SICKLE CELL DISEASE
TREATMENT DEMONSTRATION
REGIONAL COLLABORATIVES PROGRAM

Model Protocol: Strategies and Resources for Replicating the Program

NICHQ
National Institute for Children's Health Quality

SEPTEMBER 2021

Introduction

Model Protocol

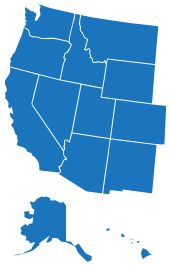
Introduction

This document contains information for the Model Protocol for the Sickle Cell Treatment Demonstration Collaboratives Program (SCDTDRCP). Between 2017 and 2021, Health Resources Services Administration (HRSA) funded this Program as part of the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018, 42 U.S.C. § 300b-5 (2018). The Program description and findings can be found in the 2021 Congressional Report.

NOTE:
Throughout this report, the Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program is referred to as "SCDTDRCP" or "the Program."

The purpose of this Model Protocol is to offer providers, community-based organizations (CBOs), public health agencies, academic institutions, healthcare organizations, policy makers, and others guidance on promising practices and strategies developed when providing care for people living with SCD. This tool was developed to support the spread and implementation of clinical guidelines and development of systems of care that can collectively improve the health and quality of life for people living with SCD. These resources and strategies have been compiled from the current RCCs and their state partners. They have been reviewed and identified as effective strategies by leaders advancing SCD care at local comprehensive sickle cell centers, regional centers of collaborative learning, and experts from across the nation. The recommended strategies work best within collaborative teams via collective feedback and through tailoring by key stakeholders that comprise the system.

The Program network was divided into five Regional Coordinating Centers (RCCs) representing 50 states and territories:



1. Pacific Sickle Cell Regional Collaborative (PSCRC)

PSCRC

2. Heartland/Southwest Sickle Cell Disease Network

Heartland Southwest
SICKLE CELL DISEASE NETWORK

3. Sickle Treatment and Outcomes Research in the Midwest (STORM)

STORM
Sickle Treatment & Outcomes Research in the Midwest

4. Sickle Cell Improvement in the Northeast Region through Education (SINERGe)

SiNERGē
NORTHEAST REGIONAL
SICKLE CELL COLLABORATIVE

5. Education and Mentoring to BRing Access to CarE (EMBRACE) in the Southeast

THE EMBRACE NETWORK

The Program built upon and expanded work begun in the previous cycles of this funding in 2014 and 2017. These initiatives were intended to develop and refine clinical protocols and to identify priority areas of care coordination to ensure that all patients receive the highest quality of care. In 2014, a Compendium of Tools and Resources was created that was designed to help spread essential tools and resources developed and tested over the course of the Program. This Compendium was updated in 2017 and again in 2018. A newly released 2021 version is part of the 2021 Report to Congress. The Compendium holds key tools and resources for providers and teams working with patients and families. It is designed to facilitate the provision of high-quality care for children and adults living with SCD and sickle cell trait (SCT) and select resources are referenced in this document.

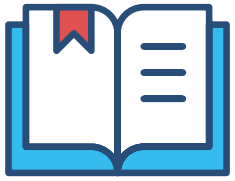
The five RCCs used a diverse set of Quality Improvement (QI) tools to test, implement, and spread effective, evidence-based clinical protocols and system changes to address the aims of this Program. While these change ideas have been tested and implemented across communities and regions, it is recommended that QI principles be employed when implementing these change ideas in new settings (Institute for Healthcare Improvement, 2020). Using QI principles to apply and test these ideas in a new environment can better ensure that local care needs are met.

Organization of the Model Protocol

This Model Protocol includes the resources, strategies, and best practices organized into four sections reflecting broad areas of Program work:

1. Increasing Access to Quality Care

2. Increasing Delivery of Hydroxyurea, Immunizations, and Transcranial Doppler



3. Increasing Provider Knowledge Through Education

4. Increasing Use of Technology That Supports Healthcare Delivery

Each of these sections includes an overview narrative, followed by a table that lists domains and rationale for activities along with resources.

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Strategies and Resources to Increase Access to Quality Care

Model Protocol

Strategies and Resources to Increase Access to Quality Care

SCD is a serious genetic condition that, while rare, can have a significant impact on affected people and their families. Those living with SCD can have acute pain episodes and are at high risk for complications, such as infection, acute chest syndrome, and stroke. These complications can have a severe impact on both the quality of life and overall lifespan for people living with SCD. Because of this impact, receiving high quality care is important. However, there are wide-ranging barriers to accessing quality care for people living with SCD.

Comprehensive SCD care teams have been established to provide coordinated care that meets current clinical guidelines. However, these teams or centers may not be accessible to people who reside in areas, such as rural communities far away from large academic health systems, preventing them from receiving new and innovative technology and enhanced treatment options that could help them live longer. Particularly, adults living with SCD may experience significant difficulties accessing quality primary and specialty care. The reasons for this disparity are numerous and include a lack of knowledgeable providers able to care for people living with SCD. Primary care providers frequently have a limited number of people living with SCD on their clinical panels, which diminishes opportunities to enhance expertise and stay up-to-date with contemporary guidelines and recommendations related to caring for people living with SCD.

INCREASING ACCESS TO CARE

RCCs used a multidimensional approach to increase quality care for people with SCD, including:

- Enhancing community partnerships
- Expanding program and provider availability
- Improving transition from pediatric to adult care
- Addressing financing

Enhancing Community Partnerships

RCCs created integrated care networks by partnering with key stakeholders and communities to increase the reach of clinical care sites within communities and connect with hard-to-reach populations. This work was supported by the development of close partnerships with CBOs that support children, adolescents, adults, and families living with SCD in their homes and communities. In addition, providers and CBOs worked together to utilize community health workers to identify and connect individuals to both primary and specialty care and address social determinants of health. These strategies helped create a bridge to additional supports for families affected by SCD and to extend the reach of clinical sites within the communities they serve.

Expanding Program and Provider Availability

In rural areas where geographic barriers challenge care access, state and regional partners coordinated transportation; set up satellite centers of care; collaborated with advanced practice professionals (APPs); and leveraged telehealth to reach rural patients to ensure they had routine SCD care. RCCs increased the use of telementoring via regional and local Project Extension for Community Healthcare Outcomes (ECHO®) sessions to bolster provider-to-provider education among providers (including specialists, PCPs, and APPs (both urban and rural providers). Project ECHO® was developed in 2002 by Sanjeev Arora, MD, at the University of New Mexico and was a key focus for the Program teams. Project ECHO® is an innovative telementoring program designed to create virtual communities of learners by bringing together healthcare providers and subject matter experts using videoconferencing to provide brief lecture presentations and case-based learning, fostering an "all learn, all teach" approach. Participants are engaged in the bidirectional virtual knowledge network by sharing clinical challenges and learning from peers and specialty experts across the country. Project ECHO® has been globally recognized as a successful tool to improve patient care outcomes.

Improving Transitional Pediatric to Adult Care

The life expectancy of people living with SCD has increased. However, the period of transition from pediatric to adult medicine is identified as a time of increased risk of morbidity and mortality. Thus, a robust transitional process during this time is essential. In many regions, provider organizations are central to the creation of systems-level changes and resources to track and facilitate transitions from pediatric to adult care. In addition, CBOs are increasingly helping to develop adolescents' life skills and capacity to self-manage aspects of their condition with specialized training curricula. Partnership between CBOs and healthcare organizations is important for reaching patients where they are, particularly at crucial time periods, such as young adulthood when the transfer from pediatric to adult healthcare systems occurs.

LIFE EXPECTANCY

The life expectancy of people living with SCD has increased. However, the period of transition from pediatric to adult medicine is identified as a time of increased risk of morbidity and mortality.

Addressing Financing

Along with established strategies to increase the number of providers and institutions delivering SCD care, RCCs discussed the need to address healthcare financing policies to allow for adequate reimbursement for health services. SCD treatment programs and other stakeholders are creating coalitions to work with local and state policymakers along with payer groups to educate about the need for appropriate reimbursement and the importance of having payment arrangements in place to support providers' ability to improve access to quality care. For example, reimbursement policies that cover coordination between specialists and primary care providers can facilitate and support seamless care. Funding made available for telehealth needs can result in better disease management and quality of life for people living with SCD.

Learning From the Program Work: The Following are Suggested Approaches to Increasing Access to Care for People Living with SCD

- Facilitate connections between CBOs and healthcare providers to ensure maximized outreach and healthcare access for people living with SCD and their families (e.g., grow and expand mutual partnerships with local organizations)
- Identify and connect people living with SCD, especially young adults, with providers and systems of care that support self-management, care coordination, and care transitions, such as transferring from pediatric to adult care
- Reach out to and provide educational opportunities for primary care providers, specialists, and APPs to enhance awareness about SCD and outline appropriate referral processes to ensure access to specialty care
- Expand physical and virtual access to care through the development of new programs or satellite locations and leveraging telehealth technologies

The following table provides suggested strategies and related rationales and resources for increasing access to care for people living with SCD.

Table 1. Strategies and Resources to Increase Access to Quality Care

STRATEGY	RATIONALE	RESOURCES

Creation of Sickle Cell Disease Programs	All regions support the development of additional sites for the provision of comprehensive care to ensure availability to all people with SCD. Both quantity and quality of these settings for care matter and several regions have been successful in setting up clinics. See the suggested resources for planning and implementing a comprehensive SCD care team.	• *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.*
		• EMBRACE Sickle Cell Disease Network (Setting up a comprehensive SCD clinic)
		• Examples of State plans (Comprehensive List in Compendium of Tools)
		  ○ Pacific RCC State Action Plan
		  ○ Texas State Action Plan

Provider Outreach and Engagement	There are a limited number of providers with expertise in the care of people living with SCD, specifically adults. As people living with SCD live longer with specialized care, providers need to be knowledgeable about this condition and up-to-date recommendations for primary and specialty care for this population.	• Illinois Provider Engagement Survey (contact storm@cchmc.org for information) • *Enhancing Access to Care for Sickle Cell Disease in South Carolina* (webinar) • *Sickle Cell Awareness Guide for Providers* (Midwest RCC)
Enhancement of SCD and SCT Awareness in the Community and Healthcare Institutions	People living with SCD are more likely to access quality care when they are knowledgeable about the care that they need and know where to obtain services. Similarly, communities affected by SCD can better advocate for high-quality, comprehensive care when they are informed about SCD and SCT. Informational materials on SCD and SCT can also be used in the clinical setting by both primary care and providers who specialize in SCD care.	**What You Should Know About Sickle Cell Trait** • English French Spanish (handout) • *Sickle Cell Trait Toolkit* (website) • Midwest RCC: *Cincinnati Children's: Sickle Cell Trait* (website) • Trait Counseling Booklet • SC Trait Explanatory Brochure **Get Screened to Know Your Sickle Cell Status** • English French Spanish (handout) **What You Should Know About Sickle Cell Disease** • English French Spanish (handout) • *5 Facts You Should Know About Sickle Cell Disease* (handout) **What You Should Know About Sickle Cell Disease and Pregnancy** • English French Spanish (handout) • *Pregnancy and Sickle Cell Disease*
Enhancement of Family and School Personnel Awareness About Management of SCD at Home and in Early Childhood and School Settings	It is essential that caregivers and school personnel are knowledgeable about SCD, related symptoms, available treatments, and necessary accommodations for children living with SCD. Resources educating caregivers and teachers about SCD management can help children and adolescents in educational and social settings.	*Tips for Supporting Students with Sickle Cell Disease* (booklet) **Living Well with Sickle Cell Disease: Tips for Healthy Living** • English Spanish (handout) • *5 Tips to Prevent Infection* (handout) • Disease education materials

Table 1. (continued) Strategies and Resources to Increase Access to Quality Care

STRATEGY	RATIONALE	RESOURCES
Support for Adolescents Living with SCD Transferring from Pediatric to Adult Care	Many people living with SCD are living into adulthood. Smooth transfer from pediatric to adult care is essential but can be fraught with complications related to changes in insurance, care providers, and care settings. Consequently, it is important to provide education about chronic disease self-management and general life skills to young adults and their families navigating the transition from pediatric to adult care.	• *Nine Steps to Living Well with Sickle Cell Disease in College* (handout) • *Pediatric to Adult Health Care Transition: A Family Toolkit* • Readiness assessment for parents • Readiness assessment for youth • Health Care Transition Timeline for Parents and Caregivers • Health Care Transition Timeline for Youth and Young Adults • Sickle Cell Transition from age 13 to 15 • Sickle Cell Transition from age 16 to 18 • Sickle Cell Transition from age 19 to 21 • Patient Empowerment Toolkit • See Compendium of Tools and Materials for additional resources
Implementation of an SCD-specific Transition Curriculum	Several clinical sites have begun to develop specific, comprehensive curricula that encompass the typical span of the transition period (12-21 years of age). Clinics should first establish a system for transition following the *Got Transition*® six core elements. Curricula should include recommendations of educational content for providers, adolescents and young adults living with SCD, and their families. Use of the entire curricula is recommended so that all topics are covered throughout the transition planning process. Additional areas that should be addressed include guidelines for discussing topics, methodologies of teaching the curricula, and techniques to measure efficacy of the teachings. Curricula can be used as a resource in both the medical and the community setting and are effective in helping organize the work conducted as a partnership.	• A program of transition to adult care for sickle cell disease (ASH Education Program) • Sickle Cell Transition Curriculum • https://www.floridahats.org/

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Increased Delivery of Hydroxyurea, Transcranial Doppler, and Immunizations

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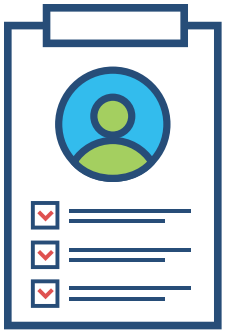

Strategies to Increase Hydroxyurea, Immunizations, and Transcranial Doppler

Promising strategies have been employed to increase delivery of Hydroxyurea (HU), Transcranial Doppler (TCD), and immunizations but they have varied greatly from region to region and provider to provider (Wang et al., 2013). The use of evidence-based guidelines, protocols, and shared decision-making tools, both in electronic and print forms, can help facilitate providers' communication with patients and their families about the clinical benefits, side effects, and various considerations related to SCD treatment. Materials also help review applicable long-term consequences of treatments and preventive and screening measures. These resources have been demonstrated to empower patients and families by increasing knowledge of evidence-based treatment options, widening their understanding of risk, and decreasing decisional conflict (Crosby et al., 2015).

Expert Guidelines

The RCCs and participating sites have successfully employed expert guidelines and protocols, such as those published by the American Society of Hematology (ASH) and the National Heart, Lung, and Blood Institute (NHLBI), to facilitate conversation between patients and providers. In addition, several tools have been developed by RCCs and their participating sites, leveraging the NHLBI evidence-based clinical guidelines for use and delivery of HU, TCD, and immunizations in SCD care (National Heart Lung and Blood Institute, 2014). Note: it is anticipated that future iterations of the Model Protocol and Compendium of Tools and Resources will include strategies to enhance the use of newly approved disease-modifying therapies for SCD, such as crizanlizumab (Adakveo) and voxelotor (Oxbryta) (Ali et al., 2020). These therapies are not included in this Model Protocol.

Shared Decision-Making Using Print and Electronic Materials

An expert panel from NHLBI encourages shared decision-making with all patients. Shared decision-making tools can help providers feel more comfortable initiating conversations and ensure that patients are making informed decisions. Materials such as brochures, flyers with infographics, and websites facilitate treatment conversations between physicians and other care team members and patients by outlining key treatment information and considerations. An advantage of these resources is that patients can take them home to read or look at them over time and review with family members. This allows time to develop and bring back questions to discuss with care teams. The Program has successfully created both print and electronic communication materials as ways to support both patients and providers during the care process with the goal of increased uptake of HU, TCD, and immunizations.

Hydroxyurea (HU)

Until July 2017, HU was the only Food and Drug Administration (FDA) approved therapy for SCD (Brawley et al., 2008; Charache et al., 1995; National Heart Lung and Blood Institute, 2014; Yawn et al., 2014). This medication decreases SCD-related complications, such as pain crises, acute chest syndrome, and associated emergency department visits and hospitalizations (Wang et al., 2013). HU can improve the quality of life for patients by reducing the frequency of these complications of SCD (Steinberg et al., 2003; Steinberg et al., 1997; Thornburg et al., 2010). Hydroxyurea has been found to lower the costs associated with care for people living with SCD. While patients who take HU have been found to have higher costs (due to paying for the medicine), these costs are outweighed by the savings from fewer inpatient hospitalizations (Wang et al., 2013). However, many individuals and their families are unaware of the drug or its potential benefits, as their providers do not discuss HU with them, leading to reduced use. Also, some patients who are aware of the therapy may be reluctant to use disease-modifying therapies (Creary et al., 2015; Oyeku et al., 2013). In these cases, providers may be able to address common questions and concerns. Increasing both provider and patient knowledge is key to increasing use of HU. Below are resources for both groups.

Table 2. Strategies and Resources to Increase Delivery of Hydroxyurea

STRATEGY	RATIONALE	RESOURCES
Evidence-Based Guidelines and Protocols for Clinical Practice Support	The use of evidence-based guidelines is recommended as they have been shown to improve the health and healthcare of people living with SCD. Guidelines should be developed using a systematic process, including literature review and grading of the evidence, to address specific clinical questions developed by an expert panel (DeBaun, 2014; Yawn et al., 2014).	*Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014*, NHLBI ASH Pocket Guide: Hydroxyurea and Transfusion Therapy for the Treatment of Sickle Cell Disease *Hydroxyurea for Sickle Cell Disease: Indications, Dosing and Monitoring* (Midwest RCC, Cincinnati Children's Hospital)

Enhancement of Patient Awareness of HU and Shared Decision-Making Tools	Though increasing, HU remains an underutilized treatment for SCD. There are several reasons for underuse of this therapy, including lack of awareness among some providers and patients about its effectiveness and use and concerns related to potential side effects. (Brandow & Panepinto, 2010). To increase acceptance and adherence to HU, patients and families need accurate information so they can discuss their treatment options with their providers. Information can be shared through brochures, flyers, and electronic shared decision-making tools (Thornburg et al., 2010).	*Sickle Cell Disease: Hydroxyurea: What You Need to Know* (NHLBI handout)
		Midwest RCC shared decision-making tools
		• Initial HU visit
		• Recurring HU visits
		• Hydroxyurea White board
		• Hydroxyurea brochure
		Southeast:
		• St. Jude informative hydroxyurea pamphlet
		PSCRC RCC Materials
		• *Treating sickle cell disease: Is hydroxyurea right for your child?* English French Spanish
		• *Treating sickle cell disease: Is hydroxyurea right for you?* English French Spanish
		• Southeast
		  ○ Webinar: Hydroxyurea & Sickle Cell Children
		  ○ Webinar: Hydroxyurea & Sickle Cell Adults

Enhancement of Provider Awareness of Disease-Modifying Therapy Initiation and Dosing Materials	Providers, especially those who treat very few people living with SCD, such as primary care and advance practice providers, need resources to stay up-to-date on current SCD treatment guidelines. Pocket guides or guideline documents that outline initiation and dosing of HU are useful for physicians who may need a quick reference tool in the clinical setting. Continuing medical education (CME) webinars are another resource for primary care physicians who seek to increase their knowledge about HU.	Hydroxyurea Treatment for Adults (CME webinar) Hydroxyurea and Transfusion Therapy (ASH) **NE RCC materials** • Boston Medical Center Pediatric Hydroxyurea Dosing Guidelines • SiNERGe Webinar - Helping Patients Adhere to Hydroxyurea Therapy • SiNERGe WEBINAR: Patient Perspectives Part II **PSCRC Materials** Improving Preventive Care for Children With Sickle Cell Anemia: A Quality Improvement Initiative. (Cabana et al., 2020)

Immunizations

People living with SCD are at increased risk of invasive bacterial disease as well as more severe illness due to influenza, making vaccination an important preventive health measure. However, national data show that vaccination rates vary widely, both by age and vaccine type (National Academies of Sciences Engineering and Medicine, 2020). Three-quarters or more of patients with SCD nationally have received at least one of two recommended pneumococcal vaccines, while only 30-52 percent of patients have received both. Influenza vaccination ranges from 30-82 percent for pediatric SCD patients and 12-61 percent for adult SCD patients; only 17-24 percent of SCD patients received the meningococcal vaccine.

Tracking and documenting completion of immunization can be challenging. Patients may receive immunizations in multiple settings, yet ensuring up-to-date documentation in the patient's medical record is required to be able to administer needed immunizations. This can be especially challenging for SCD specialists who report that they are not always able to access primary care records or immunization registries — complete immunization records may not exist with any one provider. An additional challenge arises when patients receive immunizations outside the medical system, such as community locations (e.g., schools, local pharmacies).

The differing ways of getting immunizations means that valuable information may not be seamlessly transferred between systems, adding to fractured record-keeping. Establishing consistent, standard ways of tracking and sharing immunization data, such as reminder-recall systems, state-wide registries, and interoperable electronic health records (EHRs), are essential components of any effort to increase immunization coverage. However, technology alone is not sufficient. Optimized workflow and increased collaboration between primary care and specialty sites are also key components. Table 3 describes strategies and resources to support increasing the delivery of immunizations.

Table 3. Strategies and Resources to Increase Delivery of Immunizations

STRATEGY	RATIONALE	RESOURCES
Evidence-Based Guidelines and Protocols for Clinical Practice Support	The use of evidence-based guidelines is recommended. Guidelines should be developed using a systematic process, including literature review and grading of the evidence to address specific clinical questions developed by an expert panel (DeBaun, 2014; Yawn et al., 2014).	• NHLBI immunization guidelines • CDC Immunization Best Practices • Heartland/Southwest Vaccinations in SCD (see October 19, 2018)
Increased Use of Tracking Strategies	Increased use of tracking systems that can employ EHR reports and state-based immunization registries can improve completeness of immunization records, identify missing immunizations, and increase the number of fully immunized patients. Adjusting workflows can further ensure immunization completion.	One Heartland/Southwest site improved their immunization rates by creating a tracking template. Here is the pre-authorization template.

Transcranial Doppler

People who live with SCD are at increased risk for stroke, both silent stroke and overt stroke. Without prevention, approximately 10 percent of young adults by age 20 (Ohene-Frempong et al., 1998) and 24 percent of all patients by age 45 will have a stroke (Zétola, 2012). Adults who experience stroke have severe morbidity and high mortality rates. Transcranial Doppler (TCD) is a noninvasive ultrasound procedure that allows the clinician to clearly see how quickly blood is flowing through the brain during a period of time. High blood flow velocity is associated with an increased risk of stroke. This screening test is reliable, painless, and relatively inexpensive. Given these factors, TCD use with children aged 2-16 living with SCD is strongly recommended. The NHLBI reviewed two randomized-controlled trials and 50 observational studies in making their recommendations. The Stroke Prevention Trial in sickle cell anemia (STOP trial) demonstrated a 92% decrease in the rate of stroke in children with abnormal TCD when treated with monthly red blood cell transfusions compared to observation alone (Adams et al., 1998). While this is a potential life-saving test, uptake is low, with one study finding only approximately 45% of eligible children were screened (Raphael et al., 2008). Other studies have demonstrated variability in TCD rates, all with lower rates than desired, however. For example, one study showed 25 percent of children living with SCD aged 2-5 years received screening (Bundy et al., 2016) while another found 68 percent of 338 publicly insured children living with SCD (Eckrich et al., 2013) were screened. Overall, it appears that less than half of eligible children living with SCD receive appropriate TCD screening (National Academies of Sciences Engineering and Medicine, 2020).

WHAT IS TRANSCRANIAL DOPPLER (TCD)?

Transcranial Doppler (TCD) is a noninvasive ultrasound procedure that allows the clinician to clearly see how quickly blood is flowing through the brain during a period of time.

The Program has developed materials to guide clinicians on implementing systems for TCD completion as well as how to track completion.

Table 4. Strategies and Resources to Increase Delivery of Transcranial Doppler

STRATEGY	RATIONALE	RESOURCES
Evidence-Based Guidelines and Protocols for Clinical Practice Support	The use of evidence-based guidelines is recommended. Guidelines should be developed using a systematic process, including literature review and grading of the evidence to address specific clinical questions developed by an expert panel (DeBaun, 2014; Yawn et al., 2014).	• Risk of Stroke in Children with SCD (patient poster) • Southeast: Transcranial Doppler (TCD) Quality Improvement Protocol • Spreadsheet template to track TCD • Heartland/Southwest: TCD Guidelines (see January 18, 2019)

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Increasing Provider Knowledge Through Education

Model Protocol

Increasing Provider Knowledge Through Education

Children living with SCD are surviving into adulthood. The need for adult providers — primary care, advanced practice, and specialty providers — who are trained to effectively manage SCD continues to grow. While there are geographic areas where access to engaged, knowledgeable providers is available, there is still a shortage. Many people do not live within a reasonable commuting distance to comprehensive SCD care, and people who live in remote areas often have a difficult time reaching providers with significant expertise. Therefore, continued focus on expanding provider knowledge through educational opportunities is warranted.

EXPANDING PROVIDER KNOWLEDGE

Many people do not live within a reasonable commuting distance to comprehensive SCD care, and people who live in remote areas often have a difficult time reaching providers with significant expertise.

The RCCs employed several strategies to increase provider knowledge of SCD care. Traditional provider education methods were employed, including presentations at symposiums, grand rounds, national professional society meetings, and disseminating information through publications, and are recommended to continue. In addition, the table below reflects resources and protocols used by the RCCs. These provided opportunities to build engagement and awareness and enhance knowledge across broad audiences of providers. Focused training efforts, such as QI learning sessions and direct education training, offered opportunities for more in-depth learning about relevant content. Finally, RCCs employed telementoring for providers through the expansion of Project ECHO®. These were all important strategies to increase and spread provider knowledge about caring for people living with SCD.

RCCs expanded their use of Project ECHO ®. Sessions allow experts to mentor attendees, provide feedback on difficult patient cases, and share expertise. Project ECHO® presents opportunities for in-depth learning that can be applied directly to practice. This method of knowledge expansion is particularly important for rural and other populations who are underserved. All five Program RCCs initiated Project ECHO® replications as a method to share expertise and increase knowledge with the goal of ensuring all patients in their region could have access to high quality care. While Project ECHO® was not created for use with rare diseases such as SCD, it is a promising approach that will continue to be refined.

PROGRAM ECHO REPLICATION PROGRAMS

These are Program replications of Project ECHO®. Visit these websites to register, participate, and access curricula and session recordings.

- **Heartland/Southwest:** https://sicklecell.wustl.edu/scd-teleecho-clinic-164
- **Midwest:** https://sickleecho.org
- **Northeast:** https://www.hopkinsmedicine.org/Medicine/sickle/providers/index.html
- **Pacific:** https://pacificscd.org/project-echo/
- **Southeast:** In Development

More information about Project ECHO® in Appendix B of the Report to Congress.

Table 5. Recommended Topics to Target for Improving Provider Knowledge Through Education

TOPICS	RESOURCES
General Information	• Educational Presentation on SCD for Primary Care Providers • *Health Maintenance and Management for Chronic Complications of Sickle Cell* • Effective Communication with Patients with Sickle Cell Disease • *Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action* (NASEM)
Screening for SCD	• *CDC Hemoglobinopathies: Current Practices for Screening, Confirmation, and Follow-up* (guidelines)
Pain Management	• Illinois SCDTDP Pain Chart • Wong-Baker FACES Pain Rating Scale© • Sickle Cell Treatment & Outcomes Research in the Midwest TeleECHO Clinics • Living with the Pain of SCD II (webinar) • Chronic Opioid Therapy & Sickle Cell Disease (webinar) • *Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014,* NHLBI (guidelines) • *Management of Acute Complications of Sickle Cell Disease* (pocket guide) • *Health Maintenance and Management of Chronic Complications of Sickle Cell Disease* (pocket guide) • Key Findings: CDC's Sickle Cell Data Collection Program: Data Useful in Describing Patterns of Emergency Department Visits by Californians with Sickle Cell Disease (article) • Intranasal Fentanyl: Fast Relief of Sickle Cell Pain (Massachusetts SCDNBSP, Boston Medical Center) • California SCDTDP ED IN Fentanyl • *Sickle Cell Pain in the Emergency Department: A Guide to Improving Care* • Emergency Room Pain Algorithm • SAFER card (patients to give to ER docs)

Medical Home/Care Coordination	• Individual Care Plans:
	  ○ Patient Needs Assessment
	  ○ SMART Phrase
	  ○ Care Coordination Screening Tool
	  ○ Care Coordination Checklist
	• Pre-appointment Planning Worksheet

Preventive Care	• *Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014,* NHLBI • Risk of Stroke in Children with SCD
Transitions from Pediatric to Adult Care	• *Making a Smooth Transition from Pediatric to Adult SCD Care: Eliminating Barriers, Enhancing Resources: Part I* (webinar) • *Making a Smooth Transition from Pediatric to Adult SCD Care: Eliminating Barriers, Enhancing Resources: Part II* (webinar) • *Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolescents with Sickle Cell Disease: Suggested Topics, Methods, and Efficacy Measurements* (WISCH, PDF) • Please see the Compendium of Tools and Materials

SICKLE CELL DISEASE TREATMENT DEMONSTRATION
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Increasing Use of Technology That Supports Healthcare Delivery

Model Protocol

Increasing Use of Technology That Supports Healthcare Delivery

Data Systems: Dashboards and Registries

Access to data is foundational to all high-performing QI efforts. Depending on available resources, data collection and reporting solutions can range from simple to complex and from relatively labor-intensive to highly automated. Also, levels of data-sharing can range from aggregate, summary data to more granular patient-level data. The extent to which both data collection and sharing can be done will be guided by institution governance and resource considerations.

This section will focus on the use of EHR systems for clinical care, as they are a powerful tool for improving care. The use of EHRs is now the norm, and electronic dashboards and registries are increasing in use each year. The data in these systems can and should be used to:

- Provide ongoing assessments of the quality of health and healthcare
- Identify patients with care gaps who need outreach
- Assist clinicians through decision-making support while seeing patients

EHR systems can be optimized to ensure efficient coordination of services, address care gaps, improve provider-patient communication, efficiently support medication refills, and remind clinicians about important actions. For example, incorporating transition-readiness assessments that are easily accessible at the appropriate time or programming smart phrases to sustain hydroxyurea counseling can positively impact completion rates (Cabana et al., 2020). But variation in site capacity to customize EHRs and differences between EHR products with regard to functionality can present challenges at many sites, especially if working collaboratively with other sites. EHR systems at sites may have slightly different formats that do not allow for easy export and upload into a centralized database. Also, data validation using a centralized cumulative repository is difficult without access to the source data. Nonetheless, as applicable, all teams that seek to improve care for people living with SCD will benefit from developing a strategy to optimize use of their EHRs.

All EHR systems support some degree of reporting for the underlying data in the system. Once developed, EHR reports can be run on a regular basis and be used to assess quality measures. Efforts to increase the sharing of reports for teams using the same EHR product could be expected to reduce the effort needed and broaden use of reporting.

The experience of teams during the Program reflect the experiences of others who are trying to use clinical data to support improvement work. Depending on local IT resources and access to data, some sites were limited to manual tracking of measures via desktop spreadsheets, while others were able to develop reports that could automate measurement and provide regular reports. Whatever the resources available, continuously gathering data to assess quality was seen as important throughout the Program, as were efforts to improve the degree to which electronic data could be accessed and used. The work that RCCs conducted to develop dashboards and registries reflected these sentiments.

Dashboards

Ongoing review of quality measures is an essential component of any QI activity. Quality dashboards that are updated regularly and easily accessible (embedded in the EHR system or shared externally) inform teams about their ongoing progress as they test and implement improvement strategies. For example, a pediatric site in the Pacific RCC used a healthcare quality dashboard embedded in the EHR system to monitor Program performance measures, including TCD completion and HU prescriptions, in a dynamic and interactive way. The dashboard allowed for real-time tracking of the effectiveness of interventions. Quality dashboards allow comparison between teams to identify best practices and areas in need of attention. Typically, a limited set of key quality measures are selected and updated regularly. Dashboard data can be supplied directly from the EHR system or via data extracted from IT departments. For teams where dashboards were available, they were viewed as an important communication platform that allowed them to assess whether the work they conducted was effective and to plan for new improvement activities.

Registries

Disease-specific registries can leverage data in multiple systems (EHR, patient surveys, manual entry) from various sites and have the potential to deliver optimized, curated data and reporting. Registries that focus on people with SCD have the potential to provide better access to data and ability to generate targeted quality measures, which can then be used to manage engagement though reminders and outreach. Insights learned from registry data can be used to provide education about patients and can help determine key metrics that align with specific regional programmatic efforts as well as the aims of the larger national initiative. When possible, reported quality measures for registries should be based on standard measure definitions and developed in a way that allows comparison between sites.

An important component for the data collections systems developed during the Program is one shared by most clinical systems: staff who are trained to manage the data system/applications and who understand the Program goals and quality measures. Ideal qualities for these staff include:

- Experience with gathering performance metrics in large, multisite environments (for multisite collaborations)
- Experience in end-user database design — collaborating with all principal investigators (PIs), data coordinators, and statisticians — incorporating site-specific elements in addition to common data elements (CDEs), and providing training manuals
- Ability to build databases, provide database tech support, refine the database, and provide data coordination/management services (one-stop shop)
- Ability to address missing data, validate data, and monitor performance for accurate reporting
- Ability to work with others at all levels, build relationships, be responsive, and provide excellent customer service

These tools, structures, and systems are critical to gaining access to timely and quality data:

- **Secure, Online Data Capture and Storage System**
  - Centralized database that is easily accessible and HIPAA-compliant
  - Inclusion of local PIs and site EHR representatives in sponsor discussions to see what data are possible to collect or if a program-specific query can be built, and to generate a cost estimate
  - Timely refinements based on user experiences and solicited feedback
  - Plan to back up data for verification and validation
- **Data Collection Strategy**
  - Agreement of sponsors and both regional and local PIs on CDEs and site-specific data collection and coordination strategies
  - Clarity around timelines and all data elements to be captured
  - Allowance of sufficient time for sites to submit data for cleaning
  - Validation of all data before final submission
- **Well-Specified Common Quality Measures and CDEs**
  - Team agreement on measure specifications before any programming begins. (Changes to databases cost time and money and the chance to capture some information may be lost.)
  - Central data dictionary linked to measure specifications for consistency across sites
- **Interface for Automated Data Sharing or Personnel to Enter Data**
  - Building program-specific queries or Application Programming Interfaces (APIs) to pull agreed upon EHR CDEs by specialized IT staff needs funding and should be part of pre-implementation activities
- **Analytic Functionality to Allow the Measurement and Sharing of Quality Measurement Results Over Time**
  - Analytic functionality of data in the registry

- **Legal Framework to Allow Sharing of Data Between Collaborating Institutions**
  - Data use and sharing agreements should be written into the protocol for use of a centralized program database.
- **Communications**
  - If working in a regional collaboration, planning scheduled time for meetings, initial training, updates, support, and regular communications builds a cohesive team approach to data collection. Lessons learned and issues can also be shared at these meetings.
  - Frequent, clear communication and emails to PIs and their coordinators about expected data submission timelines — with reminders — promote completion success.
  - Measures and Data Submission should be a standing agenda item on monthly meetings.
  - Regional and site performance metrics and outcome trends should be shared as updated with all partners throughout the length of a program. This promotes buy-in, points for discussion, and healthy competition.
- **Partnership**
  - Ideal local site initial planning team should include regional PIs, local PI, local data coordinator, regional data coordinator, local site EHR programmer/developer, and statistician (if applicable).
  - If payment for data is awarded, completion of data submissions must be linked and clearly articulated as a condition to sub-award payments by the lead institution.

Table 6. Resources for Dashboards and Registries

TOPICS	RESOURCES
Dashboards	• Pacific: Epic EHR Dashboard • Southeast: Sickle Cell Dashboard Infographic
Registries	https://covidsicklecell.org/ This is a COVID-19-specific SCD registry.

Table 7. Website Resources for SCD

TOPICS	RESOURCES
STORM (Sickle Cell Treatment and Outcomes Research in the Midwest)	http://sicklestorm.org/index.html
Pacific Sickle Cell Regional Collaborative (PSCRC)	http://pacificscd.org/
Heartland/Southwest Sickle Cell Disease Network	http://sicklecell.wustl.edu/
Sickle Cell Improvement in the Northeast Region through Education (SINERGe)	http://wepsicklecell.org/sinerge/
American Society of Hematology	https://www.hematology.org/research/sickle-cell-disease-and-sickle-cell-trait/sickle-cell-research-priorities
CDC	https://www.cdc.gov/ncbddd/sicklecell/index.html
NHLBI	https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease
NICHQ	http://sicklecell.nichq.org
Sickle Cell Disease Association of America	http://www.sicklecelldisease.org
American Sickle Cell Anemia Association	http://www.ascaa.org/
Sickle Cell Information Center at Emory	http://scinfo.org/
California Sickle Cell Resources	http://casicklecell.org/
Sickle Cell Disease Coalition	http://www.scdcoalition.org/
PCORI Sickle Cell Project	https://www.pcori.org/research-results/2019/disseminating-results-missed-scd-clinic-appointments-and-health-belief-model

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