



## **Sickle Treatment and Outcomes Research in the Midwest (STORM)**

Project Charter | September 1, 2014 – August 31, 2017

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### **PROBLEM STATEMENT**

Sickle cell disease is the most commonly inherited blood disorder. There are approximately, 15,000 individuals living with SCD in the STORM Midwest region. SCD is a lifelong condition complicated by acute and chronic medical problems, which can be life-threatening and disabling. SCD adversely impacts the physical, emotional, social, and vocational lives of both the affected individuals and their families across the lifespan. Early diagnosis and treatment of the disease is critical, yet access to care is variable.

The purpose of STORM is to bring together the hematology and primary care communities to collaborate with patients and families on quality improvement initiatives to improve access and delivery of care and outcomes for patients with SCD in the Midwest.

### **COLLABORATIVE MISSION AND GOALS**

Aim : STORM will build a sustainable network to improve the outcomes and care for patients with sickle cell disease (SCD) in the Midwest.

With partners from Indiana, Illinois, Michigan, Minnesota, Ohio and Wisconsin, we will work together to (1) increase the number of providers that are treating sickle cell patients in the region; (2) increase the number of providers prescribing disease-modifying therapies, such as hydroxyurea; and (3) increase the number of sickle cell patient that are receiving care from providers with greater knowledge of how to treat sickle cell disease.

#### STORM Goals

- Improve access to a continuum of high-quality, patient-centered care from knowledgeable providers
- Implement and spread evidence-based protocols and best practices among providers
- Monitor and increase the number of patients in the region receiving hydroxyurea
- Engage patients and stakeholders to improve care
- Provide technical assistance center to increase capacity of providers in the region to use data for continuous QI
- Create a Sickle Cell State Data Repository that includes data on the regional SCD population and measures related to access, quality and outcomes
- Reduce health disparities, thereby increasing health equity

### **METHODS**

Using the Institute for Healthcare Improvement Breakthrough Series Learning Model, STORM will use quality improvement (QI) methods to achieve project goals. STORM's key objective is to bring together stakeholders who can leverage resources and partnerships across their state, actively participate in the regional collaborative, meet the aims of the project within the three-year time frame (2014-2017), and participate in data collection.



All partners will receive training in Improvement Science concepts, methodology, and tools via frequent webinars and Learning Session workshops. Participants will implement recommended interventions in their state, conduct small scale tests of change through several Plan-Do-Study-Act test cycles, and share learning with all sites.

The STORM teams will submit data regarding their performance, thereby enabling teams to assess their progress individually and regionally and to provide feedback for improvement.

Other activities include monthly data collection and monthly action periods calls.

## **COLLABORATIVE EXPECTATIONS**

The STORM Regional Center, along with the Cincinnati Sickle Cell Center and the Anderson Center will:

- ✓ Create and/or maintain communication platforms to keep all stakeholders connected including the STORM website and Sharepoint site;
- ✓ Provide training in Science concepts, methodology, and tools via frequent webinars and Learning Sessions;
- ✓ Offer coaching to partners at meetings and during action periods via conference calls, emails, website, and listserv contacts; and
- ✓ Work with State-level partners to develop and/or maintain state-level Sickle Cell State Data Repositories on sickle cell clinical outcomes.

State partners are expected to:

- ✓ Perform prework activities in preparation for the initial Learning Session;
- ✓ Send a team to all Learning Sessions comprised of the project director from each state and the clinical and administrative staff who will be devoted to testing and implementing changes in their organization;
- ✓ Perform Plan-Do-Study-Act test cycles in their organization that will lead to widespread implementation of improvements in the organization;
- ✓ Collect sickle cell clinical outcomes data on a monthly basis and submit in REDCap database;
- ✓ Share information with the Collaborative, including data and tests of change, both during Learning Sessions and monthly action period calls.

## **FUNDING**

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## STORM Collaborative Key Driver Diagram

