# Sickle Cell Disease Treatment Demonstration Project
# 2017 Compendium of Tools and Materials

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## Introduction

There are over 100,000 people in the United States living with sickle cell disease (SCD).  Access to high quality healthcare and services with providers knowledgeable about SCD care is imperative. This Compendium of Tools and Materials of SCDA resources is the companion piece the SCDTDP 2017 Model Protocol, which details key strategies for improving patient access to high quality care and disease modifying treatments by knowledgeable providers. The materials listed in this compendium expand upon those included in the Model Protocol to offer a range of tools, materials and resources in support of the strategies and activities care teams are using with patients and families to ensure the best quality of life for those with living with SCD.

## Provider Education & Capacity Building Resources

All the materials in this compendium are useful tools to providers treating SCD. Some are for sharing with patients to support awareness, self-care management and shared decision making. Others are protocols and best practices that primary care, emergent care, and specialists need know and use to serve their patients with SCD. During the SCDTDP 2014-2017 project, there were resources and methods for spreading knowledge of and awareness for SCD.

### Websites

- Evidence Based Management of Sickle Cell Disease: Expert Panel Report, 2014 (NHLBI, NHI)

- Regional Coordinating Centers SCDTDP 2014-2017

  Sickle Cell Treatment and Outcomes Research in the Midwest (STORM)

  Pacific Sickle Cell Regional Collaborative (PSCRC)

  A. Sickle Cell Improvement in the Northeast Region through Education (SiNERGe)

  B. Sickle Cell Improvement in the Northeast Region through Education (SiNERGe)

  Heartland Sickle Cell Disease Network

- American Society of Hematology (Sickle Cell)

- Centers for Disease Control and Prevention (Sickle Cell)

- National Heart Lung and Blood Institute

- Sickle Cell Disease Association of America

- American Sickle Cell Anemia Association

- Sickle Cell Information Center at Emory

- California Sickle Cell Resources

## Webinar Series

- [Hydroxyurea CME Module-Johns Hopkins Sickle Cell (video CME)](#) (SiNERGe/Johns Hopkins Medicine)
- [Recorded Lectures: SCD: What the Internist Needs to Know](#) (SiNERGe/Johns Hopkins Medicine)
- [Recorded Lectures: Ethical and Health Policies in SCD](#) (SiNERGe/Johns Hopkins Medicine)
- [Recorded Lectures: Acute Complications of SCD](#) (SiNERGe/Johns Hopkins Medicine)
- [Making a Smooth Transition from Pediatric to Adult SCD Care: Eliminating Barriers, Enhancing Resources Part I & II (Webinar Series)](#) (SiNERGe)
- [Creating a New Sickle Cell Clinic: A Case Study: A few dedicated professionals discuss how and why they created a new county clinic in South Los Angeles.](#) (PSCRC)
- [Key Findings: CDC's Sickle Cell Data Collection Program Data Useful in Describing Patterns of Emergency Department Visits by Californians with Sickle Cell Disease (SCD)](#) (PSCRC)
- [Genotyping in Hemoglobin Disorders Webinar by Dr. Charles Quinn, January 25, 2016 | Presented by: Ohio Department of Health Sickle Cell Services Program & Sickle Cell Treatment and Outcomes Research in the Midwest](#) (STORM)


## Project ECHO

- [STORM TeleECHO™ Curriculum](#)
- [Project ECHO® for Sickle Cell Disease in the Northeast](#) (SiNERGe)
- [Western States Telementoring Collaborative for SCD](#) (PSCRC)
- Journal articles
    - Shook LM, Farrell CB, Kalinyak KA, Nelson SC, Hardesty B, Saving K, Whitten-Shurney W, Panepinto J, Crosby LE, and Ware RE. (2016) Using Telementoring to Improve Sickle Cell Disease Care in the *Midwest, Medical Education Online*, Nov 24;21:33616. 27887664

## Point of Care Resources

- [Dynamed Plus®](#)
- [Medscape](#)
- [Essential Evidence Plus](#)
- [UpToDate®](#)
- [Got Transition](#)
- STORM HU Clinical Decision Tool (contact [storm@cchmc.org](mailto:storm@cchmc.org) for information)

## Journal Articles

1. Shook LM, Farrell CB, Kalinyak KA, et al. Translating sickle cell guidelines into practice for primary care providers with Project ECHO. *Med Educ Online*. 2016;21:33616. http://www.ncbi.nlm.nih.gov/pubmed/27887664. Accessed May 18, 2017.

2. Whiteman LN, Haywood C, Lanzkron S, Strouse JJ, Feldman L, Stewart RW. Primary Care Providers' Comfort Levels in Caring for Patients with Sickle Cell Disease. *South Med J*. 2015;108(9):531-536. doi:10.14423/SMJ.0000000000000331.

## Screening and Trait Resources

Though carriers of the sickle cell trait do not have the same symptoms as those with sickle cell disease, it is important for individuals to know their status and how it can impact them and their families. Individuals often become aware of their status through community health fairs or during pregnancy, when screening for sickle cell disease and general education are offered. This group of resources can be used by providers to educate patients about sickle cell disease, sickle cell trait and screening.

### Educational and Counseling Strategies

- Genes for Teens Brochure (created by the TN TDP team)
- Genes for Parents of Children with Sickle Cell Disease (created by the TN TDP team)
- All You Wanted to Know About Sickle Cell Trait brochure (created by the IL TDP team)
- Trait Counseling Educational Booklet and Presentation (created by the MO TDP team)
- Sickle Cell Trait Counseling Handout Ages 0-9 (created by the MA NBSP team)
- Sickle Cell Trait EHR Counseling Prompt (created by the MA NBSP team)
- Sickle Cell Trait Presentation for the Community (created by the MA NBSP team)
- Parents' Guide to Sickle Cell Disease (created by the MA NBSP team)
- Parents' Guide to Sickle Cell Trait (created by the MA NBSP team)
- Get Screened to Know Your Sickle Cell Status (English) (CDC) (Spanish; French)
- What you should know about Sickle Cell Trait (English) (CDC) (Spanish; French)
- What you should know about SCD and Pregnancy (English) (CDC) (Spanish; French)
- Cincinnati Children's Hospital: Sickle Cell Trait (STORM)

### Pre- and Post-Tests

- Pre- and post-test for Genetic Counseling and Education (created by the IL NBSP team)
- Trait Pre- and Post-test for Genetic Counseling and Education (created by the IL TDP team)
- Sickle Cell Trait Pre-Clinic Review (created by IL TDP team)

### Other

- Sickle Cell Trait Provider CME Training (created by the MA NBSP team)
- Screening and Trait Counseling\Screening Algorithm (created by the MA NBSP team)
- Sickle Cell Trait Knowledge Tool (created by the TN NBSP team)
- The Talking Drums Project Community Survey (created by the CA TDP team)
- Sickle Cell Trait Toolkit (CDC)
- Hemoglobinopathies: Current Practices for Screening, Confirmation and Follow-up (2015) Report (CDC)

## Acute Care Resources

Due to limited general knowledge of sickle cell disease among physicians and lack of access to specialty care, many people with sickle cell disease access medical care through the emergency department. This group of resources and tools is most relevant to providers in the acute care or emergency department setting.

### Pain Assessment

- [Sickle Cell Pain Chart](#) (created by IL TDP)
- [Pain Assessment Scale](#) (created by NY NBSP)

### Standard Order Sets

- [Acute Chest Syndrome Management Checklist](#) (created by TN NBSP)
- [Iron Overload Checklist](#) (created by TN NBSP)
- [Pain Checklist](#) (created by TN NBSP)
- [Stroke Checklist](#) (created by TN NBSP)
- Pediatric ED: [VOE Protocol](#) (created by MA NBSP)
- [Sickle Cell Pain Initial Order Set Moderate to Severe Pain](#) (created by CA TDP)
- [Fever in Sickle Cell Disease Algorithm](#) (created by CA TDP)
- [ED Algorithm for Sickle Cell Disease Pain Management](#) (created by NJ TDP)

### Pain Action Plans

- [Pain Action Plan](#) - English (created by the CA TDP)
- [Pain Action Plan -](#) Spanish (created by the CA TDP)
- Adult ED: [Individualized Pain Plan](#) (created by MA NBSP)
- [Individualized Pain Plan for Children with Sickle Cell Disease](#) (created by PA NBSP/TDP)

### Patient Satisfaction Survey

- Adult ED: [Patient Satisfaction Survey](#) (created by MA NBSP)
- Pediatric ED: [Patient Satisfaction Survey](#) (created by MA NBSP)
- [ED Patient Satisfaction Survey](#) (created by CA TDP)

### Patient-Controlled Analgesia Pumps

- Pediatric ED: [Patient Controlled Analgesia Handout](#) (created by MA NBSP)

### Intranasal Fentanyl

- [ED Protocol Intranasal Fentanyl](#) (created by the CA TDP)
- [Intranasal Fentanyl Flyer](#) (created by the CA TDP)
- Pediatric ED: [Intransal Fentanyl Handout](#) (created by MA NBSP)

## Education Materials and Tools for Providers and Clinics

- [Acute Care Individual Times Tool](#) (created by OH TDP)
- [Staff training](#): Presentation on sickle cell disease to ED staff (created by OH TDP)
- [Evaluation survey](#) for presentation to ED staff (created by OH TDP)
- Video: [CRISIS: Experiences of People with Sickle Cell Disease Seeking Health Care for Pain](#) (created by MD TDP)
- Pediatric ED: [Pain Med Calculator](#) (created by MA NBSP)
- Pediatric ED: [Nursing In-service - 2012](#) (created by MA NBSP)
- Pediatric ED: [Nursing In-service - 2014](#) (created by MA NBSP)
- [APPT Scoring Guide](#) (created by CA TDP)
- Best Practices Principles Poster: [Fever and Acute Chest Syndrome](#) (created by CA TDP)
- Best Practices Principles Poster: [Priapism in Sickle Cell Disease](#) (created by CA TDP)
- [Key Findings: CDC's Sickle Cell Data Collection Program Data Useful in Describing Patterns of Emergency Department Visits by Californians with Sickle Cell Disease (SCD)](#) (CDC)
- [ASH Pocket Guide: Management of Acute Complications of Sickle Cell Disease](#)

## Medical Home/Care Coordination Resources

People living with sickle cell disease often have multiple and complex medical needs, so it is ideal to be able to coordinate care among various specialties. This group of resources is useful for patients, providers and representatives of community based organizations who are involved in coordinating care for patients.

### Individual Care Plans
- [Patient Needs Assessment](#) (created by the IL TDP team)
- [SMART Phrase:](#) Quick summary of relevant sickle cell disease management facts (created by the OH TDP)
- [Patient Needs Assessment Form](#) (created by the IL TDP)

### Health Maintenance Tracking Tools
- [Care Coordination Screening](#) (created by the IL TDP team)
- [Care Coordination Checklist](#) (created by the IL TDP team)
- [Well Sickle Checklist](#) (created by the NY NBSP)
- [Patient Event Diary](#) (created by the NY NBSP)
- [Sickle Cell Disease Clinic Worksheet](#) (created by the IL TDP)
- [Adult Patient Tracking Log](#) (created by the IL TDP)
- [Health Maintenance Form](#) (created by the NJ TDP)

## Mental Health Screening
- [Depression Checklist](#) (created by the TN NBSP)
- [Mental Health Referral Protocol](#) (created by the MO TDP)
- [Patient Referral Satisfaction Survey - Mental Health Services](#) (created by the MO TDP)
- [Mental Health Referral Flowchart](#) (created by the MO TDP)
- [Patient Health Questionnaire - Depression Screening](#) (created by NJ TDP)

## Transitions
- Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolescents with Sickle Cell Disease, includes Topics, Methods, and Efficacy Measurements (PDF)
- [What you should know about SCD: Nine Steps to Living Well with Sickle Cell Disease in College](#) (CDC)
- [SCD Fact Sheet: What you should know about sickle cell disease (English)](#) (CDC) ([French](#))
- Crosby, L. E., Quinn, C. T., & Kalinyak, K. A. (2015, April 1). A Biopsychosocial Model for the Management of Patients with Sickle-Cell Disease Transitioning to Adult Medical Care. *Advances in Therapy*. Springer Healthcare. https://doi.org/10.1007/s12325-015-0197-1
- Treadwell M, Johnson S, Sisler I, et al. Development of a sickle cell disease readiness for transition assessment. *Int J Adolesc Med Health*. 2016;28(2):193-201. doi:10.1515/ijamh-2015-0010.
- Treadwell M, Johnson S, Sisler I, et al. Self-efficacy and readiness for transition from pediatric to adult care in sickle cell disease. *Int J Adolesc Med Health*. 2015;2015(4):381-388. doi:10.1515/ijamh-2015-0014.

## Other
- [ASH Pocket Guide:  Health Maintenance and Management of Chronic Complications of Sickle Cell Disease](#)
- Ballas SK, Vichinsky EP. Is the Medical Home for Adult Patients with Sickle Cell Disease a Reality or an Illusion? *Hemoglobin*. 2015;39(2):130-133. doi:10.3109/03630269.2015.1023312.
- Hsu LL, Green NS, Donnell Ivy E, et al. Community health workers as support for sickle cell care. *Am J Prev Med*. 2016;51(1):S87-S98. doi:10.1016/j.amepre.2016.01.016.

## Hydroxyurea Resources

The drug hydroxyurea has been life-changing for those who are able to use it (it is not effective for all types of sickle cell disease), yet many people who are eligible are not using hydroxyurea. This group of resources have been used by providers to share information with patients about the benefits and risks of using hydroxyurea.

### Patient Education
- Video: Hydroxyurea: The Best Hope for Sickle Cell Anemia Patients (created by the NJ TDP)
- Keeping You Healthy with Sickle Cell Disease. An educational kit addressing knowledge/beliefs on the use of hydroxyurea (created by MA NBSP)
- Treating sickle cell disease: Is hydroxyurea right for your child? (English) (PSCRC, STORM, Heartland SCD Network) (Spanish; French)
- Treating sickle cell disease: Is hydroxyurea right for you? (English) PSCRC, STORM, Heartland SCD Network) (Spanish; French)

### Dosing Guidelines
- Hydroxyurea Dosing Guidelines (created by MA NBSP)
- Hydroxyurea Tracking Form (created by NJ TDP)
- Hydroxyurea for Sickle Cell Disease: Indications, Dosing and Monitoring Guideline (STORM)
- ASH Pocket Guide:  Hydroxyurea and Transfusion Therapy for the Treatment of Sickle Cell Disease

### Other
- Journal Article: "Improved Hydroxyurea Effect with the Use of Text Messaging in Children with Sickle Cell Anemia" (created by TN TDP)
- Crosby, L. E., Shook, L. M., Ware, R. E. and Brinkman, W. B. (2015), Shared decision making for hydroxyurea treatment initiation in children with sickle cell anemia. *Pediatric Blood & Cancer*, 62: 184–185. doi: 10.1002/pbc.25124


## Local Electronic Health Registries
Developing a local, electronic health registry to track sickle cell disease specific measures was a key component for SCDTDP RCCs to measure and improve the quality of care for patients with SCD and to track progress over time.

- SCDTDP Administrative Measures Data Dictionary (2014-2017)
- SCDTDP Minimum Data Set Data Dictionary (2014-2017) hyperlink:
- PSCRC Minimum Data Set Data Dictionary
- PSCRC Enrollment & Annual Update PSCRC Minimum Dataset
- PSCRC Abbreviated Patient Form
- PSCRC Abbreviated Provider Form
- PSCRC Minimum Data Set Data Dictionary
- Application for Study Review (PSCRC)
- Technical Assistance Visit Checklist

- [PhenX Toolkit](#)
- [Application for Study Review (PSCRC)](#)
- [REDCap](#)
- [PSCRC Abbreviated Provider Form (link)](#)

For electronic access to SCDTDP 2017 Compendium of Tools and Materials, please visit:
http://www.nichq.org/resource/compendium-resources-2017

For electronic access to the SCDTDP 2017 Model Protocol, please visit:
http://www.nichq.org/resource/model-protocol-2017

These resources were developed through the Sickle Cell Treatment Demonstration Program (2014-2017) and the  Working to Improve Sickle Cell Healthcare (WISCH) projects. As the National Coordinating Center for these programs, NICHQ is happy to share guidance, tools and resources that teams from around the country have created, tested or used to improve care for patients with sickle cell disease.

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