumer participation was held in November of 2009 and was followed by an action period.

The next phase of the collaborative will begin with a Quality Improvement workshop in the spring of 2011.

Participants

Hemoglobinopathy Learning Collaboratives teams are composed of six to eight individuals, including HRSA-funded sickle cell disease and thalassemia program grantees, partners, stakeholders, and consumers.

Funding

In October 2010, HRSA awarded a $3.5 million contract to the National Initiative for Children's Healthcare Quality (NICHQ) to be the National Coordinating Center for the Sickle Cell Disease Treatment Demonstration Program. Over the next four years, NICHQ has allocated a total of $1,292,833 to the Hemoglobinopathy Learning Collaborative.

More information: http://www.nichq.org/our_projects/sickle_cell_landing_page.html