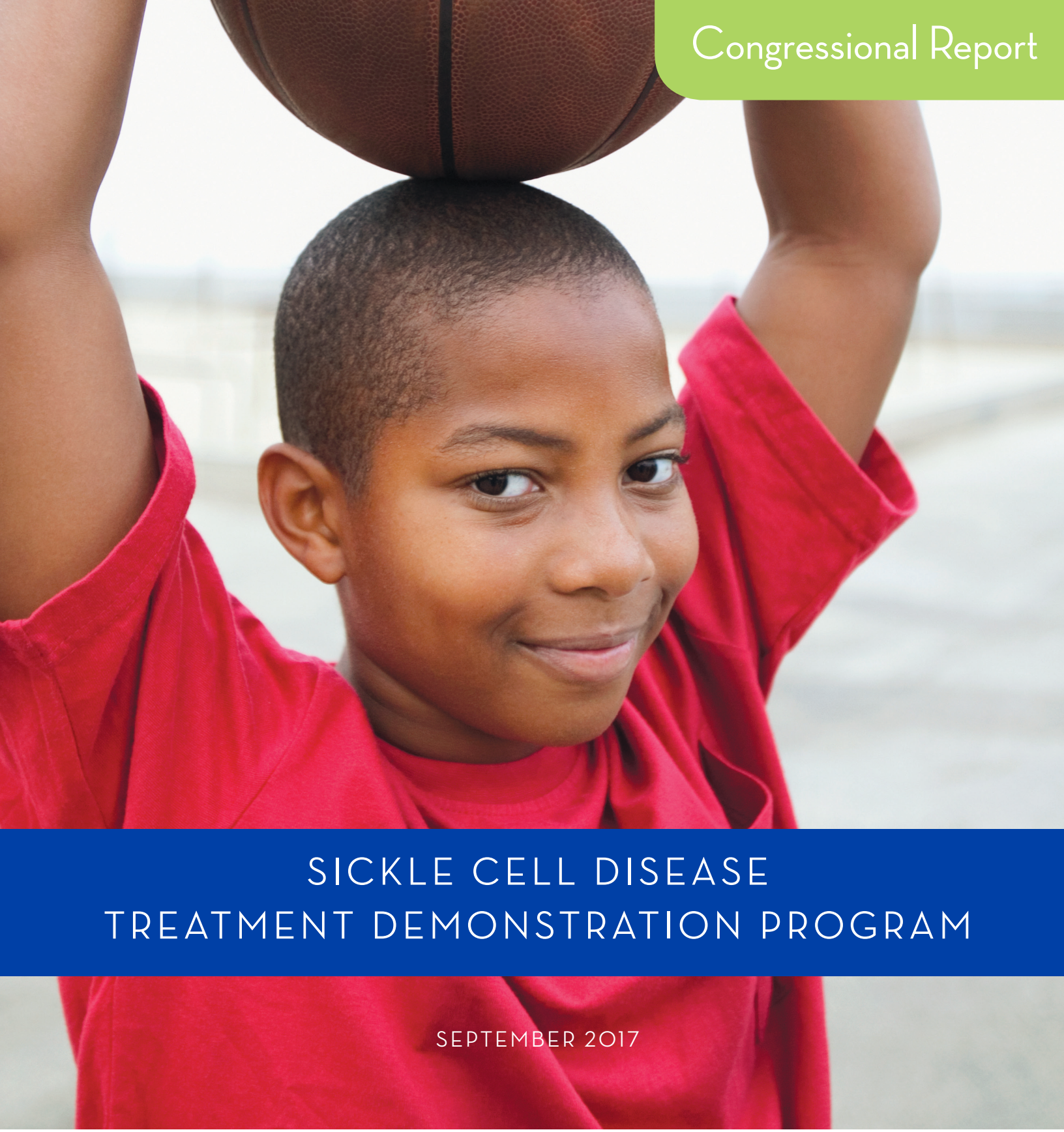
Congressional Report



SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROGRAM

SEPTEMBER 2017

NICHQ National Institute for Children's Health Quality

The National Coordinating Center for the Sickle Cell Disease Treatment Demonstration Program was suported by the Health Resources and Services Administration's Contract HHSH520201400026C.

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Sickle Cell Disease Treatment Demonstration Program 2014-2017

Impact Statement

Approximately 100,000 Americans live with sickle cell disease (SCD). One out of every 365 African American children are born with SCD each year, making it one of the most common serious genetic disorders in the United States.[1] For much of the 20th century, SCD was considered a pediatric condition, as individuals with SCD did not survive into adulthood. However, with medical advancements and improvements in care, most people with SCD are now living into adulthood. Despite these gains, people living with this illness face a lifelong battle with pain, infection and other serious health problems that can affect every organ in the body.

The Sickle Cell Disease Treatment Demonstration Program (SCDTDP) was funded by Congress in 2004 to improve the care of patients with SCD. In the most recent 2014-2017 SCDTDP award, the National Institute for Children's Health Quality (NICHQ) ran the SCDTDP National Coordinating Center (NCC). As the NCC, NICHQ led network-wide measurement activities and coordinated the sharing of best practices for improvement work done by the four SCDTDP-funded Regional Coordinating Centers.

Specifically, the SCDTDP project aims were to:

- Improve access to care by increasing the number of providers treating patients with SCD;
- Increase the number of providers prescribing hydroxyurea; and
- Increase the number of patients with SCD that are receiving care from providers knowledgeable about treating SCD.

NICHQ
National Institute for Children's Health Quality

MAKING AN IMPACT

Access to Care

Nearly 11,000 patients with SCD received care by SCDTDP regional networks, reflecting an increase of more than 3,000 patients from baseline.[2]

Four states opened clinics in areas of high need.[3] More than 1,000 more adults have access to high quality care with the newly opened Adult Sickle Cell Clinic at the Martin Luther King, Jr. Outpatient Center in Lost Angeles.

Hydroxyurea Use[4]

HEARTLAND

Pediatric patients: 12% to 20%
Adult patients: 14.3% to 17.3%

MIDWEST

All patients: 48% to 69%

NORTHEAST

Pediatric patients: 23% to 34%
Adult patients: 16% to18%

PACIFIC

All patients: 29% to 42%

Knowledgeable Providers

Telementoring and telehealth initiatives increased provider knowledge across the country. Nearly 100 Project ECHO®[5] clinics were held expanding opportunities for provider education for more than 200 providers.[6]

[1] Sickle Cell Disease (SCD) Data & Statistics. Centers for Disease Control and Prevention; 2016. http://www.cdc.gov/ncbddd/sicklecell/data.html. Accessed March 2017.
[2] SCDTDP Congressional Report, 2017; p. 45.
[3] SCDTDP Congressional Report, 2017; p. 45, 49, & 58.
[4] SCDTDP Congressional Report, 2017; p. 93.
[5] Project ECHO®. 2017; https://echo.unm.edu. Accessed Aug. 15, 2017.
[6] SCDTDP Congressional Report, 2017; p 97

Sickle Cell Disease Treatment Demonstration Program

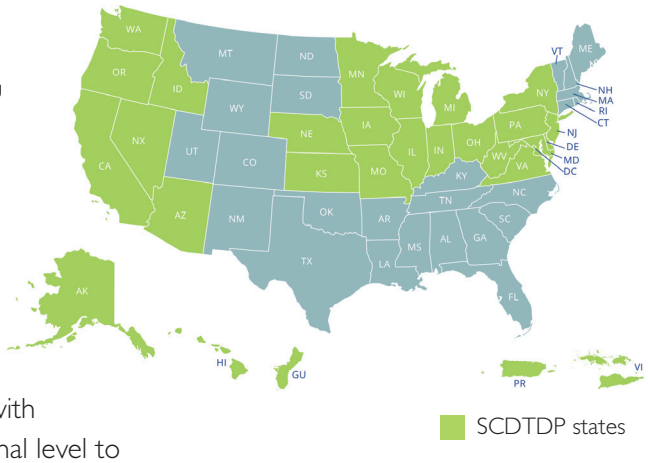
ACCOMPLISHMENTS

Heartland Regional Coordinating Center (IA, KS, MO, NE) established telementoring programs for healthcare providers to address geographic disparities in care access. https://sicklecell.wustl.edu

Midwest Regional Coordinating Center (IL, IN, MI, MN, OH, WI) addressed gaps that affect care, including setting up satellite clinics that connected patients and local providers to staff and resources at larger medical systems with SCD expertise. http://sicklestorm.org/

Northeast Regional Coordinating Center (DC, MD, NJ, NY, VA, PA, DE, WV, Virgin Islands, Puerto Rico) developed strong relationships with community-based organizations both in individual states and at the regional level to increase patient access to SCD care. http://www.hopkinsmedicine.org/Medicine/sickle/index.html

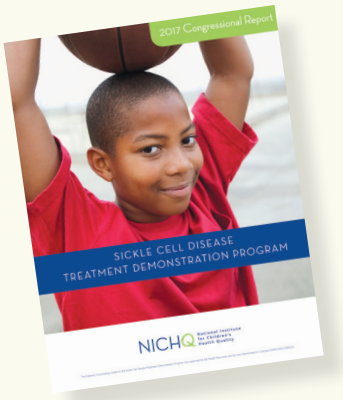
2014-2017 SCDTDP Regions/States Covered



Pacific Regional Coordinating Center (AK, AZ, CA, ID, HI, OR, NV, WA, Guam) increased patient access to care with the opening of two new comprehensive centers for SCD care in key urban areas targeting larger concentrations of patients with SCD. http://pacificscd.org/

Resources

Learn more from these SCDTDP resources:



Congressional Report

This report to Congress synthesizes the results and recommendations of the Sickle Cell Disease Treatment Demonstration Program.

www.nichq.org/resource/congressional-report-2017

Compendium of Tools and Materials

This compendium identifies promising practices and strategies used by Regional Coordinating Centers to implement changes in their health systems related to improving access to care, increasing use of Hydroxyurea and provider education.

www.nichq.org/resources/compendium-resources-2017

Model Protocol

The model protocol provides clinicians, nurses, allied health professionals, community-based organizations and public health agencies with recommendations and strategies to improve care provided to individuals with sickle cell disease.

www.nichq.org/resources/model-protocol-2017

The National Coordinating Center for the Sickle Cell Disease Treatment Demonstration Program was supported by the Health Resources and Services Administration's contract HHSH520201400026C.

Learn more at www.nichq.org/project/sickle-cell-disease-treatment-demonstration-program

Executive Summary

Overview of Sickle Cell Disease

Approximately 100,000 Americans live with sickle cell disease (SCD). One out of every 365 African American children are born with SCD each year, making it one of the most common serious genetic disorders in the United States[1]. For much of the 20th century, SCD was considered a pediatric condition, as individuals with SCD did not survive into adulthood. However, with medical advancements and improvements in care, most people with SCD are now living into adulthood. Despite these gains, people living with this illness face a lifelong battle with pain, infection and other serious health problems that can affect every organ in the body. Those with the most severe form of the disease can expect to live 20-30 fewer years than the average American.[2]

Access to high quality healthcare is critical to prevent complications and early mortality related to this disease, yet many people with SCD are unable to get the care they need. One example is access to hydroxyurea (HU), the only FDA-approved drug to treat SCD until the recent approval of L-glutamine in July 2017. Unfortunately, HU is often under-prescribed to those who could benefit from it most. This is due to concerns among both providers and patients about potential toxicity of this treatment, making some providers uncomfortable with prescribing this medication.[3] Exacerbating potential issues with access to proven treatments are the limited number of medical centers across the country that specialize in treating SCD and the reality that most people with SCD do not live near these centers. Patients with SCD also often seek care in emergency departments (EDs), which is costly, or from primary care providers (PCPs) who do not have experience treating the disease. Expanding access to care and increasing the pool of knowledgeable providers, including PCPs, for people with SCD will improve and lengthen their lives.

PURPOSE & SCOPE

Given the severity of SCD and recognizing the need for adequate resources to address the structural and societal barriers to improving the care of those living with the disease, Congress enacted legislation authorizing the Health Resources and Services Administration (HRSA) to carry out the Sickle Cell Disease Treatment Demonstration Program (SCDTDP). The SCDTDP works to improve the care of patients with SCD with a goal of improving long-term outcomes (e.g., decrease early mortality) and short-term outcomes (e.g., increased usage of HU). Over the past 13 years, the SCDTDP's activities have included training medical providers, building models of care to meet the evolving needs of people living with SCD, and supporting the transition from pediatric care to adult care.

During the 2014-2017 funding cycle of the SCDTDP, the National Institute for Children's Health Quality (NICHQ) was selected to serve as the National Coordinating Center (NCC) for four SCDTDP-funded Regional Coordinating Centers (RCCs): the Heartland, the Midwest, the Northeast, and the Pacific. Each of the RCC grantees were tasked with working with states to develop innovative regional networks of care and to increase provider knowledge around SCD to support the appropriate care and treatment of SCD. In its role as NCC, NICHQ led several network-wide measurement activities and assisted in the coordination and sharing of best practices for improvement work done in each of the RCCs.

Table below shows the SCDTDP geographical areas along with the estimated SCD populations to be reached in each region.

TABLE 1:
Regional Structure of SCDTDP

RCC	LEAD ORGANIZATION	STATES/ TERRITORIES	APPROXIMATE # OF INDIVIDUALS LIVING WITH SCD
Heartland	Washington University, St. Louis	MO, IA, KS, NE	2,620
Midwest	Children's Hospital Medical Center	IL, IN, MI, MN, OH, WI	15,000
Northeast	Johns Hopkins University	MD, VA, DE, District of Columbia, NJ, NY, PA, PR, USVI, WV	32,000
Pacific	Center for Comprehensive Care and Diagnosis of Inherited Blood Disorders	CA, ID, OR, WA, NV, AK, HI, AZ, Pacific Basin	7,100
Estimated total number of patients with SCD included in project regions			56,720

The three primary aims of the 2014-2017 SCDTDP were to:

- Improve access to care by increasing the number of providers treating patients with SCD;
- Increase the number of providers prescribing HU; and
- Increase the number of patients with SCD that are receiving care from providers knowledgeable about treating SCD.

The 2014-2017 Sickle Cell Disease Treatment Demonstration Program represented the first time in U.S. history that improvements in sickle cell disease care were tackled on a large, regional and national scale.

MEASUREMENT STRATEGY

The measurement strategy for the project included both a national and regional focus. NICHQ assisted regional teams throughout the project in their efforts to collect, analyze, and share data to identify progress towards achieving the program's aims. The measurement efforts for this SCDTDP grant cycle (2014-2017) began with a data summit in November 2014. During this summit, HRSA, the NCC, key SCD experts, and the RCCs identified shared objectives and a common measurement strategy. This work was guided by key lessons learned from the previous SCDTDP (2010-2013), also lead by NICHQ, and focused on creating a larger measurement strategy that allowed for broader state and regional level assessment of patient care and provider practice within key populations.

This summit brought together key representatives from the four RCCs with the goal of getting input from experts in the field to identify potential barriers to accessing and aligning data across the regions.

While various data sources were considered, including local registries, electronic health data, and administrative data, the following data streams were prioritized for the SCDTDP:

- Administrative Data: Aggregate data from Medicaid-managed care organizations (MCOs) and Medicaid claims data from state-level Medicaid departments
- Minimum Data Sets (MDS): Individual patient-level data from surveys and electronic health records (EHRs)

To support this shared measurement strategy, NICHQ, serving as the NCC, first developed a detailed set of measure specifications that included computable measure definitions and a data dictionary to ensure each region was collecting data the same way across regions. The data dictionary was used to inform the development of a web-based collaboration tool ("The Collaboratory" or "CoLab") to support rapid entry of aggregate data across the regions and the sharing of best practices and communication across regions. For confidentiality and privacy reasons, the NCC was only allowed to collect and share aggregate data (numerators and denominators).

The Administrative Data was identified as the source most likely to be able to capture data across the very large population among the four RCCs. Specific measures were developed related to assessing the number of providers providing, and patients with SCD receiving, consistent care (Aim 1) as well as provider HU-prescribing behaviors and patient behavior around filling HU prescriptions (Aim 2).

In parallel with the national administrative data work, the NCC and the RCCs also worked to develop local "registries" designed to capture a minimum set of data to allow the measurement of quality at the local level. This activity was called the Minimum Data Set (MDS) and allowed the RCCs to collect patient-level data from electronic health records (EHRs) and patient surveys to assess a larger number of quality measures. These measures mirrored the administrative measures, and focused on measures related to HU use (Aim 2) and patient access to providers and use of urgent care facilities, including in-patient and ER usage (Aim 1). The MDS enabled a more tailored and flexible system of local data collection that allowed patient care sites to track progress towards the three project aims as well as other improvements in quality of care. The MDS activity was a voluntary effort used locally and reported back to the NCC at the aggregate level.

The third aim of the project focused on improving provider knowledge of SCD. Because this information was a challenge to collect from the administrative or MDS data, the NCC developed program evaluation activities to better understand the provider education efforts across the regions. RCCs provided descriptions of state and regional provider education efforts as part of regular communication with the NCC. Additional information about the SCDTDP Measurement Strategy can be found in Section 2 of the report.

PROGRAM IMPACT AND ACCOMPLISHMENTS

Improving access: Increasing the number of clinicians seeing patients with SCD

Within each region, teams worked though the project period to improve access to care for both children and adults via a range of activities, such as opening comprehensive care centers in high-need locations as well as implementing patient outreach and follow-up with community health workers (CHWs) in collaboration with local SCD community-based organizations (CBOs). Section 3 of the report highlights this work. All four regions have made access to care a priority, and reported increasing the sites available to provide quality care for patients living with SCD. Nearly 11,000 patients with SCD received care from SCDTDP regional networks, reflecting an increase of more than 3,000 from baseline.

TABLE 2:

Growing Networks of Care

REGION	PACIFIC	HEARTLAND	MIDWEST	NORTHEAST
Baseline of total number of patients receiving care	1020	1723	1674	3168
% Increase in patients receiving care from baseline	24% (N= 1285)	3% (N= 1778)	20% (N= 1982)	85% (N= 5879)

Here are some examples of the strategies regions used to increase access to care for patients with SCD.

Heartland RCC - The Heartland Sickle Cell Disease Treatment Network established telementoring programs for healthcare providers to address geographic disparities in care access. For example:

- Nebraska implemented a telementoring program between the SCD Center for Excellence located at the Children's Hospital and Medical Center in Omaha and geographically distant providers so that patients and their local providers could have continued access to knowledgeable care between long distance visits with specialty providers.
- The Heartland regional lead set up a telementoring consultation practice with SCD care management teams at Centene, a large multi-state insurer running many Medicaid MCO plans across the region and other rural states.

Midwest RCC - STORM (Sickle Treatment and Outcomes Research in the Midwest) efforts have focused on helping systems address gaps that affect care. For example, when Illinois stopped accepting Medicaid patients from Indiana, there was a severe gap in access for patients in the city of Gary, IN, for which the closest geographic access to care had been Chicago, IL. Providers in Indiana filled this gap by setting up satellite clinics in Gary that connected patients and local providers to staff and resources at larger medical systems with SCD expertise across the state.

Northeast RCC - SiNERGe (Sickle Cell Improvement Across the NorthEast ReGion through Education) developed strong relationships with CBOs both in individual states and at the regional level to increase patient access to SCD care.

- CHW programs were able to identify adult SCD patients and connect them with a medical home for coordinated preventive care and specialty care to manage their disease progression and symptoms.
- The Northeast also established the first telementoring SCD ECHO® program,[4] a hub and spoke model of telementoring, which fosters education between medical providers to build skills through a structured curriculum and review of case reports. This program has created a community of practice to share and learn best practices, including providers across the region and also from the Midwest.

Telementoring and telehealth initiatives increased provider knowledge across the country. Nearly 100 Project ECHO®[5] clinics were held across regions, expanding opportunities for provider education for more than 200 providers.

Pacific RCC - PSCRC (Pacific Sickle Cell Regional Collaborative) saw increased patient access to care with the opening of two new comprehensive centers for SCD care in key urban areas targeting larger concentrations of patients with SCD:

- The MLK, Jr. Outpatient Center for Adults, with a catchment area of more than 1,000 potential patients with SCD, in Los Angeles, CA; and
- The Children's Specialty Center of Nevada in Las Vegas, which opened its doors to provide larger patient populations with access to knowledgeable physicians and systems of quality care for patients with SCD and their families.

Improving the Treatment of SCD: Increasing HU Use

The National, Heart, Lung and Blood Institute (NHLBI) recommends that all eligible patients with SCD should be offered or treated with HU.[5] Over the course of the three-year grant, all four SCDTDP regions reported increases in the number of patients with SCD being treated with HU within their partner sites. Section 4 of the report highlights these efforts. Increases in HU use have been attributed to improvements in patient access to care and improvements in care systems to better facilitate the integration of HU use in provider training and decision-making tools. Efforts to support both clinical decision-making as well as shared decision-making tools used with patients — such as patient brochures — are innovations that are beginning to show some impact. For example, the Pacific region saw an overall 26 percent increase of patients on HU after the release of the patient brochures.

All SCDTDP Regions Report Increases in HU Use

HEARTLAND:

- Among children, increased from 12% to 20%
- Among adults, increased from 14% to 17%

MIDWEST:

- Among all patients (pediatric & adult), increased from 48% to 69%
- Nearly 100% of all eligible patients now offered HU

NORTHEAST:

- Among children, increased from 23% to 34%
- Among adults, increased from 16% to 18%

PACIFIC:

- Among all patients, increased from 29% to 42%

Enhancing Care: Increasing the Number of Providers Knowledgeable about SCD

A key strategy to increase the number of providers available to care for patients with SCD is to increase the knowledge and clinical capacity of primary care clinicians. The four SCDTDP regional coordinating centers made great strides in increasing and improving provider education and knowledge about SCD treatment and care which are highlighted in Section 5 of the report. While there were many in-person events across the regions and states supported by local community efforts, teams also employed models of remote communication. Teams found online webinars and CME credit modules useful in reaching and educating providers.

The RCCs in the Northeast, Midwest and Pacific employed the innovative Project ECHO® (Extension for Community Healthcare Outcomes) Model[4] of telementoring and training. This collaborative approach to medical education and care management based at the University of New Mexico is designed to empower primary care clinicians to provide better care to more people with complex conditions where they live. This is one of the first models of an ECHO® program that looks at supporting providers to improve quality of care for a rare disease. This innovative model has provided a platform to provide best practice information to providers to help compensate for the gap in the quantity of knowledge-able providers. This has been especially critical for providers supporting care for adults with SCD, who not only require care for the disease, but whole patient care and care related to aging. Informed whole patient care will help improve patient health outcomes, enhance healthcare delivery and reduce costs overall.

LESSONS LEARNED

Key lessons learned for each of the three project aims are detailed below:

Aim 1: Increase number of providers treating patients with SCD

A challenging element for many teams was identifying providers willing to treat patients with SCD. To address this issue, teams had to be creative in their recruitment efforts. Experience from recruitment efforts suggests that:

- Often the providers most amenable to recruitment efforts are trainees.
- Partnerships of co-managing patient care between specialists in urban settings and primary care doctors in rural settings can create opportunities to improve care for patients living in geographically isolated areas.
- Many centers are most likely to add nurse practitioners as care providers for this population, particularly for adult patients.
- There is potential to increase access and linkages with providers who are knowledgeable about providing care for patients with SCD through the use of electronic media and social media (e.g., listings on the Heartland webpage).
- Redefining providers to be explicitly more inclusive (e.g., including nurses, nurse practitioners, CHWs) increases the scope and reach of recruitment efforts and reflects the reality that for many SCD centers of care, providers are often nurse practitioners, particularly for adult patients.

There was additional knowledge obtained on improving and innovating at the sites of clinical care, including:

- Inclusion of the voice of the community is critical to establishing early discussions with policymakers and decision-makers.
- Aligned electronic health record systems greatly facilitate communication and measure standardization, but this is rare and difficult to build into existing systems. For example, pediatric systems and adult systems vary greatly.

Consensus among the RCCs is that the opportunities and incentives to engage providers are very challenging. This requires programs to be flexible, adaptive and creative in thinking about their recruitment of providers who are willing to engage in SCD care and assist in increasing access to care.

Aim 2: Increase use of HU in treating SCD

For many of the regions, one of the key project impacts was strides made in increasing access to HU and increasing the number of providers willing to either prescribe or co-manage patients on HU. There were several lessons learned from programmatic efforts to increase HU use. Some of these include:

- Most providers lack the knowledge, confidence and decision-making tools to prescribe HU.
- Medical education webinars, publications and creation of provider education tools and materials to support HU prescription and management were able to increase provider comfort with prescribing HU.
- Specific tools and materials (e.g., brochures and roadmaps) directly related to HU's risks and benefits significantly helped increase the comfort level of providers around HU and their ability to explain these risks and benefits to their patients.
- Often the prescribers of HU are hematologists/oncologists rather than PCPs. Program efforts should focus on successful co-management between specialists and PCPs while also increasing knowledge of hematologists/oncologists in the overall care of people with SCD.
- For project results to be sustainable and best practices spread, providers need to be adequately reimbursed for caring for complex patients with SCD, many of whom have substantial social needs and declines in health due to complications of SCD co-occurring with the usual health problems of aging.
- Additional tools and interventions are needed to increase the number of providers prescribing HU.

With the right model of support, and with tools and educational resources, RCCs found providers to be amenable to managing their SCD patients on HU. More work is still required to ensure that adequate tools and educational opportunities are available to a wider audience of providers, and that providers are appropriately incentivized to increase their comfort with disease management for this rare and complex condition.

Aim 3: Increase Number of Providers Knowledgeable about Treating SCD and Increase the Number of Patients Seen by Knowledgeable SCD Providers

The primary lessons learned for this aim were that many activities and efforts are needed to create a scaffolded approach to create and support networks of providers who are not only willing to treat those with SCD, but appropriately trained, and provide decision support to effectively manage this condition.

Lessons learned around this aim include:

- Network calls (e.g., telemedicine, case presentations) are a critical tool that enable active provider support and mentoring for discussing challenging cases and indications for certain treatments.
- Creation of a list of willing providers who are knowledgeable in treating patients with SCD can be a critical resource for both patients and providers for identifying appropriate sites for care.
- Given time and resource constraints, it remains critically important to look beyond PCPs for educational efforts aimed at the healthcare system. Educational efforts should also target SCD specialists and hospitalists for efforts such as Project ECHO®.
- It is essential to look beyond the healthcare delivery system to the public health system to create sustainable change and to mobilize evidence-based public health approaches.
- All SCD efforts should consider integration and partnerships within the wider blood disorders community to develop synergies between various project activities.
- Workforce development of the next generation of healthcare providers is a critical focus of educational efforts and systems of reward.
- Patients remain critical partners in this work, and patient and family collaboration is key to successfully engaging knowledgeable providers.
- Even when educational opportunities are provided, measuring and linking these activities to increased knowledge and change in practice behaviors can be challenging.
- Project ECHO® is an innovative model and is a well-poised opportunity to create a community of providers who are confident treating SCD, including hematologists.

Collecting data to understand the impact of educational opportunities is a consistent challenge. However, great work has gone on over the past three years to create a wider network of knowledgeable providers treating SCD. The groundwork has been laid to identify effective and innovative practices, create standardized curriculum and standards for educational efforts, and spread educational models to new areas in order to increase the eligible pool of knowledgeable providers while also connecting patients to these providers.

TABLE 3: Project ECHO® Programs

	MIDWEST (STORM	NORTHEAST (SiNERGe)	PACIFIC (PSCRC)	TOTALS
Start date	March 2016	Sept. 2015	Oct. 2016	
Frequency	Monthly	Weekly	Monthly	
SCD Focus	Lifespan	Adult care	Lifespan	
# of sessions held	16	72	7	95 sessions
# of providers participating	15 per clinic; 50 unique	15 per clinic; 135 unique	10 per clinic; 26 unique	10-15 per clinic; 211 unique

RECOMMENDATIONS

While significant progress has been made in both understanding and caring for patients affected by SCD in the past generation, much more remains to be done for this patient population with complex healthcare needs to ensure equitable access to knowledgeable care, proven therapies, tailored forms of treatment, and cost-effective delivery of care. Throughout the three years of the SCDTDP initiative, NICHQ has worked closely with the regional coordinating centers to support their efforts in meeting the program's aims. The accomplishments of the grantees demonstrate that patients living with SCD and their families benefit when providers, community-based organizations and government agencies work collaboratively toward a shared goal of improving the health and quality of life of children and adults who live with SCD.

Enormous opportunities remain to improve the state of SCD care in the United States. In addition to the learned experiences of the grantees, NICHQ regularly engaged with a diverse group of SCD experts, such as the Oversight Steering Committee, with decades of combined experience to develop the series of recommendations outlined below, and found in Section 6 of the complete report, that are focused on future SCD initiatives, healthcare policy, and clinical care.

Recommendations for Future Sickle Cell Initiatives and Programs

It is not a coincidence that patients living with SCD have benefited from better care coordination and access to disease-modifying therapies over the past century. Rather, these advancements are a result of deliberate and direct investments made in programs and partnerships such as the Sickle Cell Disease Treatment Demonstration Program. However, despite the progress made in care that has allowed most children living with SCD to reach adulthood, systemic barriers still impede their ability to receive comprehensive, coordinated care to achieve their optimal health. As more people with SCD are surviving into adulthood, it remains imperative that demonstration programs designed to address and eliminate barriers to SCD care continue. In addition, the following recommendations strengthen the investments already made in SCD initiatives to date.

- Collect coordinated measures across aims and domains of focus, using standardized data definitions and collection methods, to follow and gain understanding of disease progression over time, including young adulthood and beyond
- Enhance the national focus on the use and coordination of sickle cell registries
- Develop standard SCD curricula and metrics of success around the application of the Extension for Community Healthcare Outcomes (ECHO®) model, a practice-guided medical education model, and other telehealth strategies for SCD care to:
    - Increasing providers who are knowledgeable about treating SCD
    - Improving SCD outcomes by ensuring patients have some access to services even if they are not close to a sickle cell program or center
- Maintain improvement science as an integral component of SCD initiatives
- Sustain and provide resources to support interagency coordination and cooperation to amplify the impact and optimize the resources of federal SCD initiatives
- Support regionalization to sustain SCD healthcare systems' capacity building using evidence-based public health practices

Healthcare Policy Recommendations

The complications of managing the care and treatment of SCD can be all-consuming for patients and their families. Increased collaboration between all SCD stakeholders, including patients and families, as well as CBOs, is critical to enhance care coordination and patient and provider education. Involving key stakeholders as true partners in care will lead to better outcomes for patients across their lifespans. To continue to support transformation within the healthcare system, the following recommendations concern policies that when implemented would substantially improve the system of care supporting patients with SCD.

- Improve access to evidence-based SCD care through telehealth, telemedicine, telementoring, and other innovative models, and enhance reimbursement for these services.
- Incorporate standardized quality measures of access and care of patients with SCD into organizational performance measures such as the Bureau of Primary Healthcare quality metrics.
- Make sure that all patients with SCD have consistent access to insurance to help ensure high quality care.
- Ensure adequate reimbursement for care transition that enables seamless and comprehensive care from adolescence through young adulthood and beyond.
- Adjust payment policies, especially for Medicaid recipients, enhancing reimbursement rates to include care coordination services, which would include CHWs, to improve access to community resources, social services, mental healthcare, and clinical services.
- Develop payment systems that support reimbursement of preventive care visits to primary care and specialty care providers as well as social services (e.g., CHWs).
- Ensure there are qualified healthcare professionals providing both pediatric and adult SCD care by creating specific workforce training and student loan forgiveness programs for broader categories of physicians (e.g., hematologists), nurses, nurse practitioners and physician assistants.

Recommendations for Clinical Care Systems

The following clinical recommendations provide further insight into the improvements necessary to ensure that those who treat SCD are adequately trained and supported by data-driven research, as well as ensure a comprehensive system is developed to meet the complex and changing needs of this patient population.

- Implement systems (e.g., electronic health record templates, order sets, tracking and feedback mechanisms) to track and work to increase rates of appropriate screening and preventative interventions (e.g., HU, penicillin prophylaxis, immunizations, and transcranial Doppler screening).
- Address deficiencies in ED care of individuals with SCD experiencing acute pain crises by establishing pain protocols; providing and making widely available pain management plans; and supporting investigation of innovative pain management strategies and routes of administration.
- Implement data systems that enable management of the entire SCD population served through a clinical system or in a geographic area and track key processes and outcomes, including the use of effective therapies (e.g., HU), ED visits, hospitalizations, and readmissions.
- Expand the evidence base related to the use of care plans and other care coordination tools for SCD.
- Design patient and family education regarding use of HU to extend beyond a discussion of benefits and risks to include discussion of patient preferences and strategies for self-management support.
- Require that healthcare systems address both psychosocial and medical needs of individuals with SCD and their families, including routine screening for mental health and social needs.
- Ensure all facilities providing care for individuals with SCD, whether pediatric, adult, or family medicine, incorporate the six core elements of transition as appropriate. This includes having a transition policy; developing a process for tracking and monitoring transition-age youth; assessing and using transition readiness assessments; planning for transition; transferring care; and completing transfers.
- Provide comprehensive care and medical homes where needed for adults with SCD; this is critical for reducing morbidity and mortality rates for this age group.
- Assess current practice patterns for screening of immigrants (including African, Caribbean, Hispanic and Middle Eastern immigrants) for SCD. Develop and/or refine screening processes and link identified individuals to systems of care based on this assessment.
- Use systematic approaches to QI based on data collected and evidence assessment that involve patients and families in both design and implementation.

The 2014-2017 Sickle Cell Disease Treatment Demonstration Program was designed to improve upon a group of measures on a national scale. While significant progress has been made on these measures and in both understanding and caring for patients affected by SCD, much more remains to be done for this high-need patient population to ensure equitable access to knowledgeable care and proven therapies. The accomplishments of the SCDTDP grantees demonstrate that patients living with SCD and their families benefit most when providers, community-based organizations, and government agencies work collaboratively toward a shared aim of improving the health and quality of life of children, adolescents and adults whose lives have been impacted by SCD.

REFERENCES

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Appendix, Tables, and Figures

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Section 1: Introduction

Sickle cell disease (SCD) is a group of inherited blood disorders that affects approximately 100,000 Americans, predominantly those of African descent.[1] Signs of SCD typically appear in the first year of life and the complications worsen over time. It is characterized by sickled (crescent-shaped) red blood cells that cause a multitude of acute and chronic complications and increase the risk of premature death. For much of the 20th century, SCD was considered a pediatric condition, as individuals with SCD did not survive into adulthood.

Advances in treatment and increasing access to high quality care have improved the prevention and management of infection, stroke, and pain episodes and substantially increased the life expectancy of people with SCD. These advancements include pre-conception counseling, routine newborn screening, comprehensive immunizations, the use of prophylactic antibiotics, and disease-modifying medications such as hydroxyurea (HU). It is now estimated that 94 percent of children living with SCD in the United States will survive to adulthood.[2]

Despite these advances, however, many people with SCD do not have access to high quality healthcare and many clinicians are not familiar with guidelines for the management of SCD. Patients with SCD continue to experience serious morbidity from pain and chronic organ damage and suffer from early mortality. While it has improved, the average life expectancy for a person with the most severe form of SCD is 20-30 years lower than the US population overall.[3,4] Geographic, economic, and sociocultural barriers impede the ability for many people with SCD to access care. Due to the rarity of the disease, many people with the disease may live in areas where there are few, if any, providers who are knowledgeable about managing the disease or have experience treating patients with the condition. When children with SCD transition to adult care, there are even fewer providers with sickle cell expertise available to treat them.[5] Medical professionals' experience with treating sickle cell patients and their attitudes toward pain care for this population profoundly affect outcomes for people suffering from this disorder.

The 2014-2017 Sickle Cell Treatment Demonstration Program (SCDTDP) is the continuation of a Congressionally mandated federal program administered by the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services (HHS). The SCDTDP supports the development of systems of care to improve the treatment of SCD and its complications. From 2014 to 2017, the National Institute for Children's Health Quality (NICHQ) served as the National Coordinating Center (NCC) for four regional coordinating centers (RCCs). Using an innovative regional approach to care, HRSA and NICHQ led the creation of four regional programs using a learning collaborative model to spread evidence-based and innovative approaches to achieve the aims of the project.

The three aims requested by HRSA were to:

- Improve access to care by increasing the number of providers treating patients with SCD;
- Increase the number of providers prescribing HU; and
- Increase the number of patients with SCD that are receiving care from providers knowledgeable about treating SCD.

Bringing together state and local teams, the RCCs created regional structures of care, and provided data on the tests of change being made through their learning collaboratives using qualitative feedback, process metrics, and clinical and administrative data.

OVERVIEW OF SICKLE CELL DISEASE

Healthy red blood cells are round and move freely through blood vessels to distribute oxygen throughout the body. In people living with SCD, a genetic mutation causes their bone marrow to produce sickled cells that die early, resulting in a shortage of red blood cells. The surviving red blood cells transform into irregularly shaped cells when they deliver oxygen to the tissues of the body. These irregular-shaped (sickle) cells are prone to blocking blood flow in small blood vessels, leading to tissue damage, infection, and pain.

100,000 Americans live with the inherited blood disorder, sickle cell disease, making it one of the most common genetic disorders in the United States.

Severe pain is the most common cause of acute morbidity and utilization of health resources for people living with SCD. The pain is severe and unpredictable, eventually leading to chronic pain (deep pain that lasts three months or more), and neuropathic pain (shooting pain resulting from nerve damage).[6] Pain management is a difficult challenge faced by patients, families, and providers. It impacts policymakers because of the high costs associated with healthcare utilization.

Adults with SCD report that their experiences of pain are often stigmatized in healthcare systems because of assumptions about drug-seeking behavior.[7] These assumptions are compounded by perceived racial biases, which can lead to patients' negative interactions with healthcare systems.[8] Since the most effective treatments for pain associated with SCD include opiates and other potentially addictive drugs, providers may be concerned about the potential risk for addiction. Providers may not believe pain levels reported by the patient, which frequently leads to inadequate pain control. As a result, adult patients may delay or avoid seeking care and cope with pain episodes at home.

Complications of SCD affect every organ, including infections of lungs, brain and joints; lung tissue damage (acute chest syndrome); bone deterioration; leg ulcers; pulmonary hypertension; chronic kidney disease; and stroke.[1] Patients require care from a variety of providers in a diversity of settings to manage this range of complications.

During the time period covered in this report only two proven disease-modifying therapies for SCD: HU and chronic blood transfusions. The Food and Drug Administration (FDA) approved HU for treatment of SCD in 1998. Despite substantial evidence of its effectiveness in reducing pain crises and acute chest syndrome, reducing the need for transfusion and preventing stroke and organ damage, HU is underutilized in patients who are eligible to benefit from it. This underutilization is due to a variety of barriers, including patients' lack of health insurance, geographic isolation from health facilities, families' concerns around potential side effects, and providers' lack of knowledge of HU treatment.[9]

A limited number of comprehensive SCD centers across the country provide multidisciplinary models of care and a range of disease management and other support services for patients with SCD. However, many patients do not live in proximity to such centers and will seek care from emergency departments (EDs) and primary care physicians (PCPs), who are often not knowledgeable about evidence-based care for this rare disease. Efforts to expand provider knowledge about treating SCD and improve care coordination for patients are critical steps towards improving the lives of individuals living with the disease.

For these reasons in 2014, the National Heart, Lung, and Blood Institute (NHLBI) published a synthesis of the available scientific evidence for the treatment of SCD in an Expert Panel Report[10] in 2014 to offer guidance to PCPs. The report includes information on comprehensive health maintenance through the lifespan, recommendations for effective management of pain episodes and common complications, and guidance on the appropriate use of HU and blood transfusions. The guidelines also recommend the coordination of care between community-based organizations (CBOs), primary care, specialty care, emergency medicine, laboratories and hospitals.

LEGISLATIVE MANDATE

In recognition of the severity of SCD, and the need for adequate resources to address the structural and societal barriers to improving the care of those living with SCD, the federal government has worked through several screening and treatment initiatives to advance healthcare access and quality of care for those with SCD over the past forty years. In 1972, the Sickle Cell Anemia Control Act was enacted, providing resources for screening for SCD, as well for the dissemination of educational materials and research that were developed through these funding streams. By directing funding for SCD-specific screening and treatment, several advances were made that allowed for transformations in how SCD was detected and treated. These advances helped to support the significant increase in life expectancy for those living with SCD, meaning this disease is no longer considered exclusively a pediatric disorder, with most patients living into adulthood.

Universal newborn screening for SCD that was put into place in the late 1980s provided early entry into appropriate healthcare and improvements in evidence-guided treatment protocols, such as prophylactic antibiotic use to prevent infections, vaccinations, and stroke prevention with transfusions. Organized healthcare also helped drive these advancements. In recognition of the need to begin treatment early to prevent complications of SCD, in 2002, a congressional funding stream was identified for the creation of the Sickle Cell Disease Newborn Screening Program (SCDNBSP) to improve the follow-up and education for families of infants identified as having SCD. Early screening programs have proven critical to ensuring the timely adoption of treatment options that delay or prevent the complications associated with SCD.

Today, SCD is considered a chronic condition and patients with SCD have evolving medical needs as they age. This includes the need for more adult specialists and PCPs for those now surviving into adulthood. In 2004, the Sickle Cell Disease Treatment Demonstration Program was created under P.L. 108-357, the American Jobs Creation Act of 2004. Section 712 of P.L. 108-357 focuses on effective treatment and access to evidence-based therapies for those with SCD. The activities of the SCDTDP have been focused on improving delivery of services; training of healthcare workers; building capacity for delivering high quality care to patients in both acute care and medical home settings; supporting transitions in care from pediatric to adult care; and building models of care that best meet the needs of those living with SCD.

OVERVIEW OF WORKING TO IMPROVE SICKLE CELL HEALTHCARE PROJECT (2011-2015)

From 2011-2015, NICHQ served as the NCC for both the SCDNBSP (2011-2015) and the SCDTDP (2010-2014). Together, these initiatives are referred to as WISCH (Working to Improve Sickle Cell Healthcare).

As the NCC, the objectives NICHQ was required to fulfill were to:

- Collect, coordinate, monitor, and report on best practices and findings regarding the activities of the demonstration program;
- Identify a model protocol for eligible entities with respect to the prevention and treatment of SCD;
- Identify educational materials regarding the prevention and treatment of SCD; and
- Prepare a final report on the efficacy of the demonstration program based on evaluation findings.

NICHQ approached its work as NCC by applying the principles and tools of improvement science (QI) to care for individuals with SCD. Employing the widely-used Breakthrough Series™ Learning Collaborative, NICHQ designed the Hemoglobinopathy Learning Collaborative to encourage the development of shared goals across multiple sites.

The structure of the Hemoglobinopathy Learning Collaborative provided a way for NICHQ to coach networks as they implemented projects focused on improving the following domains of care:

- Ensuring timely, effective and respectful care in the emergency department
- Ensuring that care is coordinated across primary and specialty providers and others providing needed services
- Improving the follow-up care and counseling for individuals detected in newborn screening programs and their families
- Offering screening and counseling to immigrant and adult populations
- Improving the support and education that young adults receive as they transition from pediatric to adult centered care
- Optimizing the use of HU

A comprehensive set of quality measures was developed as well as a centralized registry known as the Sickle Cell REDCap System, which captured data from multiple settings (ED, ambulatory care, etc.) and stakeholders (patients, parents, clinicians, etc.). Technical assistance was provided to grantees individually and collectively through calls, coaching, web resources, live meetings and on-site visits. The Hemoglobinopathy Learning Collaborative was designed to accelerate the individual efforts of grantees through creating a forum that incorporated improvement science, collaborative learning, and a centralized quality measurement system. Grantees in the SCDTDP and SCDNBSP participated in the Hemoglobinopathy Learning Collaborative, working to improve care in many of the same areas, using many of the same methods. They collaborated extensively and collected data on the same performance measures.

Recommendations Coming Out of WISCH

The experience and findings from the WISCH Project led to the recommendation that the system of care for individuals with SCD should include the main tenets of the patient-centered medical home. In the patient-centered medical home model, patients with SCD would receive long-term comprehensive care from a PCP who works in a team-based environment with clinical specialists and community providers.[11] Additionally, WISCH demonstrated that the SCDTDP should target a limited set of core activities and should develop collaborations at the regional level to improve care for a greater number of individuals with SCD.

The recommendations coming out of the WISCH Project spanned three levels of action:

- Clinical delivery and public health programs
- Design of the Sickle Cell Disease Treatment Demonstration Program
- Healthcare policy

Key Lessons Learned from WISCH Project (2011-2015)

- Targeted strategies implemented using a disciplined change approach can lead to significant improvements in the quality and timeliness of treatment in the ED and enhance patients' experience with the care.
- Use of patient navigators, community healthcare workers (CHWs), community-based organizations (CBOs), and patient self-management tools can improve access, coordination and integration of services for patients with SCD.
- An early and comprehensive approach to the transition from pediatric to adult SCD care, combined with self-management support, can help mitigate the many challenges that individuals with SCD face during this difficult time.
- Multilevel interventions targeted at the patient, family, provider and system can increase use of HU.
- Opportunity still exists to improve follow-up care after screening to ensure patients are enrolled in comprehensive care.
- Further work is needed to identify the appropriate processes for screening immigrant populations for SCD.
- A shared and coordinated measurement strategy across grantee networks can enhance the program's ability to measure improvements in key processes and outcomes related to SCD care. Coupling the measurement with a systematic approach to improvement results in better care, which will ultimately lead to better outcomes. A regional model approach would improve this coordination of measurement and strategy.

OVERVIEW OF THE SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROGRAM (2014-2017)

The current round of SCDTDP continued to be administered by the Maternal and Child Health Bureau of HRSA, which aims to improve the treatment and prevention of SCD and its complications through the development and establishment of systemic mechanisms. The goal of the program shifted from previous iterations to target fewer, higher-impact areas over a much larger geographical area (Table 1 and Figure 1). This round of the SCDTDP provides for the development of regional infrastructures to support the three project aims.

TABLE 4:

Geographic Target Areas for SCDTDP (2014-2017)

RCC	LEAD ORGANIZATION	STATES/ TERRITORIES	APPROX. # OF INDIVIDUALS LIVING WITH SCD
Heartland	Washington University, St. Louis	MO, IA, KS, NE	2,620
Midwest	Children's Hospital Medical Center	IL, IN, MI, MN, OH, WI	15,000
Northeast	Johns Hopkins University	MD, VA, DE, District of Columbia, NJ, NY, PA, PR, USVI, WV	32,000
Pacific	Center for Comprehensive Care and Diagnosis of Inherited Blood Disorders	CA, ID, OR, WA, NV, AK, HI, AZ, Pacific Basin	7,100
Estimated total number of patients with SCD as reported by project regions			56,720

As the NCC for the SCDTDP, NICHQ supported collection of data and performance evaluation through the following mechanisms:

- Project management and administrative support to the SCDTDP grantees
- Assistance to HRSA in creating and supporting the Oversight Steering Committee (OSC)
- Creation of a database with standard data elements and data dictionary allowing HRSA to collect and evaluate data from multiple regions
- Development of a model protocol and strategies for improving SCD care using information gathered from the database, the grantees, the OSC, and HRSA partners
- Creation of a web-based Compendium of Tools and Materials collected from the activities of the SCDTDP that can be accessed and utilized by other SCD stakeholders
- Development of reporting strategies that enable HRSA to report results of the program to the general public
- Generation of a written report to Congress on SCDTDP

From 2014 to 2017, RCCs in the Heartland, Midwest, Northeast, and Pacific regions received funding from HRSA under the SCDTDP. NICHQ was awarded the contract for the NCC in 2014. Although the precise number of patients in these regions is not known, available data suggests that the regions participating in this project included over 50 percent of all patients with SCD in the United States.[12]

FIGURE 1

SCDTDP (2014-2017) Map of Regions and States Covered

SCDTDP 2014 included 56,720 patients across 29 states and territories.

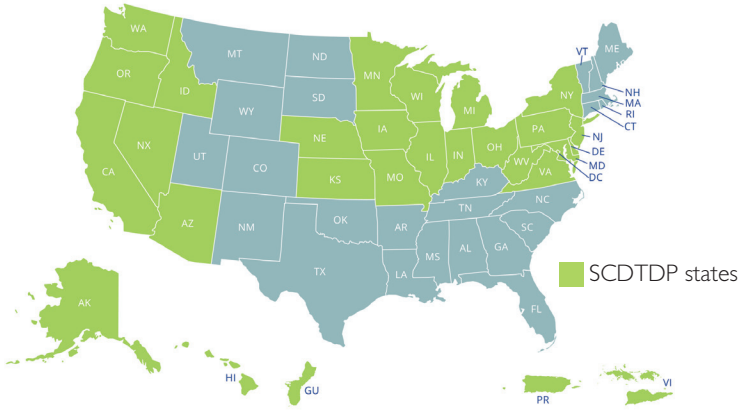


Table two summarizes the key elements of the SCDTDP initiative.

TABLE 5:
Focus of SCDTDP 2014-2017 Initiatives

	SCDTDP 2014-2017
Management	SCDTDP and SCDNBSP NCC's are managed by separate entities: • SCDTDP NCC is managed by NICHQ • SCDNBSP is managed by SCDAA

Mission	• Extend benefits of better care to larger population
	• Focus on aims to increase access to:
	  • Care
	  • Evidence-based therapies
	  • Knowledgeable clinicians

Focus	Three measure aims to promote improvement on a national scale, implemented within regional infrastructures: • # of providers seeing patients with SCD • # of SCD patients seeing providers • # of patients taking hydroxyurea
Approach	• Scale up effective interventions • Take broader approach and target larger population • Use a regional model and Collective Impact framework
Participants	Four regional collaboration centers engaging 28 states and territories: • Northeast: 10 states • Midwest: six states • Heartland: four states • Pacific: eight states and one territory
Data	Administrative Medicaid data and voluntary minimum data set of patient-level data collected and aggregated by region
Outputs	• Congressional Report • Updated Model Protocol with collective approaches to enhancing data management, increasing provider knowledge, and supporting patient access • Review and Updated Compendium of Tools and Materials to reflect additional tools developed between 2014-2017 and updates to previously developed resources from WISCH

Introduction

This report to Congress synthesizes the work of the SCDTDP NCC and RCCs from 2014 to 2017 in the following sections:

Section 2: Data & Measurement Description

This section describes the successes, challenges and lessons learned regarding collection of data and measurement of quality.

Section 3: Improving Access to Quality Care

This section highlights how this program helped to increase the number of providers treating persons with SCD.

Section 4: Increasing Use of Hydroxyurea

This section illustrates the ways that we have increased the number of providers prescribing HU.

Section 5: Improving Provider Knowledge of Sickle Cell Care Seen

This section highlights the ways we have increased the number of providers knowledgeable about treating SCD, and also increased the number of sickle cell patients seen by knowledgeable SCD providers.

Section 6: Recommendations

This section provides insight into recommended clinical care, healthcare policy, and future priorities for sickle cell initiatives.

Appendix

The appendix at the end of this report present key details regarding program measurement and feature tools and resources used by the grantees.

ESTABLISHING THE SCDTDP MEASUREMENT SYSTEM

Throughout the grant cycle (2014-2017), measurement efforts have been guided by HRSA, the NCC and a panel of sickle cell experts including our OSC members.

The primary goals have been to develop and support an SCDTDP data and measurement system that targets the three key aims of the original request for proposals:

- Improve access to care by increasing the number of providers treating patients with SCD;
- Increase the number of providers prescribing HU; and
- Increase the number of patients with SCD that are receiving care from providers knowledgeable about treating SCD.

To achieve these aims, the SCDTDP NCC used a Collective Impact (CI)[15] framework to build a common understanding of the work and guided by the need to develop a shared measurement strategy to identify progress towards achieving the initiative aims. The framework provides a structured approach, which allows collaborative efforts addressing complex social and systems-level challenges to achieve significant and lasting change.

There are five key conditions of success prescribed by CI; collaborators must have:

- A common agenda;
- Shared measurement systems;
- Mutually reinforcing activities;
- Continuous communication; and
- A backbone support structure.

Both the NCC and each of the RCCs employed the Collective Impact strategy to synergize efforts toward achieving the project aims between and within regions. First, HRSA, the NCC, key SCD experts, and the RCCs established and supported a common agenda to achieve the primary aims.

Establishing a shared measurement system involved a considerable effort at all levels of the initiative:

Local Levels | State Levels | Regional Levels

This effort is described in detail in this section.

Both the NCC and the RCCs engaged in establishing mutually reinforcing activities by reaching out to community-based organizations (CBOs) and other key partners in programs working to improve care for individuals with SCD throughout their lifespans. These groups were key to establishing connections across projects and initiatives with similar aims, as well as being a source of content knowledge and expertise, as many of these partners served as faculty and strategic advisors for the SCDTDP. Continuous communication was facilitated by linkages between the RCCs and the NCC, as well as between each RCC and the states within the region. And, in this initiative, the backbone support structure was provided by NICHQ as the SCDTDP NCC, and also by the RCCs for their state partners.

Data & Measurement Description

This section describes our efforts during the project to establish and maintain a shared measurement system. Our work was guided by key lessons learned from the NICHQ WISCH program (Section 1), but focused primarily on the three key measures across many states and more patients, rather than on many measures for a relatively small number of patients with SCD. From the start of this project, it was understood that a shared and consistent measurement strategy was essential across RCC grantee networks to measure improvements and opportunities in key processes and outcomes related to SCD care. The development and implementation of a shared measurement system was a critical piece of the current work, and aligning the work at the national level was a critical component for tracking progress with this new broader regional approach to SCD care, targeting a larger population for the SCDTDP outcomes at the state and regional level.

ROLE AND SCOPE OF NCC AND RCC FOR DATA SYSTEMS AND RELATED TASKS

As the National Coordinating Center, NICHQ was responsible for the creation and maintenance of a data system to collect, evaluate, and share data from the SCDTDP regions. This work began with gathering and reviewing data, reports, and other materials from prior years of the SCDTDP to inform the planning and development of a shared measurement system for the 2014-2017 SCDTDP. NICHQ worked with HRSA at the beginning of the project to identify partners and experts to invite to a Data Summit in November 2014. This in-person meeting was an opportunity to review the relevant information from past iterations of the program and gather input from experts in the field to identify potential barriers to accessing and aligning data across the regions and opportunities to begin to prioritize data collection strategies for the SCDTDP. This meeting and the data streams that were prioritized as a result are described further in this section of the report.

During the Data Summit, various data sources were considered, including local registries, electronic health data and administrative data. Based on considerations of patient privacy, technical complexity, population size, and project resources, the experts recommended collaboration with state Medicaid offices and Medicaid Managed Care Organizations (MCOs) as the approach most likely to successfully deliver the data to support the project aims. To protect the privacy of patients and to optimize our ability to share findings widely, the NCC only collected and shared aggregate data.

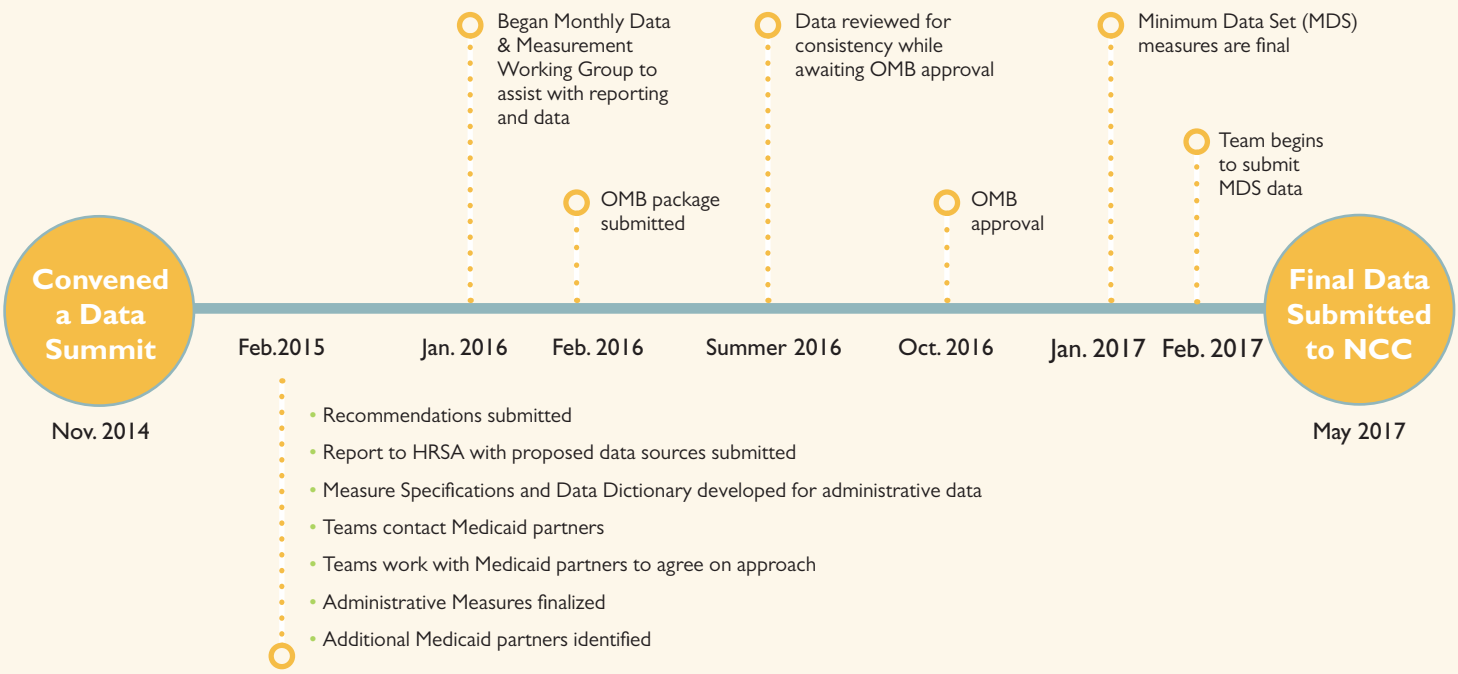
To support this effort, a key initial task for the NCC was to develop detailed measure specifications that included computable measure definitions and a data dictionary to ensure that each region was collecting consistent data. This was an ongoing, collaborative process that involved coming to common measure specifications (definition of the population for each data element) using existing data metrics and specifications, including the PhenX [16] measures and metrics from the previous WISCH measures[17], to aid in the definition of the numerator and denominator for each measure. Once the measure specifications were finalized, NICHQ used the data dictionary (Appendix, Section B) to inform the development of an online database for regional grantees to submit data for analysis.

Throughout the course of this work, NICHQ and HRSA continued to collaborate with other federal agencies and stakeholders who were working on data collection related to SCD to refine data collection strategies. NICHQ was responsible for reviewing regional grantees' data submissions to the online database and modifying the database as needed to be sure that data was collected accurately.

Data & Measurement Description

The timeline below (Figure 3) highlights the key activities involved in the development of the SCDTDP's shared measurement strategy.

FIGURE 2
Shared Measurement Development Timeline



Note: OMB denotes Office of Management and Budget.

At the regional level, each RCC performed a range of activities related to shared measurement, which began with working to establish partnerships and connections to achieve the goals of the program. RCCs provided funding to state level partners within their region who were responsible for coordinating statewide activities. Once partnerships were in place, each RCC led the development of a regional data collection strategy based on the data streams prioritized for the program.

Alignment of regional data collection strategies within the overall shared measurement system required very significant effort due to the difference in the amount of resources available and the infrastructure in place in each state required to collect and share the data. This involved implementing and maintaining data use agreements and seeking individual IRB approval or exemption for human subject data submission. RCCs provided a great deal of technical assistance to state-level partners to support these activities. Receiving IRB approval and getting the appropriate data sharing agreements in place took anywhere from several months for teams that were able to get expedited review (e.g., Washington State), to as long as one to two years (e.g., Idaho). This lengthy process delayed the ability of regions to submit data to the NCC. While initial data was submitted by teams by the early part of 2016, the data was only reviewed for technical assistance purposes (to support consistency of data metrics and specifications) due to the need for further OMB approval. Submission of administrative data officially began in October of 2016 once OMB approval was in place.

DESCRIPTION OF DATA SOURCES

The process for establishing a shared understanding of possible data sources for the SCDTDP began at a Data Summit held in November 2014. A deliverable of the NCC, this summit brought together representatives from the four RCCs, the NCC (NICHQ), as well as federal partners and other key stakeholders and experts with experience relevant to the program. Over the course of this two-day meeting, attendees had an opportunity to discuss the program, the role of the NCC, the program structure, and the proposed activities of all regional grantees. Armed with this information and the program aims, they were able to begin defining the measure concepts for the program. The following data streams (described in greater detail later in this section) were prioritized for the SCDTDP by the participants in the Data Summit.

- Administrative Data: Aggregate data from Medicaid Managed Care Organizations (MCOs) and Medicaid claims data from state-level Medicaid departments
- Minimum Data Sets (MDS): Individual patient-level data from surveys and electronic health records (EHRs), not prioritized but developed as voluntary effort

The administrative data was identified as the data source most likely to be able to deliver data for the three aims across a very large population within the four regions targeted in the project. In addition, a minimum data set was identified to provide more granular data from surveys and EHRs for the smaller number of patients that were accessible from the EHR systems of participating clinics and centers of care. The MDS allows for a more tailored and flexible system of data collection, which permits greater specificity to track progress on the three project objectives and assess improvements in quality of care at the treatment sites.

In addition to the administrative data and MDS, the NCC and RCCs assessed the feasibility and utility of accessing national Center for Medicare and Medicaid Services (CMS) data from the national Research Data Assistance Center (ResDAC) system. ResDAC is the contracted technical assistance center for parties interested in using CMS Medicare or Medicaid data for research purposes.

The primary goals of accessing this data were to determine:

- The prevalence of SCD within CMS;
- The percentage of providers treating patients with SCD;
- The percentage of patients with SCD receiving HU; and
- Other predictors and descriptive information.

The Pacific region developed a sample submission for accessing the necessary data from ResDAC to perform a retrospective review of the data elements for this initiative using CMS data. This review showed that the necessary data elements were present in the claims database. However, the process of developing the data request and necessary analytics to create clean and analytic-ready databases for ongoing analysis was not possible because of the limited resources available for data management in this project. A further query to the contracted supplier of CMS data outputs suggested that the required data draw and analysis for annual measures for these key indicators of SCD care would cost approximately $150,000 per annum. While the ability to access these measures long-term would be an asset to our understanding of SCD care at a national level, there were insufficient resources available to utilize this data stream for the current iteration of SCDTDP. This was compounded by the significant lag time that exists for administrative data coming from claims, as there is often a several year lag time between when an event takes place, when a claim is made, and when this data becomes available via the national data system. This is also true for state level administrative data captured by the RCCs, but the ResDAC data compounds the time lag seen at the state level. This is especially pronounced when compared with the near real-time data that is produced via the MDS data streams.

The third aim, focused on improving provider knowledge of SCD, could not be assessed via either administrative or MDS data. To better understand the provider education efforts across the regions, the NCC developed program evaluation activities focused on this topic. RCCs provided descriptions of state and regional provider education efforts as part of regular communication with the NCC. In addition, in Year 2 of the program, an NICHQ analyst performed semi-structured interviews with providers in SCDTDP-funded regions who had participated in provider education programs, such as Project ECHO®*, as well as providers who had not participated in SCD education. The purpose of these interviews was to determine the activities' impact on provider knowledge; whether providers found the educational activities useful; and the motivations for providers to participate. The results of these efforts are presented in Section 5 of this document.

DESCRIPTION OF ADMINISTRATIVE DATA STREAMS

During the November 2014 Data Summit, RCC teams and expert partners identified aggregated data from MCOs and Medicaid claims data from state Medicaid agencies as the best data sources for population level impact. Because all state Medicaid offices collect claims data, and analysis of hospital claims data suggests that the majority of patients with SCD are insured by Medicaid (approximately two-third of patients), this source of data is both comprehensive and population-based. The central collection of Medicaid offices at the state level meant the data would span multiple provider types allowing for analysis across pediatric and adult providers, including both specialty-based and primary care. While there is state-to-state variation, there are systems for common nomenclature and coding of Medicaid data to help standardize claims data across states and regions. It was felt that using this approach would reduce the need to create a standardized process across a national initiative. During the data summit, RCC teams and measurement experts suggested this data source had the potential to measure quality improvement (QI) impact by providing timely quarterly data that was not possible using national CMS data due to the substantial lag time and procedural delays in accessing access data. Therefore, they recommended that state Medicaid and Medicaid MCO data be reported quarterly to support the project's QI framework.

Although lag times for MCO data differ across regional sites and across MCOs, it was determined that MCOs might be incentivized to participate in collaborative efforts such as SCDTDP by the potential cost savings provided by improvements in the availability and quality of SCD care for their participants. MCO data from RCCs was used both to help create opportunities for comparison across MCOs, and to inform descriptive uptake of treatments (e.g., HU) and patient care (e.g., providers seeing patients two or more times in a year) between the various data sources used as part of this initiative. The value and descriptive data from MCOs is described in more detail in Sections 3 and 4 of this report.

Measures were developed based on the aims of the project; literature review; evidence-based practice and guidelines for quality SCD care; previously developed metrics; expert opinion; and the measurement strategies proposed by the RCCs. Content experts and a group of grantee representatives evaluated all measures (Appendix, Section C, Tables 1-2). These Administrative Data measures are show in Table 3.

* For additional information about Project ECHO TM, visit the University of New Mexico School of Medicine's website: https://echo.unm.edu/. Additional information about SCDTDP Project ECHO efforts are found in Section 5 of this report.

TABLE 6:
Administrative Data Measures for the Project Aims

MEASURES	DATA SOURCES
Measure Aim 1: Increase the number of providers treating persons with sickle cell disease **Measure Concept:** Number of providers who have seen same patient with SCD for two or more outpatient visits – excluding urgent visits and acute visits; providers type: hematologist, PCP, Family Physician (FP), Physician Assistant (PA), Nurse Practitioner (NP), OB-GYN	
1a: Number of providers who saw at least one patient younger than 18 years of age with SCD two or more times during the past 12 months	Medicaid claims data from Medicaid MCOs or state Medicaid records
1b: Number of providers who saw at least one adult patient with SCD two or more times during the past 12 months	
1c: Number of providers who saw any patient with SCD two or more times during the past 12 months	
1d: Number of children with SCD who had at least 2 outpatient visits in the past 12 months.	
1e: Number of adults with SCD who had at least 2 outpatient visits in the past 12 months	
Measure Aim 2: Increase the number of providers prescribing HU **Measure Concept:** Numbers of prescribers whose SCD patient(s) filled prescription for HU in a specified time-period; prescribers would include hematologists, PCPs, NPs, and PAs	
2a: Number of providers in Plan who prescribed HU to a child with SCD at least once during the past 12 months	Medicaid claims data from Medicaid MCOs or state Medicaid records Filled prescription: Medicaid claims data: fills (broader focus)
2b: Number of providers in Plan who prescribed HU to an adult with SCD at least once during the past 12 months	
2c: Number of providers in Plan who prescribed HU at least once during the past 12 months	
2d: Number of children with SCD who filled a prescription for HU at least once during the past 12 months	
2e: Number of adults with SCD who filled a prescription for HU at least once during the past 12 months	
AIM 3: Increase the number of patients with SCD that are receiving regular care seen by providers knowledgeable about sickle cell disease.	
Could be: Number of providers who see patients with SCD who have received clinical recommendations of the NHLBI	**In process:** Qualitative Data; Process measures

Data & Measurement Description

To support standardization of the measures, the SCDTDP NCC worked with SCDTDP faculty and RCC leads to codify and define Measure Specifications and a Data Dictionary that would help operationalize data collection at the state level with a consistent set of data specifications and definitions (Appendix, Section B). The Data Dictionary is the tool by which RCC leads would be able to clearly and consistently communicate their data needs to their Medicaid data partners. It was also a tool used to ground the collective work of the RCC teams and the NCC teams

A key task for the NCC was facilitation of the data sharing to inform improvement activities across the RCCs. To support this task, NICHQ expanded its web-based collaboration framework ("The Collaboratory" or "CoLab)") to support rapid entry of aggregate data across the regions. The CoLab also supported the sharing of best practices and general communication across the regions. A data request template was developed for the RCCs to submit to the state Medicaid and Medicaid MCO offices to ensure uniform data collection. Most regions received data from their Medicaid partners in a pre-computed format (numerators and denominators), but several received patient-level data and performed the analyses themselves. Once processed, aggregate data for periods of interest were entered into the NICHQ Collaboratory system.

As part of the relationship building with the Medicaid and MCO data holders, the RCCs and states worked with key Medicaid personnel to establish a pipeline for the creation of algorithms and data requests to create data pulls for the SCD measures from the administrative claims databases. Data collection requests from the State Medicaid and Medicaid MCOs supported the generation of quarterly data reports by the RCCs, which were used to: monitor changes; document improvements in care; and provide data for educational activities at a state and regional level. Aggregate data obtained by the RCCs on provider encounters with patients with SCD and prescriptions of HU is stored in local databases within each RCC. The RCCs were asked to complete one QI data collection and entry quarterly for each State Medicaid and/or Medicaid MCO in their region and to submit the data for the NCCs final report. This aggregate data was entered into NICHQ Collaboratory.

To summarize, the process outlined for administrative data collection by the RCCs was as follows:

- RCCs identified and contracted with state Medicaid Agencies and Medicaid MCOs for a pull of data fields that would provide the required measures.
- RCCs compiled and aggregated the data collected from each state and submitted it to the NCC for entry Into a dedicated database located on CoLab.
- Once entered, data was further analyzed for designed reports, run charts shared with RCCs on their own designated dashboards, and key data visuals available on CoLab.

ADMINISTRATIVE DATA IMPLEMENTATION

As the RCCs began the work of accessing administrative state-level Medicaid and MCO data for the states in their regions, they soon realized that the process for accessing state-level data was more complex than anticipated. The RCCs identified a series of unique steps necessary for gaining access to and compiling necessary data for each of the states in their region.

Partnership Identification

The first step was identifying the partners within each state Medicaid agency or Medicaid MCO that could and would provide the required data. Because the types of organizations, partners, and relationships varied from state to state, the RCCs found it was challenging to identify the appropriate contact or department for requesting data. RCCs and their collaborative state teams found that it was not always clear where data resided or who could provide access to data. The data source could be the state Medicaid agency or a Medicaid MCO or, in some cases, both the state agency and multiple MCOs. The data may need to be mined across multiple sites each of which may require a separate data request and require funds for the data pull. Funding for data pulls was not included in the SCDTDP budget.

Relationship Management

Once identified, RCCs developed ongoing relationships with new contacts to develop a common understanding for how the data could be used. Relationship development and management has been key to developing strong data use agreements that define specifics on who, what, where, why, and how the data will be used. Policies for sharing data vary from state to state. Negotiating data use agreements was time-intensive and the RCCs dedicated significant effort to negotiating these collaborations and partnerships for data access across multiple states.

Infrastructure and Data Systems Development

Data use agreements and IRB approval were established for each region to support data collection and analysis. Data use agreements formulate a common understanding of the purpose, process, and sharing of data between organizations while assuring patient confidentiality and security. The IRB can set standards in place for staffing, including levels of certification and experience that relate to security and confidentiality of data involving personal health records.

The RCCs recognized the need to build systems and infrastructure to manage the data once received from the state. Staff time and expertise were necessary for cleaning the data pulls, analyzing data, and compiling the datasets coming from the states before turning the data over to NICHQ. The data files received were large and complex and were found to need extensive work requiring analytic applications for those who received non-aggregated data. For disaggregated data, personnel with skills in statistical programming or experience using Medicaid data were required to manage and prepare the data to go to the NCC.

Funding had not been allocated for all of this work. Many of the costs associated with data access and data systems development were unanticipated costs that RCCs needed to adjust for in their budgets. The costs varied across states within a region as well as across organizations within a state. There were costs related to paying for data pulls from state agencies and MCOs as well as costs reflective of staff or consultant time to process data into specifications formats.

Office of Management and Budget and the Paperwork Reduction Act of 1995

Due to the funding mechanism, the NCC was employed as a contracted agent of the federal government and was therefore subject to all applicable federal laws, which limit the burden that can be placed on grantees. To assess the burden to RCC teams to submit the requested Medicaid data, an Office of Management and Budget (OMB) package was created, coordinated by the NCC with input from RCCs and HRSA. After expedited review, the OMB package was submitted for public review in February 2016. The 30-Day Federal Register Notice (FRN) was published in April

2016, which opened a period for public comment. Final approval from OMB to begin collecting data came in October 2016. The process of getting OMB approval did alter project timelines. The delay limited data collection by the NCC prior to approval to necessary elements for technical assistance purposes only.

Analytic Challenges and Limitations

Despite our best efforts to establish clear and computable measure specifications, there was variation in interpretation of the metrics by Medicaid partner organizations. In addition, since the data were received by the RCC in aggregate form, further analysis/re-computing was not possible. Nonetheless, all the regions and most of the states were successful in delivering data and, for those where the measure was interpreted differently, valuable insight was provided. For example, the data received and the quality of data was often contingent on partnerships with State Medicaid and Medicaid MCOs. For some data streams, individual level data may have been received, even when aggregate data requested, which required aggregating prior to sending to the NCC. There were also delays in receiving data from data sources as well as delays related to the OMB clearance process. Some regions were unable to get full coverage (all states within SCDTDP regions), often due to costs or small numbers of people living with SCD in the area. It was additionally a challenge to aggregate data from multiple data sources despite common definitions, leading to varying formats and definitions. While patients in the key administrative measures would likely be unique due to the nature of claims databases, the providers could be represented in multiple data streams (MCO and state Medicaid). It was also not possible in some cases to know with certainty what the type of provider was (e.g., doctor, nurse, home health aide, lab technician).

Despite these limitations, valuable insight was obtained in most cases. We were able to assess access to care on a very large scale in two critical domains: provider practice (providers seeing patients with SCD) and one dimension of quality of patient care (HU access by patients). Our key findings are described in Sections 3-5. We should note, however, that although many patients with SCD are insured by Medicaid, many are not. Our administrative data does not capture data on individuals eligible for Medicaid but not enrolled, or for individuals that are commercially insured and receiving SCD care, or those without any insurance.

DESCRIPTION OF MINIMUM DATA SET (MDS)

The MDS was co-created by the RCCs to obtain patient-level EHRs and survey data. This method was a voluntary effort with the purpose of obtaining real-time, tailored information on pediatric and adult patients with SCD. The RCCs and the NCC worked together to identify measures the RCCs were already collecting that could be reported across regions to show the impact of the SCDTDP. This process included aligning definitions of the measures and data collection methods to enable RCCs to learn from each other's successes and challenges, while ensuring that the data collected across regions was consistent.

The process of creating and utilizing the MDS had many steps. The measures were leveraged using existing SCD resources, including the National Institutes of Health (NIH) PhenX toolkit[14] that is comprised of standard measures with uniform definitions and methods of collection for use in biomedical research. PhenX measures are intended to facilitate cross-study analysis of data. The RCCs also pulled measures from the former WISCH project for inclusion in the MDS.

NICHQ hosted monthly data calls with the RCCs to develop the MDS measures. They considered the SCDTDP goals and how the measures could complement the administrative data that was being collected for the project. During the RCC monthly calls, shared measures were defined and specific methods were developed (Appendix, Section D). Data collection methods used by each RCC were analyzed to determine where they were aligned or not aligned. Systems and processes were defined for data reporting, such as a REDCap (Research Electronic Data Capture)[16] data entry dashboard. States also had to receive IRB approval to use summary reporting of patient level data. Additionally, states had to get Data Use Agreements for the collection and reporting of data. RCCs began entering their MDS data into CoLab beginning in March 2017 for aggregation and creation of descriptive tables.

The development and utilization of the MDS had several benefits for the project. The process of developing the MDS measures collaboratively between the RCCs and the NCC using a Collective Impact framework facilitated cross-region learning. For example, some regions adopted the same data collection methods and instruments as other regions to provide as much consistency across the regions as possible. This was key to ensuring that measures were comparable across regions and that the RRCs' work was minimized through sharing of existing, successful approaches.

In monthly data calls, RCCs were also able to ensure measure definitions and collection specifications were consistent across data collecting efforts. This also allowed the RCCs to troubleshoot reporting issues with the group when there were differences in their efforts. The team used crosswalks (Medicaid cross-references), data dictionaries, and annotations to make sure reporting efforts were realigned as much as possible.

The use of the CoLab dashboards as a data entry platform for reporting the MDS measures improved the coordination of efforts. The dashboards provided a consistent framework for RCCs to see how data should be reported. The dashboards were also flexible enough for the RCCs to customize the design of the data entry platform to conform to their formats and allow annotations for measures that deviated from standard reporting. The dashboards also allowed the NCC to create different measures for RCC teams to allow

them to report on measures that were collected differently across regions. However, measures were consistently reported between states within each of the regions.

The work that was put into creating a common group of shared measures will be beneficial for the RCCs who will be participating in the next grant cycle; they will be able to start with the MDS measures already in use and collectively create additional measures based on the needs of their future work. This expanded MDS will help provide high data quality, encourage use of existing systems and common metrics, and increase the ability of data to validate SCD key processes and outcomes at a regional and national level.

There are many strong points to the MDS, but there are also limitations. One challenge that emerged was the time required to obtain IRB approval for data collection and reporting. While the aggregate MDS data was voluntarily submitted to the NCC, it required a waiver of consent. The full data set that was useful for teams doing the improvement work at the state and pilot site level required informed consent. Additionally, IRB protocols required the inclusion of the completed MDS specifications and data capture system. IRBs were therefore delayed due to the timing of the MDS development. There were also differences in data format and stipulations that made comparison across regions difficult.

The process of creating common measures required the RCCs to align data definitions and data collection methods. Despite these efforts, all four RCCs were not defining and collecting the data in the same way for some measures. The variations were annotated and separate metrics for these regions were used in the final data analysis. Also, because the MDS effort was voluntary, most of the resources for this project were dedicated to obtaining the administrative data from state Medicaid offices and MCOs. The MDS data was not part of the original data collection strategy emerging from the first-year data summit. Instead, this process began later in the funding cycle, only rising in priority as the delays and challenges with the administrative data became more apparent. Because of this delay, and the need to split resources between the MDS and administrative data requests, there was limited time for RCCs to collect and enter data, and the period for data collection was limited as it took substantial time and effort to standardize the data measures between the RCCs. A potential limitation of the MDS is that it only includes patients from specific sites rather than across an entire state like the Medicaid administrative data. This is relevant for SCD because much of the population receives care outside of specialty centers that contribute data to the MDS.

SCDTDP: MEASURE DEFINITIONS

The core project measures that were defined at the data summit held on November 3-4, 2014, and are shown in Table 4.

TABLE 7: Aim 1 Operational Definitions

MEASURE	DENOMINATOR[a]	NUMERATOR[a]
1a. Providers seeing pediatric SCD patients	Providers who had at least one claim submitted to the plan	Providers from the denominator population who saw at least one patient with SCD who was less than 18 years old at the time of the visit for at least two non-emergent outpatient visits
1b. Providers seeing adult SCD patients	Providers who had at least one claim submitted to the plan	Providers from the denominator population who saw at least one patient with SCD who was 18 years of age or older at the time of the visit for at least two non-emergent outpatient visits
1c. Providers seeing any SCD patients	Providers who had at least one claim submitted to the plan	Providers from the denominator population who saw any patient with SCD for at least two non-emergent outpatient visits
1d. Pediatric SCD patient outpatient visits	Patients less than 18 years old as of the end of the reference month who have ever had a diagnosis of SCD and who had at least one health care event (any claim)	Patients from the denominator population who had at least two non-emergent outpatient visits
1e. Adult SCD patient outpatient visits	Patients who were 18 years old or older as of the end of the reference month who have ever had a diagnosis of SCD and who had at least one health care event (any claim)	Patients from the denominator population who had at least two non-emergent outpatient visits

TABLE 8: Aim 2 Operational Definitions

MEASURE	DENOMINATOR	NUMERATOR
2a. Number of providers in plan who prescribed HU to a child with SCD at least once	Providers who submitted at least one claim to the plan	Providers from the denominator population who had a patient under 18 years old and who have a diagnosis of SCD who filled at least one HU prescription
2b. Number of providers in plan who prescribed HU to an adult with SCD at least once	Providers who submitted at least one claim to the plan	Providers from the denominator population who had a patient over 18 years old and who have a diagnosis of SCD and who filled at least one HU prescription
2c. Number of providers in plan who prescribed HU at least once	Providers who submitted at least one claim to the plan	Providers from the denominator population who had any patient with a diagnosis of SCD who filled at least one HU prescription
2d. Number of children with SCD who filled a prescription for HU at least once	Patients less than 18 years old as of the end of the reference month who have ever had a diagnosis of SCD and who had at least one health care event (any claim)	Patients from the denominator population who filled at least one HU prescription
2e. Number of adults with SCD who filled a prescription for HU at least once	Patients 18 years of age or older as of the end of the reference month who have ever had a diagnosis of SCD and who had at least one health care event (any claim)	Patients from the denominator population who filled at least one HU prescription

[a] All definitions are for the 12-month period ending with the reference month.

DESCRIPTION OF QUALITATIVE DATA AND SECONDARY DATA SOURCES REVIEW

The qualitative data collected for the SCDTDP includes information gathered from primary stakeholder interviews (as part of the program evaluation activities) as well as review of secondary data sources. Due to the funding mechanism, the NCC was employed as a contracted agent of the federal government and was therefore subject to all applicable federal laws, which limit the burden that can be placed on grantees. As such, the number of stakeholders interviews were limited to ensure compliance.

Primary stakeholder interviews took place during two periods of the project: May-July 2016 (mid-point program evaluation) and April-May 2017 (summative evaluation). Each source of qualitative data is described further below.

Midpoint Evaluation: Primary Stakeholder Interviews

The purpose of the midpoint evaluation interviews was for RCC leads and select state level partners to describe key accomplishments to date and progress with project activities. The leads also identified challenges and made recommendations for improvement in the final year of this iteration as well as the future of the SCDTDP. NICHQ analysts completed midpoint evaluation interviews, including an interview with representatives from each of the four RCCs as well as several state-level partners. State partners were selected for interviews to represent a range of geographical locations as well a range of challenges and successes in key areas, such as data capacity, telementoring, provider education, and appropriate use of HU. The midpoint evaluation interview guide is located in Appendix, Section E.

The general categories of the questions posed during these interviews were:

- Successes and challenges to achieving the project aims
- Project activities that have and have not worked well
- Requests and suggestions to be able to accomplish more

Summative Stakeholder Interviews

The goal of the summative evaluation was to gain a better understanding of how the RCCs were accomplishing Aim 3 of the project (in particular, their efforts in engaging providers around caring for patients with SCD, and increasing educational resources for providers about SCD treatments and the benefits of prescribing HU). The summative evaluation sought to discover the strengths and challenges of regional efforts and what lessons could be learned. This focus emerged from results of the mid-point evaluation where teams expressed their difficulties engaging participants in provider education activities. Many teams were having trouble recruiting and retaining participation of providers, particularly PCPs. Using key stakeholder interviews allowed for a more in-depth evaluation of the reasons providers may or may not engage in regional provider education efforts.

The interviews were semi-structured phone interviews. The providers/stakeholders selected for the interviews included those who had participated in an RCC's continuing medical education initiatives about SCD (e.g., ECHO® groups, workshops, symposiums), and those who did not participate. In the interviews, providers/stakeholders who participated were asked about how and why they engaged in SCD provider education efforts, and what worked or didn't work from their perspective. Providers/stakeholders who did not participate were asked about their experiences treating patients with SCD, and why they did not engage in the provider education activities. Both sets of providers/stakeholders were asked about the barriers or challenges in engaging in SCD continuing medical education activities. For more information on the midpoint and summative evaluations, please see Appendix, Section E.

Secondary Qualitative Data Sources

Qualitative data was also gathered from reviewing secondary data sources throughout the three years of the program. These data sources captured important information and provide an additional qualitative narrative to supplement the quantitative data. One of the key sources of information was the annual progress and performance reports prepared by the RCCs, which contained valuable observations about the population served within each region and the context for patients' overall access to SCD care.

In addition to the reports prepared by the RCCs, qualitative data was also gathered through regular communications between the NCC and RCCs, including:

- Monthly 1:1 calls between the NCC and each RCC lead;
- Frequent workgroup meetings focused on data and measurement, telementoring, and provider education;
- Quarterly webinars with all RCCs;
- Monthly newsletters highlighting regional efforts, progress with workgroups, and upcoming conferences;
- Quarterly surveys completed by RCC leads;
- Conference presentations;
- Three all-state partner webinars; and
- Participation in the program's online community (CoLab).

Strengths of Qualitative and Secondary Data Sources

The qualitative data was used by the NCC as part of the evaluative efforts to describe the state of SCD care within the participating states and regions across the nation. These stories and experiences illustrate the activities taken up by the RCCs with their state teams and link these activities to the perceived impact on the three project aims of SCDTDP.

Qualitative data provided opportunities to guide the work of the NCC in supporting the collective framework for SCDTDP. For example, input from the mid-point evaluation showed that grantees and state partners wanted to learn about how other states and regions were accomplishing the project aims. In response, the NCC created the biannual All State Partner Call where states from each region highlighted their work. Qualitative data also provided the framework for the SCDTDP Model Protocol and Compendium of Tools and Materials, the companion piece to this Congressional Report. Best practices collected from one-on-one meetings and working groups are highlighted in the protocol and inform the recommendations made. The resources compiled enabled dissemination of tools and approaches useful in spreading the impact of the SCDTDP. The qualitative data also provides critical contextual framing for understanding the strengths and limitations of the quantitative analyses. For example, describing the challenges faced by RCCs in engaging providers and also the reasons why providers chose to engage in the SCDTDP initiative can offer important insights into the analysis of data for Aim1, increasing the number of providers treating patients with SCD. Qualitative data including meetings with the OSC, the faculty and experts, as well as the RCCs were also the source of the refinement of the lessons and learned and recommendations stemming from this initiative (Section 6).

Lessons Learned

Many lessons were learned through the process of acquiring administrative data for the SCDTDP work that would be helpful for others seeking to use administrative Medicaid claims data in assessing efforts to improve quality of care for patient populations. They include the following, in no particular order:

- Even with sufficient resources, timeliness and availability of claims data may vary among state agencies and MCOs, which makes data availability for QI activities in real time difficult. (Medicaid MCOs were found to have a longer delay between the collection and reporting of claims data than state agencies.)
- Administrative data can provide key insights and, with work, is an available and potentially useful data source to measure access and utilization on a national scale.
- Success in obtaining Medicaid data in one state does not necessarily provide useful approaches to access in another state. (As one SCDTDP faculty member put it, "You learn how one state's process works and you understand one state's process.")
- Identifying and building relationships necessary to move data requests forward are time-consuming and costly.
- Interpretation of measure specifications may vary across entities and states; extra care is required to ensure the collected data is comparable across states and regions.
- There are costs with accessing Medicaid data.
- Some MCOs with research institutes may require grantees to assign their staff co-PI status with salary support and authorship agreements before agreeing to provide data.
- Some MCO and state agency data may be managed by third parties, incurring costs for the data
- Opportunities to provide non-financial incentives for sharing data are few.
- Some MCOs may have too few patients with SCD on their roster to warrant the time and costs required to set up data requests in their system.

Section 3: Improving Access to Quality Care

Access to quality care is a matter of life or death for patients with SCD. Care is not consistently available, particularly for the majority of patients who do not live in close proximity to the few SCD specialty centers. Many primary care clinicians are hesitant to accept patients with SCD due to the complexity of their care and lack of commensurate reimbursement. In this section, we highlight how the SCDTDP worked to engage providers in educational efforts with the goal of increasing the number of providers treating persons with SCD.

As SCD is a rare disease, PCPs with relatively few or no patients with SCD have little incentive to stay up to date on treatment guidelines. This makes it very difficult for individuals with SCD, particularly those who live in rural areas or who don't live near large SCD centers, to find knowledgeable providers. This problem worsens as patients transition to adult care. Prior to advancements in SCD care and treatment in recent decades, SCD was considered only a pediatric disease. The number of adult providers treating patients with SCD has not kept up with the demand as more patients survive into adulthood. The implications of poor access to care on patient outcomes are substantial, including preventable deaths, unnecessary emergency and inpatient admissions, increased complications, increased costs, and poor quality of life.

All of the SCDTDP RCCs reported that their patients with SCD had challenges accessing care. Our regional teams used a variety of approaches to increase the number of providers treating patients with SCD. To address the well-recognized need for knowledgeable and experienced specialty advice from hematologists in primary care settings, many teams worked to implement telehealth-based approaches designed to support the care of patients virtually, with the goal of providing both medical and educational services. The NCC also provided opportunities to bring regions together to share lessons learned, strategies, and resources. The methods specific to supporting provider engagement to improve access to quality care for SCD are described below, followed by descriptions of provider engagement activities and data related to this aim for each region.

SUPPORTING TELEMENTORING ACTIVITIES

The Midwest, Northeast, and Pacific regions all launched Project ECHO® clinics for sickle cell care. The Project ECHO® model is a hub and spoke knowledge-sharing network for experts to conduct virtual clinics with other providers. This form of telementoring (provider-to-provider education) was developed at the University of New Mexico. Overall goals of the Project ECHO® model are to improve access to scarce healthcare resources, share best practices to reduce variations in care, develop specialty expertise in primary care settings, and ultimately, improve and monitor patient outcomes.[17] Project ECHO® has mainly been used for care of more common conditions that require specialty care; the application of Project ECHO® to SCD care was a key innovation developed during the 2014-2017 SCDTDP grant cycle.

SUPPORTING PROVIDER ENGAGEMENT ACTIVITIES

The NCC supported regional efforts to increase the number of providers treating persons with SCD and addressing SCD-related issues in several ways. Each of the all-state partner webinars organized by the NCC included speakers that addressed key topics related to increasing the number of providers treating persons with SCD. These topics included capacity building through stakeholder engagement, establishment of new SCD treatment centers, outreach efforts to PCPs, and patient navigation programs.

The telementoring work group meetings provided an opportunity for regions to share strategies for recruiting spokes for their Project ECHO® clinics and for recruiting providers within those spokes to participate in ECHO® clinics. Ultimately, the goal is that more providers will be willing and able to treat persons with SCD because of participating in the SCDTDP Project ECHO® clinics. The NCC supported the development of a promotional tool that highlights these efforts, found in Appendix, Section H.

100,000 Americans live with the inherited blood disorder, sickle cell disease, making it one of the most common genetic disorders in the United States.

SUPPORTING DATA COLLECTION AND MEASUREMENT ACTIVITIES

In addition to the development of a national collaboration website (CoLab) for data submission, the NCC also worked with the RCCs to develop two core data and measurement strategies for the project. First, the team developed detailed measure specifications for a limited number of core measures (see Section 2, Table 4) that could feasibly be measured using administrative data. Second, the NCC assisted teams as they worked to coordinate efforts with Medicaid MCOs and state office partners. The goal was to establish a core set of metrics that would allow the assessment of two key aspects of Aim 1 (Access to Quality Care) resource availability (number of providers seeing any patients with SCD) and continuity (number of patients with two or more visits within a year). By partnering with Medicaid organizations, the goal was to leverage the work and expertise within these groups to support measurement on a national scale.

The following five measures were the primary measures for Aim 1:

- Number of providers in plan who saw at least one patient younger than 18 years of age with SCD two or more times during the past 12 months
- Number of providers in plan who saw at least one adult patient with SCD two or more times during the past 12 months
- Number of providers in plan who saw any patient with SCD two or more times during the past 12 months
- Number of children in plan with SCD who had at least 2 outpatient visits in the past 12 months.
- Number of adults in plan with SCD who had at least 2 outpatient visits in the past 12 months.

KEY FINDINGS FROM SCDTDP REGIONS

The NCC served as the data coordinating center for the quality measures and coordinated the reporting and summarizing of improvement activities within the network. Importantly, and somewhat unexpectedly, variation in interpretation of measure definitions led to variation in outcomes measured. However, this variation did provide further insight and value. Findings are presented below by region following the description of program efforts related to increasing access to care. Each of the regions saw increases in their networks of care from baseline to expand the networks to nearly 11,000 patients across the regions (Table 2).

TABLE 2:
Growing Networks of Care

REGION	PACIFIC	HEARTLAND	MIDWEST	NORTHEAST
Baseline of total number of patients receiving care	1020	1723	1674	3168
% Increase in patients receiving care from baseline	24% (N= 1285)	3% (N= 1778)	20% (N= 1982)	85% (N= 5879)

HEARTLAND REGIONAL COORDINATING CENTER

The Heartland regional coordinating center is led by Washington University in St. Louis, Missouri, and includes state partners in Nebraska, Kansas, Iowa, and Missouri. Key efforts in the Heartland region related to improving access to care include implementing a telehealth program in Nebraska and opening two clinics to transition adolescent patients with SCD from pediatric care to adult care. These initiatives are described in more detail below, followed by highlights from an event to promote access to care and the development of a life skills curriculum.

Telehealth Program

In Nebraska, the center for pediatric specialty care in hematology for SCD is located at Children's Hospital and Medical Center in Omaha at the far east end of the state. Accessing this center is challenging for families whose children were diagnosed with SCD or sickle cell trait (SCT) through the newborn screening program, but do not live near Omaha. As shown in Figure 4, many families have to travel large distances to access SCD care. Though a referral system was in place, families were not keeping their follow-up appointments in Omaha due to a variety of challenges, including access to long distance transportation and the time required for travel that conflicted with schooling, jobs, and other commitments. The Nebraska team identified that most of the missed appointments were for children who tested positive for SCT. These families need education and a genetic counseling session, but the child has no follow-up healthcare requirements related to SCD.

To address this need, the Nebraska state team set up a telemedicine link from the People's Health Clinic, a Federal Tort Claims Act (FTCA) deemed community health clinic in Lincoln, Nebraska, to manage remote telehealth sessions for SCT education and counseling. Families with a newborn who screened positive for SCT were offered an education and counseling session via remote consultation. Patients whose newborn screening results were positive for SCD were still seen in person at Children's Hospital and Medical Center to establish a relationship with a pediatric hematologist with expertise in SCD care. The telehealth program in Nebraska is an example of a successful effort by a state team to identify a gap in access to sickle cell care and implement an innovative approach to meet their population's specific needs.

Opening Adult SCD Clinics in St Louis, Missouri

The Heartland RCC worked with partners at Barnes' Hospital and Integrated Health Network to open up two adult SCD practices. These new clinics created pathways to care for adolescents with SCD transitioning to adult care as well as for adults with SCD who had not been receiving routine care.

A young adult clinic at the Center for Advanced Medicine at Barnes Hospital is working to transition young adults out of the pediatric program to another Barnes' Hospital location in St. Louis, closer to where more SCD patients live. In the seven months since the opening of the new clinic, 25 new patients between the ages of 18 and 25 have established care (approximately one new patient per week). Patients can get an appointment within a week.

In August 2017, the team at Washington University opened another clinic for adults in North St. Louis County. This opportunity now provides care in a predominantly African American community. Twenty-five percent of Missouri's SCD population lives in North County. This new clinic allows greater access in their neighborhood without having to drive to the major academic medical center.

In partnership with Integrated Health Network in Missouri, the Heartland developed aims for improving care access for adult patients with SCD. Now in its third year, the clinics at Washington University continue to connect research and education for both patients and providers.

Promoting Access to SCD Care

In partnership with the Sickle Cell Disease Association of Missouri, the Heartland RCC held an event at the State Capitol in Jefferson City, Missouri, to promote access to SCD care. Over 70 people (medical providers, patients, and caregivers) participated in talks about SCD that raised awareness of several key issues, including access to care. The group met with more than 24 state lawmakers, including the state's Black Congressional Caucus. As a result of this meeting, the state will officially recognize September as Sickle Cell Awareness Month. In addition, the Heartland RCC's Principal Investigator was invited to speak to the Missouri State Health and Mental Health Board to discuss SCD.

Life Skills Curriculum for Young Adults with SCD

The Heartland RCC team and Missouri state leads developed and tested a comprehensive life skills curriculum for adolescent patients with SCD to help them manage their health and healthcare for SCD within the context of broader life skills. The idea is to move the responsibility of disease management from the parent or guardian to the patient. The curriculum includes health management (including sexual health and sickle cell genetics), job skills, money management, housing, and nutrition. Embedded within this general curriculum are modules addressing SCD care management, including medication management, acute pain episodes and follow-up, preventive screenings, and SCD-specific screenings. Ideally, adolescents who have used this curriculum will be more likely to seek routine care and build relationships and connections with care providers in their adult lives, ensuring continued access to continuity care beyond their pediatric experience.

TABLE 9:

Heartland Region Data Received for Aim 1: Access to Care Measures

STATE	DATA RECEIVED
Iowa[a]	Data Not Submitted. State reported resource constraints that precluded their ability to pull data despite RCC offers to fund the data pull. IL Medicaid
Kansas[b]	Medicaid
Missouri[a]	Medicaid; IL Medicaid
Nebraska	Data Not Submitted. State reported resources constraints that precluded their ability to pull data despite RCC offers to fund the data pull.

a The Iowa and Missouri data from the Illinois Medicaid office covers part of 2015 into the second quarter of 2016.

b The Kansas Medicaid data presented covers the full calendar year 2014, and is a look back at provider services for this period.

Data Collection Efforts

In the Heartland region, data collection efforts were uneven across states. Resource constraints at the agencies with access to the data needed for the SCDTDP measures prevented Nebraska and Iowa from accessing this data despite the RCC's offer to fund the data pull. No states could provide data for multiple time periods that would allow comparison of trends over time. The Heartland data requests stood out among the RCCs for having several data sources from MCOs and Medicaid offices outside of their states. The Illinois Department of Healthcare and Family Services provided data for patients living in Iowa and Missouri near the border of Illinois who had claims submitted for SCD services occurring in Illinois. The Centene Managed Care Organization (MCO) provided data for their patients in Kansas and Missouri for multiple time periods in addition to several other states.

This overlap in data reporting for regions such as the Heartland and the Midwest is just one of the numerous challenges in regional data collection. State boundaries may overlap with those of provider and payer networks. For this report, we have chosen to present all data that is relevant to a region without consideration for the regional source of the initial data request (although this information is provided) where there was a sufficient number of patients or providers to allow for confidentiality (n=5). This type of overlap in data infrastructure was greatest between the Heartland and Midwest regions. Table 5 presents all available data sources for the Heartland region, by state, as well the source of the data request.

Measurement Summaries

Summary data for Access to Care measures for the region are described below. In Table 6, you will see data only for Kansas. Although data was submitted from Illinois Medicaid for the states of Iowa and Missouri, the data was not included in the table below because there were low numbers reported from these states (n= <5). Therefore, that data was suppressed to ensure privacy of provider and patient data.

TABLE 10:

Heartland Region Aim 1 (Access to Care) Measures

	MEASURE DATA (NUMERATOR/DENOMINATOR (%))				
PLAN (REFERENCE PERIOD)	**1a.** Providers seeing pediatric SCD patients	**1b.** Providers seeing adult SCD patients	**1c.** Providers seeing any SCD patients	**1d.** Pediatric SCD patient outpatient visits	**1e.** Adult SCD patient outpatient visits
Kansas Medicaid (CY 2014)	9/357 (3)	9/357 (3)	17/357 (5)	16/102 (16)	9/85 (11)

KANSAS

For the 357 providers submitting Medicaid claims in Kansas, 17 providers, or almost 5 percent, saw a patient with SCD two or more times in the past year. This is higher than what was seen for many other states in other regions where percentage of providers seeing SCD patients tended to be lower. Overall, the number of providers treating a patient with SCD two or more times in Kansas was generally high compared to Medicaid data reported by other states and regions.

In contrast, the number of patients with two or more outpatient visits was much lower than what was seen with other states and regions. Of the 102 pediatric patients with SCD in Kansas, only 16, or about 16 percent, of patients had two or more outpatient visits in the past year. Of the 85 adult patients with SCD, only 11 percent of these patients had an outpatient visit two or more times.

MIDWEST REGIONAL COORDINATING CENTER: STORM

Sickle Treatment and Outcomes Research in the Midwest (STORM) brought together the hematology and primary care communities to collaborate with patients and families on QI initiatives. STORM's focus was on building a sustainable learning network to improve access to and delivery of care with positive outcomes for patients with SCD in the Midwest region.

IMPROVING ACCESS:

Over 10,000 patients with SCD in the Midwest were served or impacted in various capacities through SCDTDP efforts.

This region included six states (Illinois, Indiana, Michigan, Minnesota, Wisconsin, and Ohio) with a total population of roughly 52 million people. A recent study found that there are approximately 15,000 individuals with SCD in the Midwest. It has been estimated that over 700,000 African Americans and 35,000 Hispanic individuals with SCT live in this region.[18] These six states joined together to design, implement and evaluate a project to engage regional state partners and patients in a collaborative network to improve outcomes for all individuals with SCD in the Midwest.

Participation in the STORM collaborative was at the institution or practice level. Each participating institution identified a lead physician and additional clinical faculty and staff who worked as members of local site-specific and topic-specific improvement teams. Teams developed specific approaches to increase the number of physicians seeing patients with SCD based on the contextual factors within their state.

In implementing its collaborative QI approach, STORM brought state teams together in biannual learning sessions to build their QI capacity, focusing on efforts related to the three aims of the SCDTDP. At biannual meetings, teams had opportunities to share what they learned and report on the impact made through testing innovative processes and ideas in their day-to-day work. To keep connected between learning sessions, the STORM team met virtually every month. During monthly action period (AP) calls, teams would share best practices and updates on their QI efforts. Guest presenters shared additional resources and activities related to state teams' identified needs and interests. A provider engagement expert provided opportunities for learning and support to teams during learning sessions.

There were many shared practices among the state teams focused on improving access to care. These included outreach to state and specialty medical societies and chapters to create awareness of and interest in treating patients with SCD. State teams also learned from each other about best approaches for partnering with CBOs, including local Sickle Cell Disease Association of America (SCDAA) chapters. Three approaches STORM teams used to address provider engagement and improve access to care are described below: STORM TeleECHO™, engaging providers via a statewide survey, and enhancement of geographic access to care in Indiana.

STORM TeleECHO™

In March 2016, the STORM team launched a Project ECHO® clinic with Cincinnati Children's Hospital as the hub. The STORM TeleECHO™ uses a lifespan approach to address pediatric and adult care of SCD. The clinic met monthly and all state level STORM partners participated. This clinic has been particularly successful in recruiting "spokes" — primary care physicians receiving mentoring and feedback from experts located in a "hub." State partners in the region recruited several additional participants, including PCPs with a history of seeing patients with SCD, as well as hematologists with limited experience treating SCD. On average, 15 sites participated in monthly STORM TeleECHO™ sessions. Each session included a 20-minute didactic presentation based on NHLBI guidelines, and then a case presentation presented by a participant. Both Continuing Medical Education (CME) and Maintenance of Certification (MOC) credits for the American

Board of Pediatrics (ABP) and American Board of Internal Medicine (ABIM) were available to participants. The STORM TeleECHO™ clinic for SCD required a substantial amount of resources to implement. It has been a major part of this region's efforts to expand access to SCD care and has shown great promise for the future spread of quality, evidence-based SCD care in the Midwest.

Engaging Providers Using a Statewide Survey

To deliver effective provider education efforts, the STORM team in Illinois set out to gain a better understanding of what providers would need to care for patients with SCD. With IRB approval, the team developed and implemented a twelve-question electronic survey using Survey Monkey®. The survey was mailed to 170 PCPs previously identified through two SCD treatment centers. The survey was distributed electronically to 2300 medical providers through the Illinois Chapter of the American Academy of Pediatrics and the Illinois Emergency Nurses Association. The survey received 80 responses (3.2% response rate). The survey collected demographic information and asked about providers' comfort level in managing patients with SCD, barriers to caring for patients with SCD, resources to assist them in providing care for SCD, level of training, and preferences for medical education opportunities.[19]

Survey findings identified opportunities and barriers for providers in caring for patients with SCD. Several strategies were identified by providers to help them feel more comfortable caring for patients with SCD. These included having a central phone number to call for consultation or assistance from a specialist in SCD care; being mentored by a provider experienced in SCD care; having access to a treatment guide and clinical decision support tools; and additional training. The team learned that most providers who responded to the survey were willing to manage patients with SCD and were comfortable with basic care for SCD. They found that respondents were somewhat comfortable with pain management, but were not comfortable prescribing HU or managing complications.

The survey not only helped the Illinois state team identify areas of need, but also helped to pinpoint next steps for STORM. Since treatment with HU was an area where providers needed more information and was a topic that lent itself well to clinical decision-making support, the STORM team prioritized the development of the HU decision-making tool for dissemination across the region. Other recommendations prompted from Illinois' survey results included establishing phone-a-friend programs for providers to access SCD experts and assessing the roles of care coordinators and patient navigators to support patients and providers in facilitating appointments for SCD and monitoring health.

Enhancing Geographic Access to Care in Indiana

The Indiana state team, based at the Indiana Hemophilia and Thrombosis Center (IHTC) in Indianapolis, identified two priorities for improving access to SCD care in their state. They identified the need to 1) reach patients in Lake County in Northwest Indiana, a medically underserved area where patients do not have access to pediatric hematologists; and 2) improve access to adult care for adolescents and young adults (AYA) with SCD in Allen County in Northeast Indiana. IHTC reviewed data showing state counties with high frequencies of newborns screening positive for hemoglobinopathies since January 2008 versus the number of hematology practices in Indiana. The team also reviewed research articles concerning circumstances of deaths in patients 18 years or older related to transitions to adult care.[2]

Indiana had developed a strong pediatric program, Sickle SAFE (Screening, Assessment, Follow-up, and Education), that focused on improving access to quality care for children ages birth through 5 years. However, there were still areas of the state with large numbers of infants with hemoglobinopathies who had limited resources or low access to hematology care. One example of this was Lake County, which had one of the highest rates of infants identified with SCD and where over half of residents are Medicaid recipients. Many patients and families from Lake County had accessed SCD care in Chicago, Illinois, due to proximity. Unfortunately, many of these patients lost access to care when Illinois healthcare providers and facilities stopped accepting Indiana Medicaid plans.

To help address this problem, the IHTC partnered with a local Northern Indiana CBO and held a daylong SCD education event for Lake County community members and healthcare providers. In addition, they hosted an educational dinner for identified Lake County PCPs who treat Sickle SAFE enrollees. This event reviewed the NHLBI guidelines, focusing heavily on early prescription of HU and the importance of SCD screening. Dinner attendees earned CME credits.

The IHTC's approach to the dearth of adult providers in Northeast Indiana was to look for existing resources to help meet the needs of these patients. They identified a family medicine residency program in Fort Wayne that was a certified patient-centered medical home (PCMH) for HIV-infected adults. This PCMH had resources that would cover many of the needs for adult patients with SCD, including behavioral health services, health educators comfortable with cross-disease complications, pharmacist on staff, coverage at all Fort Wayne area-hospitals (allowing for continuity of care), and confidence collaborating with sub-specialists.

IHTC worked with this PCMH to build relationships and support for their staff to develop the will and knowledge to begin seeing patients with SCD. Residency staff shadowed adult hematologists at the IHTC. They implemented a phone-a-friend program for adult and pediatric hematologists to be available for questions as they arise. They shared online SCD knowledge modules with residents, including HU for the treatment of SCD, SCD emergencies, comprehensive care for AYAs with SCD, and transition best practices. In addition, they applied for funding to provide patient navigation assistance with insurance issues, transition to adult care, and other issues related to access.

These two examples from Indiana showcase efforts to identify gaps in access to SCD care and test innovative solutions. Key factors to the success of this project were meeting face to face with physician leaders of the PCMH, exploring their concerns about HU, and providing educational materials that addressed these concerns. Continued dialogue between the two programs was key in maintaining the relationship.

Data Collection Efforts

In the Midwest region, Medicaid data collection efforts varied between states. Some states, including Indiana, Ohio, Michigan and Illinois, were able to provide data for multiple time periods, allowing for comparison of trends across time. Minnesota and Wisconsin were unable to provide any data for the SCDTDP due to resource constraints at the agencies with access to the data needed (e.g., staffing) despite the RCC's offer to fund the data pull. The Midwest data requests stood out among the RCCs as having fewer additional fees for data pull requests, and great willingness by Medicaid offices to provide data for multiple time periods.

For some states within the Midwest, additional MCO data was contributed in data requests from other regions. Table 7 presents all available data sources, by state, as well the source of the data request.

While data from a large multi-state Medicaid MCO that had patients in Illinois, Indiana, Ohio, and Wisconsin was provided by the Heartland Region, it was solely focused on measures related to Aim 2, and will not be part of the data tables or figures in this section.

TABLE 11:

Midwest Region Data Received for Aim 1: Access to Care Measures

STATE	DATA RECEIVED
Illinois[a]	Medicaid
Indiana	Medicaid
Michigan	Medicaid
Minnesota	Data not submitted
Ohio	Medicaid
Wisconsin	Data not submitted

[a] Includes data from patients living in Indiana, Iowa, Wisconsin, and Missouri, but receiving care from providers in Illinois.

Table 8 describes the variation in time period for each data pull in each state. The periods with darker coloration are those with more states covering that same period. For the Midwest, the time period with the greatest coverage by the states submitting data was the first through third quarter of 2015. The results of this data collection should be understood within the context of the timeframe during which data was submitted. In three out of the four states providing data for the Midwest, the state Medicaid offices were able to provide rolling quarterly data with a one calendar year look back provided.

TABLE 12:

Time Periods Covered for Midwest Data Received

STATE	2014				2015				2016			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Illinois[a]												
Indiana												
Michigan												
Ohio												

[a] Summed to include patients living in IN, IA, WI, & MO

Measurement Summaries

Access to Care measure data for states in the Midwest Region are shown in Table 9. Each data source provided data for different time periods; these are specified in Table 9 as "Reference Period."

TABLE 13:

Midwest Region Aim 1 (Access to Care) Measures

PLAN (REFERENCE PERIOD)	MEASURE DATA (NUMERATOR/DENOMINATOR (%))				
	1a. Providers seeing pediatric SCD patients	**1b.** Providers seeing adult SCD patients	**1c.** Providers seeing any SCD patients	**1d.** Pediatric SCD patient outpatient visits	**1e.** Adult SCD patient outpatient visits
Illinois: Medicaid[a] (7/1/15-6/30/16)	145/38898 (<1)	823/38898 (2)	911/38898 (2)	318/3166 (10)	665/3338 (20)
Indiana: Medicaid (7/1/15-6/30/16)	N/A	N/A	N/A	388/440 (88)	487/601 (81)
Michigan: Medicaid[b] (7/1/15-9/30/16)	N/A	N/A	N/A	513/907 (57)	509/1294 (39)
Ohio: Medicaid (10/15-12/15)	4688/155914 (3)	13676/155914 (9)	16336/155914 (10)	2081/2225 (94)	2326/2512 (93)

[a] Provider denominators were pulled as the pool of providers seeing pediatric, adult, and any SCD patients separately, which led to different denominators for each provider measure.
[b] Reference periods are overlapping, which may contribute to double counting.
N/A- data reported had a difference in measure definition or data quality issue

ILLINOIS

In Illinois, 2 percent of providers had seen at least one patient with SCD in the previous year, which was a similar proportion as the ones reported in other regions. However, only 20 percent of adult patients and 10 percent of pediatric patients had at least two outpatient visits in the previous year.

INDIANA

In Indiana, a very high percentage of providers was reported to have seen a patient with SCD. However, this is due to a difference of interpretation of the denominator by the state Medicaid office. The denominator was meant to be all providers that submitted a claim within the past year for the administrative dataset. For the Indiana data request, this measure was interpreted to be an examination of practices and standards of care ONLY among providers who have seen patients with SCD.

Using this definition, the proportion of providers who saw an adult or child with SCD was 56 percent and 52 percent respectively based on their definition of the denominator. The number of patients with outpatient visits was high in Indiana, with 88 percent of pediatric patients and 81 percent of adult patients receiving two or more visits in the past year.

MICHIGAN

In Michigan, the measures were derived differently than for other states. For the definition of the provider pool that determines the denominator for measures 1a-1c, were the providers who had submitted a Medicaid claim for a pediatric patient with SCD, an adult patient with SCD, or any SCD patient was used. The operational definition chosen as the definition for other states included all providers with any Medicaid claim in the system. The denominators for the patient level specifications for Michigan were correctly interpreted and reflect a denominator that is comparable to those used by other states in the region and throughout the initiative. In addition, for Michigan, the reference period used was 15 months, which includes the initial 3-month quarterly period plus a look back at the previous year as defined by the 12-month look back in the measure definition. As with Indiana, the outcome measured was actually different than the measure requested. Using the different definition, the Michigan sample shows that the proportion of providers who saw any patient with SCD two or more times was 32 percent for pediatric doctors and 41.5 percent for clinicians treating adults. Among pediatric patients, 57 percent were able to see a provider two or more times in the past year, while 39 percent of adults saw a provider for two or more outpatient visits.

Additionally, we received multiple time points for Michigan, as can be seen in the run charts in the Appendix, Section I showing additional analyses.

OHIO

In Ohio, a high proportion of providers accepting Medicaid (compared with other states and regions) had seen at least one patient with SCD. In addition, a high proportion of patients with SCD had two or more outpatient visits. Provider denominators were defined as any provider in the Ohio Medicaid system that had a claim in the measurement year. The numerators were extracted as providers who were in the denominator who had at least one patient with SCD for both adult and pediatric patients. In Ohio, nearly 10% of providers had contact with a patient with SCD and over 90 percent of patients had two or more outpatients visits within the past year.

Ohio was also able to provide additional data that allowed comparisons across time (Appendix, Section I). We would hope to see these numbers rise over time as efforts to increase provider engagement with patients with SCD improves the reach of available providers to patients with SCD. Similar to the provider measures (1a-1c), the measures related to patients receiving two or more outpatient visits (1d and 1e) would hopefully increase. Interpretation of Ohio data should be considered within the context that there is variation in who is considered a provider in Ohio, and by the fact that patients are frequently reassigned to providers in Ohio.

ACROSS REGION

Data from the Midwest provides a snapshot of SCD care in the region for the period September 2015 through September 2016. The data in some areas is inconsistent and should be interpreted cautiously due to different interpretation of measure specifications. Nonetheless, the data reveals several very important findings for the region. While many clinicians may be practicing in areas without many affected patients, the data highlights a substantial potential to expand the capacity, which could improve access to patients and distribute the effort of caring for this needy population. Secondly, we observed considerable variation in the proportion of patients who had two or more outpatient visits in the previous year. Two visits of any kind are a very liberal measure of "continuity of care" and as such sets a relatively low bar for evaluation. In Table 9, a range of 20 percent to 93 percent of adult patients met this measure. Outpatient visits are essential to ensure that SCD patients receive optimal care that includes preventive and therapeutic services. Inadequate or inconsistent outpatient care places SCD patients at increased risk for ER and inpatient care. While our data does not allow additional analysis of whether preventive and therapeutic services were received, it can serve to help target populations in need of additional services and guide regional QI activities.

NORTHEAST REGIONAL COORDINATING CENTER: SINERGE

The Northeast RCC, also known as SiNERGe, includes 10 states, districts, and territories: Delaware, District of Columbia (Washington, D.C.), Maryland, New Jersey, New York, Pennsylvania, Puerto Rico, US Virgin Islands, Virginia, and West Virginia.

Based out of Johns Hopkins Medicine in Baltimore, Maryland, SiNERGe brings the state teams together annually to celebrate accomplishments, share progress and learn from each other. SiNERGe was a pioneer in both the use of the Project ECHO® telementoring model and building partnerships with CBOs, developing community health supports for patients with SCD where they live so that they can coordinate their care and manage their day-to-day living with SCD. Both of these strategies have increased SiNERGe's ability to support patient access to quality care (Aim 1) and to build provider capacity and knowledge to meet the needs of patients with SCD (Aim 3).

Johns Hopkins Sickle Cell Disease ECHO®

The Johns Hopkins Sickle Cell Disease ECHO® provides access to SCD quality care for patients by spreading knowledge, learning, and sharing best practices for treating SCD across the Northeast RCC state partners. Of the three SCDTDP Project ECHO® clinics (in the Midwest, Pacific, and Northeast regions), this was the first to be established. The program launched in September 2015 and meets on a weekly basis. In order to meet the greatest regional need for access to care, the clinic is focused on adult care. Each session includes two 30-minute case presentations as well as 10-15 minutes of didactic material that covers core components of SCD care. CMEs are offered to attendees.

As of July 2017, the Johns Hopkins Sickle Cell Disease ECHO® has provided over 90 hours of training and reached 135 providers. Nearly half of participants (47%) have attended more than one session, and of those participants who have joined more than once, the average number of sessions that they have attended is over 11. Each session includes a survey for session-specific feedback. A separate pre-evaluation is sent to participants after his or her first participation and a post-evaluation is then sent after six months of participation. To date, the ECHO® clinic staff have shared over 66 cases and 41 unique didactic SCD-specific topic presentations with PCPs, nurse practitioners, nurses, pharmacists, hospitalists, pediatricians, social workers, ED physicians, palliative care specialists, and hematologists. Interest in the Johns Hopkins Sickle Cell Disease ECHO® clinic continues to grow and, with it, greater access to care from knowledgeable providers for patients with SCD and their families.

Community Partnerships

Partnering with CBOs as well as using CHWs and patient navigator programs are both hallmarks of the Northeast RCC's efforts to improve patient access to care by including community stakeholders in the collaborative and initiatives. Although CHWs are not always formally considered members of medical care teams, they play influential roles in the healthcare delivery system helping to connect patients and families to healthcare for treating SCD. Of the 10 states/territories/districts in the Northeast collaborative, five state partners have a CHW program (Deleware, Maryland, New Jersey, Pennsylvania, and Virginia) and the District of Columbia Center for Sickle Cell Disease at Howard University utilizes family and patient advocates. The CHWs' scope of work within each program varies from HU educator to more in-depth patient support that includes home visits. Just as the function of these CHWs in the SCD team varies, so do their case-loads based on the intensity of supportive services they provide. Just these CHW programs alone have served over 450 individuals living with SCD in this region.

In Maryland, a partnership between The Johns Hopkins Urban Health Institution Community Health Worker program and SiNERGe has trained and supervised CHWs to empower patients, improve access to SCD and other healthcare services, and generally help improve SCD outcomes. In this model, CHWs are under the direct supervision of lead physicians and serve as community-based extenders of the medical team. CHWs serve as cultural brokers, community advocates, communication facilitators, health educators, motivational speakers, and SCD management coaches for caregivers, family members, and individuals with SCD. CHWs also help to clarify provider instructions and improve patient adherence to prescribed treatments. The program began under the Maryland Regional Improving Health Outcomes and Medical Education for Sickle Cell Disease (iHOMES) Network and has expanded its reach under the current project.

In addition to CHW programs, SiNERGe has sought to forge a strong alliance with local and regional CBOs that are advancing SCD initiatives. The William E. Proudford Sickle Cell Fund, Inc. (WEP) serves as the regional CBO coordinator. The RCC has encouraged state and local partners to work together with CBOs in the northeast. WEP has provided support to CBOs in the region by facilitating bi-monthly calls and offering small grants. Twenty-three CBOs have worked side by side with partner healthcare organizations to host a multitude of educational, support, and awareness events. In addition to fostering relationships and supporting events, WEP has also coordinated a bi-monthly webinar series with special topics in SCD care that is open to the public.

Using Patient Navigation in SCD Care

In Virginia, a patient navigator program called SHiP HU (Start Healing in Patients with HU) aims to improve access to SCD specialty care. This program is designed to serve and increase the number of adult patients, defined in the program as age 15 and older, receiving SCD specialty care in the Richmond and Tidewater regions of Virginia. The Virginia Commonwealth University (VCU) Department of Internal Medicine developed a curriculum for SHiP HU to train patient navigators. This included a 4-day training on SCD, HU, the Health Belief Model, and Motivational Interviewing techniques. In addition to this initial training, the curriculum also included experiential training in SCD clinics, site visits, and 12-month motivational interviewing follow-up and team building.

IMPROVING ACCESS:

5 state partners in the Northeast, developed successful community health worker (CHW) programs. Through these programs, CHWs have served over 450 individuals living with SCD.

Data Collection Efforts

In the Northeast region, data were not available for all states due to cost or inability of the Medicaid partner to manage the technical complexity of the request. Some states, such as New Jersey, were able to provide data for multiple time periods allowing for comparison of trends across time, while Delaware, Puerto Rico, and the Virgin Islands were unable to provide any data at all for the data request. Please see Table 10 for the reasons why data could not be submitted for these states. During the project period, the Northeast region was able to gather administrative data from the Maryland Medicaid office, and MCO data from the District of Columbia and New Jersey. Two other states, New York and Virginia, have data requests that are still being processed and may be able to provide data at a later date. A summary of the data status of each jurisdiction is provided in Table 10.

For the Northeast region, data were available for different, but in some cases overlapping, time periods as shown in Table 11. The darker the shade of blue, the more data received from state Medicaid or MCOs in that time period.

TABLE 14:

Northeast Region Data Received for Aim 1[a]: Access to Care Measures

STATE	DATA RECEIVED
Delaware	Data Not Submitted *cost prohibitive ($30k)*
District of Columbia	• AmeriHealth Managed Care Organizations • Trusted Managed Care Organization • HSCSN Managed Care Organization
Maryland	Medicaid
New Jersey	Horizon Managed Care Organization
New York	Data Not Submitted *in process*
Pennsylvania	Data Not Submitted *no contact person*
Puerto Rico	Data Not Submitted *no funding; red tape*
U.S. Virgin Islands	Data Not Submitted *no contact person*
Virginia MCO	Data Suppressed *low numbers and differences in measure definitions*
West Virginia	Data Not Submitted *small numbers*

[a]Virginia MCO data was received but suppressed due to low numbers and differences in measure definitions.

TABLE 15:

Time Periods Covered for Northeast Data Received

STATE DATA SOURCE	2014				2015				2016 [10]			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
District of Columbia: AmeriHealth												
District of Columbia: Trusted												
District of Columbia: HSCSN												
Maryland												
New Jersey												

Measurement Summaries

Table 12 provides summaries of how data was pulled in the Northeast region and examples of how data elements were defined and interpreted at the state level. As previously stated, the varying data interpretations allowed us to see how different interpretations of data impacted the ways the data can be used to understand the state of care for SCD patients.

TABLE 16:

Northeast Region Aim 1 (Access to Care) Measures

PLAN (REFERENCE PERIOD)	MEASURE DATA (NUMERATOR/DENOMINATOR (%))				
	1a. Providers seeing pediatric SCD patients	**1b.** Providers seeing adult SCD patients	**1c.** Providers seeing any SCD patients	**1d.** Pediatric SCD patient outpatient visits	**1e.** Adult SCD patient outpatient visits
District of Columbia: AmeriHealth[a] (July 2015)	N/A	N/A	N/A	65/84 (77)	68/105 (65)
District of Columbia: Trusted[a] (July 2015)	N/A	N/A	N/A	18/28 (64)	17/24 (71)
District of Columbia: HSCSN[a] (9/1/2014-8/31/2015)	N/A	19/3404 (1)	43/3404 (1)	57/68 (84)	24/38 (63)
Maryland: Medicaid (2/1/2015-1/31/2016)	183/48881 (<1)	248/48881 NA	396/48881 (1)	482/925 (52)	450/1070 (42)
New Jersey: Horizon[b] (Jan 2016-Mar 2016)	N/A	N/A	N/A	56/196 (29)	71/160 (44)

[a]Provider denominator is of providers who see SCD patients, and then the numerator is of those providers, how many have seen an SCD patient 2 or more times in the past 12 months.
[b]Provider denominators were pulled as the pool of providers seeing pediatric, adult, and any SCD patients separately, which led to different denominators for each provider measure.
N/A data reported had a difference in measure definition or data quality issue.

DISTRICT OF COLUMBIA

Both AmeriHealth and Trusted used a definition for provider measures that did not align with other data sources in the region. Among the 453 providers in the DC AmeriHealth network, a much higher percentage of providers was seeing patients with SCD one or more times compared to other states. Almost a third of providers seeing pediatrics patients and 44 percent of those seeing adult patients reported seeing patients with SCD two or more times in the past year. However, more than two-thirds of the patient population had claims for two or more outpatient visits in a calendar year.

Another MCO that serves the DC area is Trusted. For this MCO, in the third quarter of 2015, 76 percent of their 17 providers were submitting claims for patients with SCD two or more times in a year. The number of providers seeing adult SCD patients two or more times in a year (47%) was less than the number of providers seeing pediatric patients with SCD in that time (70%).

Although serving similar geographic areas, Trusted is smaller in size compared with the other MCOs submitting data, with only 52 enrolled patients with SCD. Among these patients, the majority was seen for outpatient visits two or more times within the past year. However, at 64 percent for pediatric patients and 71 percent for adult patients, there is room for improvement to ensure continuity of care for patients with SCD in this network.

The third MCO that provided data on care for patients with SCD in the DC area was Health Services for Children with Special Needs (HSCSN). This network was the largest of the participating MCOs that submitted data for the DC area with more than 3400 providers. Among these providers, only one percent of providers were seeing patients with SCD two or more times in a given year.

Among the 106 patients with SCD in this MCO, 57 of the 68 pediatric patients (84%) were seen two or more times for an outpatient visit within the past year. A smaller number of adult patients with SCD, 24 out of the 38 (63%), were seen at least twice for an outpatient visit.

MARYLAND

In Maryland, there were 48,881 providers. Among those providers, fewer than one percent were seeing either pediatric (0.4%) or adult (0.5%) patients with SCD two or more times in the past year. But among the almost two thousand patients with SCD in Maryland who had submitted a Medicaid claim in the past year, 52 percent of pediatric patients and 42 percent of adult patients had a documented claim for two or more outpatient visits in the past year.

NEW JERSEY

In New Jersey, data were available for the Horizon MCO. This MCO has 71 providers that see pediatric patients with SCD. Among these providers, about a third are seeing patients with SCD two or more times within a year. Among the 137 providers seeing adult patients with SCD, 40 percent are seeing patients with SCD two or more times in a year. Among the total provider population seeing patients with SCD, 40 percent are seeing patients two or more times. These numbers are similar to other MCO data that are looking at a limited provider pool of those already seeing patients with SCD, and looking at values of seeing their patients with SCD more than once in a calendar year. This data suggests there are still opportunities in practice sites to ensure appropriate follow-up care among providers treating patients with SCD.

In the Horizon MCO network, they treated 356 adult and pediatric patients with SCD. Among these patients, less than a third of pediatric patients (29%) and less than half of adult patients (44%) had been seen for two or more outpatient visits in the past year. Given the complexities of managing SCD care, these low values suggest an area where additional inquiry could be fruitful to explore and ensure that patients are receiving the care they need.

As is shown in Table 12, 30-40 percent of providers are seeing their patients with SCD two or more times in the past year. Provider measures were not included in the above table because these measures are taken from providers treating patients with SCD, and should not be compared to measures that are using the entire population of providers as their denominator.

PACIFIC REGIONAL COORDINATING CENTER: PSCRC

The Pacific Sickle Cell Regional Collaborative (PSCRC) is comprised of SCD partners representing the eight states of Alaska, Arizona, California, Hawaii, Idaho, Nevada, Oregon and Washington and the territory of Guam. The PSCRC is co-managed by The Center for Comprehensive Care and Diagnosis of Inherited Blood Disorders (CIBD) and USCF Benioff Children's Hospital Oakland (BCHO). CIBD brings experience as the HRSA grantee for the Western States Regional Hemophilia Network while BCHO brings long-standing expertise in SCD care and research to the collaborative. Both have been CDC awardees for blood disorders surveillance. Both have also worked in close partnership with the Sickle Cell Disease Foundation of California (SCDFC), the oldest SCD CBO in the U.S. In fact, the SCDFC served at the highest leadership levels of the PSCRC, lending patient-centered input into project planning and implementation.

The PSCRC encompasses roughly one-third of the continental U.S. land mass and its population is one of the most diverse in the nation. Over-arching barriers to accessing adequate healthcare for patients with SCD throughout this region include workforce shortages and economic disparities. However, the PSCRC is also characterized by varying geographies, widely different healthcare system structures across the region, and unique challenges associated with diversities of language and culture for families of Hispanic ethnicity and pockets of recent immigrants from Africa and the Middle East. The PSCRC leadership at CIBD and BCHO therefore worked closely with each of the state leads, utilizing the CI framework to develop a regional approach to tackling the complexities of improving access to knowledgeable SCD care, while simultaneously fostering approaches to increasing access tailored for each state. The PSCRC brought together SCD experts, patients and family members, PCPs, SCD CBOs, government partners, healthcare professional organizations, institutions of higher learning, and public health departments in the service of this aim.

The PSCRC leadership and state partners initially convened monthly with conference calls and gathered annually in person at Strategic Planning Meetings. These annual gatherings helped forge the regional network through professional networking and skill building in Transcranial Doppler screening, QI, and transition from pediatric to adult care among other topics. The PSCRC leadership and state partners used these meetings to prioritize initiatives to address key regional strengths and gaps, and allowed sharing of best practices for improving access to SCD care for patients and families. Key regional strategies included outreach and recruitment efforts to engage pediatric and adult physicians, building a government partners work group with HHS Region IX and X representatives, and providing input into emerging state Medicaid policies. Initiatives in California and Nevada highlight tailored strategies for those two states that nevertheless have implications for other urban areas targeting larger concentrations of patients with SCD.

Increasing Access to Care for Children with SCD: Children's Specialty Center of Nevada

Prior to 2016, there was no comprehensive pediatric SCD center in Nevada providing coordinated medical and social services to children with SCD and their families. This is despite the fact that 85 babies with SCD were identified in Nevada between 2010 and 2015 through the state's newborn screening program. The Children's Specialty Center of Nevada (CSCN), which treats roughly 200 patients with SCD annually, saw a need to increase access to care for these children and their families. The PSCRC leadership provided technical assistance, including a site visit to the state lead for Nevada at CSCN and other staff members. The CSCN SCD program medical director also visited the comprehensive SCD center at BCHO and maintains close contact with BCHO staff as she implements evidence-based preventive and acute SCD care. The CSCN works closely with CIBD, drawing on their long collaboration as a hemophilia treatment center, and with the SCDFC, who provided mentoring to the CHWs. In 2016, CSCN began providing patients with access to a multidisciplinary team, with added core team members (e.g., social worker, data manager/clinical research associate and others).[19] CSCN is now able to foster more integrated and coordinated SCD care and surveillance, including offering psychological assessments and school consultations. Information and resources are provided to parents and families to support their functioning as informed and effective caregivers. Despite significant outreach efforts, no local physicians have stepped forward to build an adult SCD program, so many patients in their twenties are forced to remain in CSCN's pediatric specialty care, mirroring severe regional and national gaps in adult SCD care.

Increasing Access to Care for Adults with SCD: Martin Luther King, Jr. Clinic in Los Angeles

The SCDFC and CIBD partnered to build a new collaboration with the Los Angeles County Department of Health Services (LADHS), leading to the creation of an Adult Sickle Cell Clinic at the Martin Luther King, Jr. Outpatient Center in South Los Angeles, which opened in August 2016. Los Angeles has the highest concentration of adult patients with SCD in the state[20] and the lowest life expectancy for adults with SCD under 40 years of age.[21] The new clinic is located next to a subway stop and within five miles of the largest concentration of Los Angeles residents with SCD age 15-45, thereby reducing transportation barriers. The clinic closes a significant care gap created when Los Angeles' prior safety net adult SCD treatment center closed several years ago, cutting this community off from therapeutic advances and preventive care that build life expectancy. The sustainability of the new clinic is enhanced by its position as part of the larger LADHS healthcare delivery system of hospitals and clinics.

PSCRC leadership initially reached out to the medical director of the LADHS with a problem statement and request for assistance for the over one thousand adults with SCD in the MLK, Jr. Outpatient Center catchment area in September 2015. PSCRC leadership met with the deputy director of the LADHS, who indicated that a focus on SCD would align with the MLK, Jr. Outpatient Center mission to develop Advanced Practice Medical Homes for individuals with complex medical disorders. The PSCRC leadership next met with the Chief Medical Officer of the MLK, Jr. Outpatient Center, Dr. Ellen Rothman, and established a formal communication strategy that included biweekly teleconferencing focused on planning for staffing, training, and public relations for the new clinic. Another PSCRC partner, the California Rare Disease Surveillance program, provided data about the patient population, and the PSCRC provided funding for ongoing data management. The PSCRC underwrites the services of a social worker for the clinic and the SCDFC provides staffing in the form of CHWs and a nurse educator.

Lessons learned in establishing a new clinic include the importance of gaining approval at the highest levels of decision-making, in this case at the LADHS. Following up on existing connections is important e.g., the CIBD hematologist had had previous contact with the LADHS deputy director. PSCRC team members took the time to research the interests of the leaders whom they approached in order to pose win/win scenarios, e.g., how solving the gaps in SCD care fit in with interests in e-consults and other strategies to reduce health disparities of interest to the LADHS. The input of the community (SCDFC) was critical to the early success in generating interest in the project. Participating PSCRC team members anticipated that they would have only brief meetings with busy administrators, so they presented tightly crafted problem statements and left detailed materials for review after meetings.

Clinically, the inclusion of a PCP co-managing patients with the hematologist (physically together in the exam room), CHWs, and a nurse educator has been critical to streamlining patient care, linking patients to resources in their community, and providing education about disease management. It is also important that the clinic operates within a closed system with a common electronic health record system. The clinic includes on-site mental health services and complementary pain management therapies, including acupuncture and yoga. Careful attention to public relations messaging about the clinic has been important to gaining the trust of the community. For example, promotion flyers were in English and Spanish; webinars and Grand Rounds were conducted to educate the local pediatric hematologists and pediatric SCD teams; and the SCDFC provided a unique telephone number that was answered by SCDFC staff, where prospective patients could call to get information about the clinic. The Adult Sickle Cell Clinic at the MLK, Jr. Outpatient Center is a 2017 Brilliance Award Recipient from the National Association of Counties, in the category of Health.[22]

Increasing Access to Care for Adults with SCD: University of California Davis Medical Center

PSCRC partners at the UC Davis Cancer Center in Northern California follow approximately 230 pediatric and adult patients with SCD. They identified that there were 180 encounters for vaso-occlusive episodes in their emergency department (ED) for adults with SCD in 2015. The average time to first IV opioid was 5.2 hours (the NHLBI guidelines recommend 30 minutes as the appropriate time to first opioid), average length of stay in the ED was almost 13 hours, and 68 percent of presenting adults were admitted. The UC Davis team initiated a project to transfer care from the ED to the outpatient setting for uncomplicated vaso-occlusive episodes with a goal of improving patients' experiences. They established therapeutic relationships between high utilizers of ED/inpatient care and a nurse navigator and implemented protocols to improve standards of care for vaso-occlusive episodes in the ED as well as the infusion unit. Results in 2016 showed that time to first opioid in the infusion unit was 45 minutes, average length of stay was 6.5 hours, only 7 percent of patients needed to be admitted, and patient overall satisfaction was 80 percent (the highest rating). The PSCRC lead at UC Davis prepared a business case for sustaining acute care in the infusion unit that was accepted by the institution as a best practice.

CBO Impact in the PSCRC (California)

The Sickle Cell Disease Foundation of California (SCDFC) was a full partner in the PSCRC from the initial design and implementation of the collaborative and remains a valuable asset to the successful work within the region. The SCDFC has been the community voice of the leadership team of the PSCRC and has participated in driving efforts to address the barriers to quality healthcare access for the patient, family and community. Through the combined efforts of the PSCRC team, the collaborative has been successful at leveraging key stakeholder partnerships on multiple levels within the federal, state and local community. Key areas of notable interest include the collection of more than 30 years of data on individuals with SCD and their families and their integral role in the design of the Sickle Cell Adult Clinic at MLK, Jr. Outpatient Center for Los Angeles and San Bernardino counties. The data collection efforts included identifying the names and contact information of providers in California, many of who were unknown to the SCD community prior to implementation of the PSCRC Collaborative. SCDFC provides a nurse advisor, healthcare navigator, and a CHW as a part of the clinical care team.

Since it's opening in August 2016, many of the patients finally have access to care after not seeing a PCP or specialist for several years. The main source of treatment for these individuals had been the use of the ED as a source of primary care. The SCDFC is the first point of contact for many of the new patients that are seen at the MLK, Jr. clinic. CHWs and healthcare navigators provide support through ensuring a complete intake assessment, and smooth clinic visits that include transportation arrangements, insurance pre-authorizations, follow-up treatment and appointment scheduling. and CHWs also assist adolescents and young adults with transition from pediatric to adult care, training patients on self-care, and patient advocacy and communication with providers to prevent loss of care during this vitally important phase. The nurse advisor provides pre-assessments before each patient sees the PCP in order to make recommendations for treatment changes or to highlight key areas of concerns. PCPs then utilize these recommendations during their one-on-one visits with patients. Because many of the individuals seen at the clinic have not had primary or specialist care for many years before initial contact with the clinic team, special notes are made to assess patient vaccination compliance and medication management and maintenance.

Other PSCRC sites, including CSCN and BCHO, employed CHWs to empower patients and increase access to SCD and other healthcare services to improve SCD outcomes. The CHWs in Oakland support families in two of the most challenging areas in Northern California — maintaining insurance and obtaining mental health services. Their newest CHW received her certification through the SCDAA and serves as a community advocate, health educator, and health coach. The SCD program at UC Davis Health utilizes a nurse navigator to assist patients who have high ED utilization in transferring that care to the outpatient setting for uncomplicated vaso-occlusive episodes with a goal of improving patients' experiences.

Project ECHO®

The Pacific region is one of three SCDTDP regions to adapt Project ECHO®, the innovative distance learning and telementoring program coming out of the University of New Mexico. As this report describes, each region implemented their ECHO® project clinics in ways best suited for their needs. Outreach and recruitment of providers proved to be a challenge across all regions, and each team addressed this in different ways.

Additional Activities to Increase Access to Care – Healthcare Professionals

The PSCRC took a multi-pronged approach to improving access to care. This approach included outreach to healthcare professionals such as the Los Angeles and Bay Area Chapters of the National Medical Association, which promotes the collective interests of physicians and patients of African descent; and the Los Angeles, Orange County (California), and Arizona chapters of the National Association of Hispanic Nurses (NAHN). PSCRC leadership and state leads also

participated in the African Immigrant Health conference sponsored by the HHS Office of Minority Health. PSCRC mobilized and educated local, state and regional government partners both to widen their reach and to provide input into policies and programs that might be leveraged to reduce SCD care access disparities.

The purpose of PSCRC's healthcare workforce development initiatives was to improve access to knowledgeable SCD care by building a new cadre of healthcare professionals who are aware of SCD's prevalence, symptoms, and evidence-based treatments, and to encourage the next generation of physicians, nurses and nurse practitioners to devote their careers to SCD and related catastrophic genetic blood disorders. Sites of this education include the medical schools at the University of California San Francisco and Davis and the nursing program at Samuel Merritt University in Oakland, California. The PSCRC region-wide initiatives to educate practicing physicians focused on implementing Project ECHO® and state leads conducting grand rounds and mentoring junior faculty and fellows.

Our state clinical leads also conducted numerous educational seminars to build the workforce throughout their local communities. In 2016, PSCRC leadership were invited to be plenary speakers on SCD at the Northwest Regional and US Conferences on African Immigrant and Refugee Health, the American Public Health Association, the National Convention of the SCDAA, and the American Society of Hematology. In 2017, PSCRC leadership presented on SCD at the National Minority Quality Forum's Sickle Cell Satellite, the Foundation for Sickle Cell Disease Research, and at a local convention of the National Association of Hispanic Nurses (NAHN). The PSCRC leadership also presented national webinars on developing the Adult SCD Clinic at the MLK, Jr. Outpatient Center and Addressing Challenges to Optimal SCD Care within the Health Literate Care Model.

As Hispanics comprise greater than 43 percent of California's population, 29 percent of Arizona's and 28 percent of Nevada's, and Hispanics are at risk for SCD, the PSCRC initiated a partnership with NAHN. With NAHN-Los Angeles as chief partner, the PSCRC leadership educated NAHN-LA leaders and general membership, NAHN-Orange County (California) membership, and NAHN-AZ on SCD care and related topics. SCD was added as a priority education topic for NAHN-National's Office of Minority Health ACA Enrollment Grant, educating greater than 2000 residents of multi-cultural communities about SCD in English and Spanish using a low literacy slide set created by PSCRC and the SCDFC. The PSCRC-NAHN partnership was the focus of invited presentations a APHA (2016) and the NAHN Nation convention (2017).

To build a new cadre of next generation healthcare professionals who are aware of SCD and evidence-based treatment and interested in devoting a career to care of people living with SCD, the PSCRC initiated a pilot program with the Charles R. Drew University of Medicine and Science (CRDU), an Historically Black Graduate Institution. This pilot's purpose is to devise, implement and evaluate a new blood disorders curriculum for healthcare professionals, focusing on SCD, Thalassemia and Hemophilia. The pilot's first phase launched in CRDU's Mervyn M. Dymally School of Nursing in May 2017, reaching greater than 30 Family Nurse Practitioner students who will be in clinical practice in a year. Pre/post-test evaluations document that students perceived their knowledge increased 100 percent in the areas presented. CRDU is located on the campus of the MLK, Jr. Outpatient Center, opening opportunities for practicum placements at the new Adult SCD Clinic.

IMPROVING ACCESS:

The PSCRC increased the number of providers engaged in direct sickle cell care by 14%, with 77 providers in the region now serving patients with SCD.

To reduce language barriers to disseminating HU information, the PSCRC collaborated with the Heartland RCC to create educational brochures at appropriate levels of health literacy, one for adults and one for pediatric patients. These were translated into Spanish and French and disseminated nationwide. PSCRC staff successfully sparked the CDC's willingness to translate CDC SCT and SCD factsheets into French to broaden access to this information among African immigrant communities. These are on the CDC's website and were used by community agencies as well as healthcare providers to connect families and individuals with SCD to local centers of excellence.

Additional Activities to Increase Access to Care – Government Partners

The PSCRC invited HHS Region IX and X government partners into the collaborative to further extend the reach of education about the healthcare needs for SCD populations, and to rapidly gain access to information about new opportunities to leverage policies and programs to reduce SCD access disparities. PSCRC convened three annual Government Partners meetings from 2015 to 2017. Attending Region IX and X leaders included the Regional HHS Administrators, Chief Medical Officers of CMS, HRSA Directors, and officials from the Bureau of Healthcare Workforce, Offices of Minority Health, Women's Health, Pacific Health, Home Visiting, and Maternal and Adolescent Health. Federal officials from HRSA in DC, the CDC in Atlanta and NICHQ joined, as well as California State Health Department Directors from Maternal and Adolescent Health and the Black Infant Health Program. During these meetings, the PSCRC team educated officials about the needs of the region's SCD populations, gained input on their strategies, demonstrated progress, and obtained key contacts that led to a partnership with NAHN and CRDU. An invited presentation at the CDC's Division of Blood Disorders in January 2017 was an opportunity for the PSCRC team to highlight their successful partnership model that bridges CBOs, SCD clinical experts, and public health organizations, and draws on their experience with hemophilia regionalization innovations. The government partners also brought to PSCRC's attention opportunities to provide public input into policy changes in the Medicaid, Public Hospital and Physician Payment Reform Programs. For example, PSCRC submitted comments that contributed to the California Medicaid Pharmacy Policy branch's decision to include adult immunizations as a covered Medicaid benefit. As adults with SCD are at higher risk for infections, this serves as a concrete example of the SCDTDP's influence in promoting access to critically needed care.

Data Collection and Measurement Efforts Related to Access to Care

In this section, we present data for Aim 1 measures 1a-1e. Due to the complexity and timing of data activities with each Medicaid partner, we were only able to obtain data for one time period during the project in most cases and these periods varied by partner. While the data does reveal important insight into the current levels of access and continuity, comparisons over time and between states and regions are limited due to these differences.

In the PSCRC, data collection was greatly enhanced by team leads' previous experience using Medicaid data for SCD outcomes while working on the NHLBI's Registry and Surveillance System for Hemoglobinopathies (RuSH) initiative.[23, 34] This state-based initiative included California as one of the sites working to identify and partner with data sources, including Medicaid offices. The relationship building during RuSH laid the groundwork for the spread of SCD measures from administrative data sources throughout the Pacific region.

TABLE 17:

Pacific Region Data Received for Aim 1: Access to Care Measures

STATE	DATA RECEIVED
Alaska	Fee for Service (FFS) only (no MCO in AK)
Arizona	Non-participating
California	MCO and FFS
Guam	Non-participating
Hawaii	Non-participating
Oregon	MCO and FFS combined
Idaho	Medicaid
Nevada	Medicaid
Washington	MCO and FFS

The first step for all regions was to contact the appropriate personnel in their states to identify the staff or personnel who could facilitate the data request for the administrative data sets. As described previously in Section 2, this was a time-consuming, and at times costly, process that varied from state to state. However, the Pacific was successful in moving data requests forward in all but two of the participating states. The participation by states for the administrative data collection effort was high for the Pacific, with 70 percent of the participating states providing some data (Table 13 for breakdown by state and data source).

The breakdown of the timing of data being pulled can be seen in Table 14. The color saturation in the table provides information on the number of state teams providing data for each of the quarters. The darker the shade of blue, the more of the data streams that included this time period as part of their data pull. While the initial data request was intended to capture rolling annual measures that would update quarterly, the cost and resources available only allowed for single time-point data draws from the state Medicaid offices in most states.

TABLE 18:

Time Periods Covered for Pacific Region Data Received

STATE DATA SOURCE	2013				2014				2015				2016			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Alaska																
California: MCO																
California: FFS																
Idaho: Medicaid																
Nevada: FFS																
Oregon: Medicaid																
Washington: MCO																
Washington: FFS																

For purposes of aggregate summary reports and to ensure that reported values were within one year of each other, we chose the most recent quarter between Q4-2014 and Q4-2015. Importantly, for several measures, the Medicaid partners interpreted some data definitions differently. These variations will be described in each of the state-level analyses and in the overviews of the descriptive tables and figures for the state-specific data highlighted on the following pages.

Measurement Summaries

Table 15 summarizes how data was pulled in the Pacific region and examples of how data elements were defined and interpreted at the state level. As previously stated, the varying data interpretations allowed us to see how different interpretations of data impacted the ways the data can be used to understand the state of care for SCD patients.

TABLE 19:

Pacific Region Aim 1 (Access to Care) Measures

PLAN (REFERENCE PERIOD)	MEASURE DATA (NUMERATOR/DENOMINATOR (%))[a]				
	1a. Providers seeing pediatric SCD patients	**1b.** Providers seeing adult SCD patients	**1c.** Providers seeing any SCD patients	**1d.** Pediatric SCD patient outpatient visits	**1e.** Adult SCD patient outpatient visits
Alaska (9/14-9/15)	+	5/2480 (<1)	8/2480 (<1)	+	+
California: MCO (9/14-9/15)	439/64859 (1)	804/64859 (1)	1172/64859 (2)	769/1176 (65)	709/1542 (46)
California: FFS (9/14-9/15)	N/A	N/A	N/A	160/297 (54)	188/677 (28)
Idaho: Medicaid (1/14-12/14)	13/7043 (<1)	11/7043 (<1)	24/7043 (<1)	7/12 (58)	+
Nevada: FFS (9/14-8/15)	N/A	N/A	N/A	79/98 (81)	139/200 (70)
Oregon: Medicaid (9/14-8/15)	83/8020 (1)	149/8020 (2)	218/8020 (3)	38/46 (83)	99/105 (94)
Washington: MCO (9/14-8/15)	56/5815 (1)	103/5815 (2)	136/5815 (2)	95/108 (88)	99/105 (94)
Washington: FFS (9/14-8/15)	26/3314 (1)	72/3314 (2)	92/3314 (3)	33/38 (87)	63/75 (84)

[a] For these sources, the operational definition of "provider" included non-clinical staff such as ambulance services and home healthcare.
N/A-Data reported had a difference in measure definition or data quality issue.
+ data suppressed due to low numbers (n<5).

ALASKA

The state of Alaska has a small population overall, and a small SCD population. There are few people living with SCD in the state and few providers caring for them. However, the proportion of pediatric patients being seen for outpatient visits during the measurement period are similar to proportions in Idaho and California (Alaska: 57%, Idaho: 58%, California: MCO & FFS average 59.5%).

CALIFORNIA

In California, fewer than two percent of providers from the MCO sample had seen any patient with SCD within the past year. Fewer than one percent had seen either a child or adult. However, as noted in the footnote on Table 15, the data includes a broad definition of provider.

While the number of providers treating patients with SCD was low, a substantial number of SCD patients (65.4% of children and 46% of adults) had at least two outpatient (non-emergency room) visits, a conservative and indirect measure of "continuity of care."

Data were not available to assess the number of providers seeing patients with SCD in the California FFS sample. However, the state was able to present information related to the number of outpatient visits among SCD patients. In the FFS sample, the proportion of patients with at least two outpatient visits in the previous year was substantially lower than for the MCO sample, especially for adults.

IDAHO

The state of Idaho has a much smaller SCD population overall and few providers caring for these patients. However, the proportion of providers to patients with SCD is similar to California's. The number of pediatric and adult patients being seen for outpatient visits during the measurement period are similar to California's numbers: Pediatric 58 percent, Adult 50 percent in Idaho and Pediatric 65 percent, Adult 46 percent in California MCO data.

OREGON

Oregon data was pulled for three time periods ending in August of 2014, 2015, and 2016. Due to an error in the way the provider denominator was originally pulled, the provider denominator from the 2014 data pull was used across all three data pulls. The assumption is that the number of providers submitting a claim would not change significantly from year to year. This analysis will focus on the most current data pull ending August 2016. For an example of how multiple time points can be used to show additional analysis, please refer to the Ohio run charts in the Appendix, Section I.

In Oregon, 3% of providers in the Medicaid sample had seen a patient with SCD in the previous 12 months. Additional analysis (not shown in Table 15.) showed a decrease in the number of providers that had seen at least one patient with SCD (2014, 3.3% vs. 2015, 2.7%), a finding that could represent natural year-to-year fluctuation in provider coverage of patients with SCD as patients move on and off Medicaid or move out of provider areas; or, this may reflect a true restriction in number of providers accepting patients with Medicaid or SCD.

Additional data looking at outpatient visits among pediatric and adult patients with SCD suggests a high level of coverage beyond inpatient visits, with 80-90 percent of patients having two or more office visits in a year. There also do not appear to be the same differences between pediatric and adult care seen within some other states. In Oregon, the proportion of both pediatric and adult patients having two or more office visits in a year was substantially higher than in California and Idaho, but was similar to Washington.

NEVADA

In Nevada, a surprisingly large proportion of providers had seen at least one patient with SCD (Pediatric: 4%, Adult: 14%); however, this may be an overestimate due to misinterpretation of the measure definition by Nevada Medicaid. The provider measures were found to be more than 2.5 standard deviations away from the mean, making the data an outlier. Because an explanation for the large proportions could not be obtained, the data was removed from the analysis. Data report creation is external of RCC site control and, although we believe this instance to be a simple over-reporting of SCD provider taxonomy, this question is difficult to rectify through third party work with Medicaid data centers. The proportion of patients with SCD who had at least two outpatient visits was similar to several other states for both children and adults (Pediatric 81%, Adult 70%).

Nevada submitted FFS data for their administrative data pull. Initially, a second MCO dataset was constructed by the Nevada Medicaid group, and communication did not indicate that FFS data was the only data included in the initial data. It was later found by researchers within the Pacific RCC that the FFS data is held separate from the MCO data. MCO data is reported by an external body that only contracts with Nevada Medicaid. Although a second dataset of MCO data was requested, it was not available in time for the preparation of this congressional report.

WASHINGTON

In Washington, 2 and 3 percent of MCO and FFS providers respectively had seen at least one patient with SCD in the previous 12 months. Overall, both FFS and MCO data for Washington showed a high proportion of SCD patients, both pediatric and adult, having two or more outpatient visits in the past year.

Interpretation of Measurement Data

Data from the PSCRC provides a limited snapshot of SCD care in the region for the period September 2014 through September 2015. While the data in some areas is inconsistent and should be interpreted cautiously due to differing interpretations of measure specifications, the data nonetheless reveals a number of very important findings for the Pacific Region. First, a relatively small number of available clinicians (i.e., those who accept public insurance for a high-risk population with a disproportionate number of patients with SCD) are actually seeing patients with SCD. While many clinicians may be practicing in areas without many affected patients, the data highlights a need to expand the proportion of providers available to patients with SCD within the region in order to improve access for patients and distribute the effort of caring for this needy population. Secondly, considerable variation in the proportion of patients who had two or more outpatient visits in the previous year was observed. Two visits of any kind is an extremely liberal measure of "continuity of care" and as such sets a relatively low bar for evaluation. In Table 15, a range of 23 percent to 94 percent of adult patients met this measure. Outpatient visits are essential to ensure that SCD patients receive optimal care, which includes anticipatory, preventive and therapeutic services. Inadequate or inconsistent outpatient care places patients with SCD at increased risk for poor outcomes and increased reliance on emergency and inpatient care. While our data does not allow additional analysis of whether preventive and therapeutic services were received, this data could serve to help target populations in need of additional services and help coordinate regional activities.

MINIMUM DATA SET ACCESS TO CARE MEASURES FOR PATIENTS WITH SCD

As was previously described in Section 2 of this report, in addition to the collection of administrative data through state Medicaid offices and MCOs, states were also engaged in a voluntary effort to develop a set of key measures within their region to track progress towards the aims of the project. This was the initial impetus for the development of the minimum data set (MDS), which refers to a set of measures created within local registries at the state level. The MDS efforts were, in part, in response to the extensive infrastructure and relationship building requirements that were necessary to develop the Medicaid data requests, which were compounded by additional requirements tied to the creation of the OMB package to allow for reporting of administrative data elements to the NCC. These requirements in combination created a substantial time lag in the collection and reporting of administrative data.

Creation of the MDS allowed state teams to continue to develop a common set of shared metrics and build the necessary infrastructure and data elements for a platform for continued data collection that would be consistently collected across states and regions. There was a high degree of participation in the MDS data collection effort in each of the RCCs. In the Heartland, all four states submitted MDS data: Iowa, Kansas, Missouri and Nebraska. In the Midwest Region, five states were able to submit MDS data: Illinois, Michigan, Ohio, Minnesota and Indiana. In the Northeast Region, eight states were able to submit MDS data: Delaware, District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Virginia and West Virginia. In the Pacific Region, seven states were ultimately able to submit MDS data: Alaska, Arizona, California, Idaho, Nevada, Oregon and Washington. However, the consistency of reporting by state, time period, and across measure did vary (Appendix, Section J).

The NCC supported each of the four RCCs in working with each of their states to identify data collection methods to inform the creation of a set of overarching metrics that would be consistently collected across the initiative.

Multiple working group calls over the course of several months were devoted to discussing and refining these measures, and ultimately a day-long meeting in December 2016 hosted by the Heartland Sickle Cell Disease Network in St. Louis, MO, was held to address remaining issues concerning data measure operationalization and standardization across region. These meetings were successful in the creation and development of a set of common measures focused on HU use (see Section 4 for more details). However, despite a substantial investment of energy and resources devoted to creation of a similar set of metrics for healthcare access and utilization, it was not possible to develop a single set of measures across all regions.

A common set of conceptual definitions was created and, where possible, a common metric was set for all regions. Where consistency was not possible, variations in data collection methods and differential ability to pull data elements from local EHR registries meant that the metrics for healthcare access and utilization were region-specific.

Despite variation in data collection across regions, most states within each region were able to create a pool of patients from their MDS data collection that covered some portion of the grant period. In reviewing the tables on healthcare utilization, information is included that highlights the time period for which patient data was collected, provides estimates of the percentage of patients accessing basic healthcare (seeing a PCP in past 24 months) along with detail on the percentage or average number of patients with SCD accessing emergency care (hospitalization, ED visits, etc.). To aggregate the data across states and regions, a cumulative average was used for regions that reported a snapshot of the data for each quarter. For other regions that reported the data on a rolling basis, the aggregate of the last reported quarter was used. Midwest data is a cross-sectional pull and is not dependent on previous quarter data pulls unlike the other three regions.

In Table 16 below, it can be seen that there was a great deal of variation across regions in the uptake of patients who had seen a PCP within past two years across the regions. The Heartland region had the highest percentage (>90%) of SCD patients who had seen a PCP for routine care. In both the Northeast and Pacific regions, children with SCD were much more likely to have seen a PCP within the past two years compared with adults in these regions (Northeast: 80% versus 60%, Pacific: 75% versus 52%). This is consistent with the experience of providers in the RCCs, and what the scientific literature would suggest[5], which is that it remains more difficult to provide consistent access to regular care for adult populations compared with pediatric populations. The Midwest was not able to report on this measure.

TABLE 20:

Percentage of SCD Patient Population seeing a PCP in the past 24 months[a]

MEASURE	HEARTLAND REGION[b]		NORTHEAST REGION[c]		PACIFIC REGION[d]	
	Children n= 281	Adults n= 99	Children n= 1669	Adults n= 3778	Children n=171	Adults n=155
% of SCD Patients Seeing a PCP	264 (94)	91 (92)	1340 (80)	2279 (60)	128 (75)	80 (52)

[a]Midwest data is not available for this measure. [b]Heartland data is for Q3 2016-Q2 2017. [c]Northeast data is for full calendar year 2015. [d]Pacific data is for Q1 2016-Q2 2017.

Access to Specialty Care

The section below outlines the usage of specialty care services, including inpatient (e.g., hospital admissions) and outpatient (e.g., day visits and ED visits) services. Each of the measures related to accessing specialty care shown below were unique to each region, but within each region there was consistency in ability to report across the states in the region.

HEARTLAND

In the Heartland, they were able to create a metric of outpatient hospital visit usage combining utilization of ED and day hospital visits (Table 17). This metric demonstrates the differential in hospital outpatient visits between children, who on average have less than one visit per calendar year, and adults, who average more than seven hospital visits in a year, emphasizing the increasing complexity of care needs for patients with SCD as they get older.

TABLE 21:

Average Number of ED/Day Hospital Visits for SCD Patient Population in the Past 12 Months for the Heartland

MEASURE	HEARTLAND REGION[a]	
	Children n= 295	Adults n= 90
SCD Patients with ED/Day Hospital Visits	183 (0.62)	692 (7.69)

[a]Heartland data is for Qt. 2 2016-Qt. 2 2017.

In Table 18, we can see that, like outpatient visits, children had less than one hospital admission in the past year in the Heartland, but adults with SCD had an average of two hospital admissions per year in the Heartland.

TABLE 22:

Average Number of Hospital Admissions for SCD Patient Population in the Past 12 Months for the Heartland

MEASURE	HEARTLAND REGION[a]	
SCD Patient Population	Children n= 296	Adults n= 91
SCD Patients with Hospital Admissions	152 (0.51)	184 (2.02)

[a]Heartland data is for Q2 2016-Q2 2017.

MIDWEST

In the Midwest, the number of outpatient ED visits is smaller than seen in the Heartland (Table 23). This is due in small part to the fact that the Midwest was able to separate out their ED visits from day hospital visits. However, even with this distinction, the average number of visits remains smaller for the Midwest. Additionally, this data is also consistent with other tables showing that children make less use of specialty care, with an average of 0.12 visits to the ED in a given year compared with 0.23 visits per year for adults. For the Midwest, ED visits were the most common form of specialty care accessed among those for which data was provided.

TABLE 23:

Average Number of ED Visits for SCD Patient Population in the Past 12 Months for the Midwest

MEASURE	MIDWEST REGION[a]	
SCD Patient Population	Children n= 368	Adults n= 68
SCD Patients with ED Visits	31 (0.08)	37 (0.54)

[a]Midwest data is for Q2 2017.

Table 24 shows once again the outpatient hospital visit usage for adult populations was higher than for pediatric patients.

TABLE 24:

Average Number of Day Hospital Visits for SCD Patient Population in the Past 12 Months for the Midwest

MEASURE	MIDWEST REGION[a]	
SCD Patient Population	Children n= 368	Adults n= 68
SCD Patients with Day Hospital Visits	11 (0.03)	16 (0.24)

[a]Midwest data is for Q2 2017.

In Table 25, we once again see a trend of increasing healthcare utilization for adults, where hospital admissions for adult patients with SCD in the Midwest were almost double the number of hospital admissions for pediatric patients (0.16 versus 0.09). However, similar to the outpatient utilization, the average number of visits is lower overall in the Midwest region compared with the Heartland region.

TABLE 25:

Average Number of Hospital Admissions for SCD Patient Population in the Past 12 Months for the Midwest

MEASURE	MIDWEST REGION[a]	
SCD Patient Population	Children n= 368	Adults n= 68
Number of Hospital Admissions for SCD Patients	27 (0.07)	21 (0.31)

[a]Midwest data is for Q2 2017.

PACIFIC

In the Pacific region, the data for specialty care usage was collected as part of an intake survey. In this survey, patients reported on the frequency of use of specialty care and used a categorical metric to report on their usage with categories of 0, 1, 2, 3, or 4+ visits. While we don't have the overall number of specialty care visits for the highest category, this does allow us more detailed information on the percentage of patients who are not using any specialty care services within each category of specialty care (inpatient versus outpatient).

When looking at outpatient use of ED and day hospital visits (Table 26), it can be seen that pediatric populations are more likely to have had no visits within the past year (49%) compared with adult populations (30%). Additionally, at the highest level of usage (4+ visits), there is a reversal, with adult populations being twice as likely to have four or more specialty visits compared to pediatric populations (16% versus 37%).

TABLE 26:

Percentage of ED/Day Hospital Visits for SCD Patient Population in the Past 12 Months for the Pacific

MEASURE	PACIFIC REGION[a]	
SCD Patient Populations	Children n= 171	Adults n= 153
0 visits	83 (49)	46 (30)
1 visit	26 (15)	17 (11)
2 visits	19 (11)	13 (8)
3 visits	17 (10)	20 (13)
4+ visits	27 (16)	56 (37)

[a]Pacific data is for Q1 2016-Q2 2017.

The difference between pediatric and adult populations is less pronounced for hospital admissions in the Pacific region. For instance, as shown in Table 27, the pediatric population is more likely to have had zero admissions in the past year (56% versus 34%), but the differential is smaller. This also holds true for the highest category of 4+ admissions, where pediatric populations are only slightly less likely to have the highest possible value of admissions compared to adults (11% versus 24%).

TABLE 27:

Percentage of Hospital Admissions for SCD Patient Population in the Past 12 Months for the Pacific

MEASURE	PACIFIC REGION[a]	
SCD Patient Populations	Children n= 171	Adults n= 154
0 visits	95 (56)	53 (34)
1 visit	27 (16)	24 (16)
2 visits	19 (11)	23 (15)
3 visits	11 (6)	17 (11)
4+ visits	19 (11)	37 (24)

[a]Pacific data is from Q1 2016-Q2 2017.

Lessons Learned

This section describes activities and metrics related to the first aim for this project, which was to improve access to care in multiple US regions and to assess two key indicators of access on a population level. As described above, the regional teams successfully implemented telementoring processes in multiple states, and hosted a variety of activities to engage and educate clinicians with the goal of improving the number of clinicians available to see patients with SCD. In parallel, changes at the regional level were monitored using Medicaid data from state partners and data at the clinical level through the MDS.

Our experience has demonstrated three key findings.

- Innovative approaches to outreach and support providers (telemedicine, conferences, etc.) are feasible and effective.
- State and MCO level Medicaid partnerships can be used to deliver data and insight related to access to care measures for large numbers of patients at a regional level.
- Local registries and a common data structure and set of data elements and measures can be used to provide more detailed information on the effectiveness of the activities at a local level.

One of the challenging elements for many teams was identifying providers willing to treat patients with SCD. To address this issue, regions had to be creative in their recruitment efforts and found that there is potential to increase the number of providers who are contacted through the use of electronic media and social media (e.g., listings on the Heartland webpage). Experiences from recruitment efforts suggest that including nurses, nurse practitioners, and CHWs in the definition of providers expands the scope and reach of recruitment efforts in ways that are effective in increasing access to care for SCD patients. At many centers, for instance, hires are most likely to be nurse practitioners to assist with care, particularly for adult patients, and often the providers most amenable to recruitment efforts are trainees. Regions also found that one way to improve care for patients living in rural areas was through an increase in partnerships of co-managing with PCPs.

In terms of improving and innovating clinical care, regions gained the following insights from their collective experience:

- It is crucial to gain approval at highest level of decision-making in establishing new clinical programs.
- It is important to bring the voice of the community to discussions with policymakers and decision-makers early on or risk losing critical input.
- Common EHR systems greatly facilitate communication (but are unfortunately rare).
- Pediatric and adult systems vary greatly and there is a much larger gap in adult care.

Overall, the consensus remains that the opportunities and incentives to engage providers are very limited, requiring programs to be flexible, adaptive, and creative in thinking about their recruitment efforts to engage providers around SCD care and access to care.

Section 4: Increasing Use of Hydroxyurea

The NHLBI guidelines address two proven therapies for treating SCD: hydroxyurea (HU) and chronic blood transfusions.[10] Both therapies have been proven to prevent strokes and can have a positive impact on quality of life. HU has been shown to be effective in decreasing morbidity and healthcare utilization among children despite lack of Food and Drug Administration approval for pediatric use. However, many patients who are eligible for HU treatment do not receive it. Part of the explanation for this lag in adoption of approved therapies can be attributed to lack of provider knowledge.[3] To address this issue, the second aim of the SCDTDP grant was to increase the number of providers prescribing disease-modifying therapies, in particular HU.

This section will describe SCDTDP efforts related to promoting HU in each region and how this work was supported through the NCC. An array of provider education activities described throughout this report addressed the lack of provider knowledge and comfort related to prescribing HU. Representatives from all regions worked to spread knowledge through publications and presentations in various forums, including at conferences, in webinar series, and at additional CME events. Regions with Project ECHO® clinics (described in Sections 3 and 5) include the NHLBI guidelines and appropriate use of HU in their curriculum. Patient education materials and clinical decision-making tools were developed to support providers' capacity to prescribe HU. These tools are highlighted below and appear within the Compendium of Tools and Materials.

ROLE OF NCC TO SUPPORT PROVIDER ENGAGEMENT ACTIVITIES

As with the other project aims, the NCC facilitated collaboration across regions related to HU promotion efforts by providing regular opportunities for sharing progress on calls with other regions and state partners. The Provider Education workgroup included representatives from each region, who worked together to identify, catalog and compile tools and resources that were developed and used by grantees for increasing the appropriate use of HU. These included both patient education materials as well as tools to increase provider knowledge and uptake for prescribing HU.

The Data & Measurement workgroup refined and collected data, and measured the following quality outcomes related to increasing provider prescribing of HU.

- Number of providers in plan who prescribed HU to a child with SCD at least once during the past 12 months
- Number of providers in plan who prescribed HU to an adult with SCD at least once during the past 12 months
- Number of providers in plan who prescribed HU to any patient with SCD at least once during the past 12 months
- Number of children with SCD who filled a prescription for HU at least once during the past 12 months
- Number of adults with SCD who filled a prescription for HU at least once during the past 12 months

Operational Definitions

As previously mentioned, the goal of Aim 2 was to increase the number of providers prescribing HU. The measures were defined at a data summit in November 2014 and, based on recommendations from key faculty and content experts, a data dictionary was created with the definitions and specifications for the Aim 2 measures and sub-measures. The definitions for each of the Aim 2 measures can be found in the Table 24 below.

TABLE 8:

Aim 2 Operational Definitions

MEASURE	DENOMINATOR	NUMERATOR
2a. Number of providers in plan who prescribed HU to a child with SCD at least once during the past 12 months	Providers who submitted at least one claim to the plan during the 12-month period ending with the reference month	Providers from the denominator population who had a patient under 18 years old who have a diagnosis of SCD filled at least one HU prescription during the 12-month period ending with the reference month
2b. Number of providers in Plan who prescribed HU to an adult with SCD at least once during the past 12 months	Providers who submitted at least one claim to the plan during the 12-month period ending with the reference month	Providers from the denominator population who had a patient 18 years old or older, who have a diagnosis of SCD and filled at least one HU prescription during the 12-month period ending with the reference month
2c. Number of providers in Plan who prescribed HU at least once during the past 12 months	Providers who submitted at least one claim to the plan during the 12-month period ending with the reference month	Providers from the denominator population who had any patient with a diagnosis of SCD who filled at least one HU prescription during the 12-month period ending with the reference month
2d. Number of children with SCD who filled a prescription for HU at least once during the past 12 months	Patients less than 18 years old as of the end of the reference month who have ever had a diagnosis of SCD and had at least one health care event (any claim) during the 12-month period ending with the reference month	Patients from the denominator population who filled at least one HU prescription during the 12-month period ending with the reference month
2e. Number of adults with SCD who filled a prescription for HU at least once during the past 12 months	Patients 18 years of age or older as of the end of the reference month who have ever had a diagnosis of SCD and had at least one health care event (any claim) during the 12-month period ending with the reference month	Patients from the denominator population who filled at least one HU prescription during the 12-month period ending with the reference month

The RCCs submitted the data for these measures to the NCC based on data extracted from state Medicaid offices and/or MCOs within their region. The data submitted for each state is presented below by region, following the description of program efforts to increase prescriptions of HU.

Key Findings from the SCDTDP Regions

HEARTLAND REGIONAL COORDINATING CENTER

The Heartland Sickle Cell Disease Network has approached its activities to increase the use of disease-modifying therapies, specifically HU, by using data to identify variance in HU-use; creating and disseminating patient HU education and decision-making tools to help support HU uptake and adherence by patients; and creating tools and other opportunities for provider education. These included clinical decision support tools to provide support for both patient engagement and for providers in prescribing and monitoring SCD therapies for improved patient outcomes.

Data to Identify Patterns of HU Use and Areas for Improvement

The Heartland Sickle Cell Disease Network has set up a strong platform for data collection and analysis of its Medicaid administrative claims data. A recent analytic study, *Geographic Disparities among Hydroxyurea (HU) Medicaid Claims from 2013-2015 in Missouri*,[23] sought to determine the prevalence of HU prescriptions among Medicaid patients with SCD and to identify any disparities in how these prescriptions were distributed across the state.

The study found that the majority of patients with SCD reside in St. Louis and Kansas City, the largest urban areas of the state. There are also clusters of patients near Columbia, Missouri, and in the southeast corner of the state near Memphis, Tennessee. Geospatial analysis revealed that while many patients with SCD in Missouri did not receive any prescriptions for HU from 2013 to 2015, there were more prescriptions observed in urban areas than rural areas. Additionally, the total number of prescriptions for HU increased each year (by 8% from 2013 to 2014, and by 37% from 2014 to 2015). This study reveals the need for additional HU education for providers, particularly those working in areas of the state where SCD patients reside but HU prescription rates are low or non-existent.[27]

To better understand barriers to using HU, Heartland local and state partners worked together to lead focus groups with both SCD patients and providers. These findings were used in collaboration with the PSCRC and STORM teams to develop HU education materials for patients and families (Model Protocol and Compendium of Tools and Materials).

Spreading Awareness, Knowledge, and Best Practices for Prescribing HU

The Heartland worked to spread best practices and share specific protocols for the use of HU with physicians interested in treating patients with SCD. They also offered educational opportunities for providers already treating patients with SCD to help build their knowledge and capacity to manage and monitor HU use. In more rural areas, where patients have poorer access to specialists and subspecialty care, the team has implemented telemedicine practices as well as online webinars with local and state partners to help build provider experience and comfort with prescribing HU for their patients.

In 2017, the Heartland sponsored a special symposium and working meeting to both inform and strategize with pediatric and adult SCD care providers to increase use of HU with their eligible patients. This strategic planning was particularly important for the Heartland region due to the expansive area and the paucity of providers to treat SCD in both children and adults, especially in Iowa, Kansas, and Nebraska. The Heartland continued to meet annually with providers to provide training and best practices across the region on prescription and monitoring within the context of comprehensive care management for SCD.

Data Collection Efforts

The data in these data collection effort summaries for each region will focus on measures 2a-2e from the defined metrics for this project. These measures support Aim 2, to increase the number of providers prescribing HU. These measures look both at the number of providers who prescribed HU at least once in the past 12 months (2a-c) and the number

of patients with SCD who filled HU prescriptions at least once in the past year. As mentioned in Section 3, given the variation in the time period covered for data presented, it must be acknowledged that any comparisons made between states and regions will need to factor in the potential for bias based on the period for which data was available.

As previously mentioned, data collection efforts were uneven across states in the Heartland region. Only Kansas was able to provide Administrative Data as requested for inclusion in this report, and only for a single time period. Nebraska and Iowa were unable to provide any data for the SCDTDP data request. Missouri data was submitted, but the measures were defined differently than the SCDTDP request and are featured in the Appendix, Section I, Additional Data section as an example of an alternative way to use data for understanding access to care and HU use for people with SCD. The Heartland data requests stood out among the RCCs by having several data sources from MCOs and Medicaid offices outside of their states. The Centene MCO data included the states of Kansas and Missouri for multiple time periods. Illinois Department of Healthcare and Family Services also provided data for patients living in Iowa and Missouri near the border of Illinois and receiving SCD services in Illinois.

As mentioned in Section 3, this overlap in data is a normal part of collecting regional data. Regional structures often overlap with organizational structures of providers and payers. We present all data that is relevant to a region without consideration for the source of the initial data request. As stated previously, this type of overlap in data infrastructure was greatest between the Heartland and Midwest regions. Table 9 in Section 3 describes in detail all available data sources by state and specifies the source of the data request for data provided.

For the Heartland region, the timeline covered by the data submitted varied within and across states. While the period of 2014 was covered by both MCO and Medicaid data for Kansas, the MCO data continued through 2016. However, the data for the state Medicaid office for Kansas did not go beyond 2014. The data received from the Illinois Medicaid office for residents of Heartland states represented the most frequent period represented in that data extraction, which ran from the third quarter of 2015 through the second quarter of 2016. However, the numbers in this data set were small, so they were not represented in the descriptive state-level data presented in Table 10 in Section 3.

Measurement Summaries

Due to pending data requests and small numbers, the only data in Table 28 is for the Kansas Medicaid data extraction.

TABLE 28:

Heartland Region Aim 2 (Increase HU Prescription) Measures

PLAN (REFERENCE PERIOD)	MEASURE DATA (NUMERATOR/DENOMINATOR (%))				
	2a. Providers prescribing HU to pediatric SCD patients	**2b.** Providers prescribing HU to adult SCD patients	**2c.** Providers prescribing HU to any SCD patients	**2d.** Pediatric SCD patients filling HU prescriptions	**2e.** Adult SCD patients filling HU prescriptions
Kansas: Medicaid (Jan 2014-Dec 2014)	12/357 (3)	15/357 (4)	24/357 (7)	14/102 (14)	17/85 (20)

Kansas

The Kansas data was a combination of Medicaid and MCO data and the higher percentage of providers writing prescriptions for HU seem to reflect this combination of data streams (i.e., they combined MCO and Medicaid data). Based on values seen in other regions, MCO data has tended to reflect higher percentages than Medicaid data. Overall, 7 percent of providers within the state had a record of having written a prescription for HU in the past year; this was evenly distributed between pediatric (3%) and adult (4%) populations for whom they were providing care.

Among the pediatric measures, the percentage of pediatric patients with SCD that filled at least one HU prescription in the past year according to claims data was 14 percent, which was on the low side compared to other states. For example, in Illinois in the STORM region, the fraction of pediatric patients with SCD filling at least one HU prescription in the past year was 25 percent. The adult patients with SCD filling a prescription for HU was a little higher at 20 percent, but still was not as high as seen in some other states. For example, in Washington in the Pacific region, 40 percent of adult SCD patients filled at least one HU prescription in the past year. Looking at the variation in state level information, there is room for improvement everywhere in ensuring that all eligible patients have access to HU at a population level among Medicaid populations.

Illinois Department of Healthcare and Family Services

As stated previously, the Midwest region submitted Illinois Medicaid data that included two other Heartland states for patients receiving services in Illinois. The Aim 2 measures submitted do not include the patient measures, only provider data. However, the small numbers from these states (below threshold of n=5) do not allow for their inclusion in this report.

Centene Data

The Heartland region submitted Centene MCO data that included two states, Kansas and Missouri. Data measures from the Centene MCO data did not align with administrative data measure specifications. There was one measure, however, that closely aligned to the Aim 2 measure related to SCD patients filling a HU prescription. The measure is also broken out by patients 9 months to 18 years old and 18 years old and older. However, small numbers (below threshold of n=5) precluded incorporation into this report.

Interpretation of Measurement Data

The Heartland region's data was not considered for a cross-region analysis as the differences in reference period, measure definitions and interpretation of data elements were not conducive for further comparisons.

MIDWEST REGIONAL COORDINATING CENTER: STORM

The Sickle Cell Treatment Outcomes Results in the Midwest (STORM) collaborated with state partners on a range of strategies to increase the number of providers prescribing disease-modifying therapies, including HU. These activities included the development and dissemination of clinical decision support tools for prescribing and monitoring HU, shared decision-making tools for HU use and adherence, and other educational materials such as curriculum modules and protocols on HU-prescribing practices. STORM team members also held a variety of training sessions for providers to increase their knowledge and comfort level with prescribing HU, including the Project ECHO® telementoring clinic as a regular opportunity for teaching and sharing. Efforts to increase patient education and public awareness about how disease-modifying therapies like HU can improve quality of life and reduce hallmark symptoms of SCD were also an important part of increasing HU uptake.

STORM applied leveraged efforts to increase HU uptake state and national strategies that have been successful in other collaborative improvement networks focused on enhancing patient engagement in the use of therapeutics with chronic

illness. This involved supporting STORM sites to test best strategies for implementing HU shared decision-making tools and spreading best practices for assessing and monitoring HU use among patients in the region. STORM team members have participated in several meetings with other collaborative improvement networks to share insights and lessons learned about the network process across the three years of the grant.

Hydroxyurea (HU) Clinical Decision Support Tools

The STORM Education Workgroup received a grant from the University of Cincinnati Center for Clinical and Translational Science and Training (CCTST) to create a HU toolkit for healthcare providers (pediatric and adult, both primary care and specialists) that will include clinical decision support tools aligned with the NHLBI evidence-based guidelines for SCD treatment. This co-creation activity was a partnership with the Live Well Collaborative and integrated a design-thinking approach to co-create materials with design students, healthcare providers, and patient and family members. STORM state leads have been involved in the design of the tools, anticipated to launch by fall 2017.

Shared Decision-Making Tools for Hydroxyurea (HU)

The Cincinnati Children's Center for Education and Research in Therapeutics developed shared decision-making tools for prescribing HU, including videos for patients and families, through a federal Agency for Healthcare Research and Quality (AHRQ) grant. Five STORM sites were trained in administering the shared-decision making tools and have been testing the usefulness of these tools in clinics. Data on HU decision-making has been collected and included as part of broader patient level data collection.

Illinois: Quality Improvement for Urea Adherence In Kids With Sickle Cell Disease (QUAKS)

A major barrier to success in HU treatment of patients with SCD has been non-adherence. To address this issue, SCDTDP partners in Illinois developed a model of care to improve HU adherence among pediatric SCD patients, QUAKS. Between June and December 2016, several Plan-Do-Study-Act (PDSA)[28] cycles were conducted to help refine the care model. Data was collected on 25 patients to measure HU adherence using fetal hemoglobin percentage (Hb F %) and red blood cell mean corpuscular volume (RBC MCV) lab values; sharing the monthly lab values with patients and parents was one component of the model. A recently acquired clinic microscope allowed us to show them the patient's actual blood smear and the lack of sickle-shaped red blood cells in the HU-adherent patients as another component of the model. At baseline, 33 percent of patients were identified as adherent to the HU regimen through the lab values. After 6 months of implementing and adapting the new model of care, the percentage of HU-adherent patients had increased to 73 percent (the original goal was 75 percent by December 2017).

Another major component of this model was two monthly phone call reminders, one for HU pick-up at the pharmacy and one for completion of lab work. Originally, we called the pharmacies after calling the families. However, through several of PDSA cycles, we found a more positive effect on adherence when pharmacies were called to verify HU pick-up before the family reminder call as a means to corroborate the family call information. These reminder phone calls also provided an opportunity for additional information sharing between the medical caller and families on topics that included trouble-shooting a child's refusal to swallow liquid HU, annual flu shots, other medications, and appointment reminders. It was noted early on that the response of caretakers to new SCD clinic staff was significantly less interactive at first than after two to three months of continued phone contact. This demonstrated the need to establish a relationship with the family before they were comfortable sharing information, not only about HU, but also other issues related to SCD care. It is possible that this relationship building also had a positive influence on HU adherence.

Another intervention we believe positively influenced HU adherence is our development of a mechanism to ship compounded liquid HU to families in more rural parts of Illinois. Since no pharmacies outside of major urban areas will compound liquid HU in Illinois, it was very difficult for families in rural areas to obtain it for their young children. This solution may be beneficial in other states or regions where a similar HU compounding problem exists.

Indiana: Validating a Scale for HU Adherence

The Indiana Hemophilia and Thrombosis Center (IHTC) has been working to validate a scale to determine HU adherence levels and is currently in the final phase of this work. This tool will be helpful for providers to be able to track and improve HU adherence and overall SCD management. Patients will be asked to report their adherence to their HU prescription using a scale. As part of the validation process, some patients will also be asked to participate in a Medication Event Monitoring System (MEMS) that will track whether and how often patients are opening their medication bottle to take HU. It is anticipated that this validation process will be complete by the end of 2017.

HU Training for Providers

STORM partners organized a variety of training sessions for providers on disease-modifying therapies. This included presentations with professional societies, symposia, online curriculum modules, the dissemination of educational materials, and protocols on HU-prescribing practices. The Cincinnati Children's Hospital Project ECHO® clinic recruited and sustained many state partner participants and provides a regular opportunity to increase providers' capacity to manage patients on HU.

Data Collection Efforts

As previously stated, data collection efforts in the Midwest region varied between states. Some states, such as Illinois, provided data for multiple time periods, allowing for comparison of trends across time. Minnesota was unable to provide any data for the SCDTDP data request. Also, as mentioned in Section 3, the Midwest region stood out as having fewer data pull requests that required additional fees for the requests. It seemed that there was less reluctance by Medicaid offices to provide data for multiple time periods, which may reflect a greater degree of cultural acceptance for sharing of data and using administrative data for learning than in some other regions or states.

For some states within the Midwest region, additional MCO data was contributed not through an initial data request, but as part of additional data submitted from a separate region's data request. This overlap in data is part of the challenge in these types of national efforts where regional structures may overlap with the area of service for provider networks and payers.

As described for the Aim 1 measures, we have chosen to present all data that is relevant to a region without consideration for the source of the initial data request (although the source of the data request is provided). This type of overlap in data infrastructure was greatest between the Heartland and Midwest regions. Table 11 from Section 3 describes the data sources for the Midwest in greater detail.

As reflected in the descriptions provided for Aim 1 data, we also saw a great deal of variation for the Aim 2 measures in what data was extracted across states within the region. The data consistently covered periods of time within the grant timeline, however, the actual data submitted often varied depending on when requests went through and the length of time it took to process requests. The way that data draws were interpreted varied from state to state. More detail on timing of data extractions can be found in Table 12 in Section 3. When describing and interpreting the data presented in Tables 26 and 27 the time period being represented should be considered for interpreting the results.

Despite the variation in time periods represented, the overlap in timing of data described between the states in the Midwest is higher than for other states and regions. Several states were also able to repeat their data requests and provide the rolling quarterly data with a one-year calendar look back as originally requested. The rolling data has the potential to increase understanding of how these measures may vary across time.

Measurement Summaries

Below we describe the data results from the Midwest region based on the data extraction from each state's administrative files. Table 29 provides a summary of the common measures that are comparable across the states. For most states in the Midwest, the data extraction was consistent enough to allow for comparison. In addition, Table 27 combines data from Section 3 to display the number and percentage of providers who saw at least one patient with SCD two or more times during the measurement period and who also prescribed HU at least once. This measure estimates the proportion of providers who might be expected to prescribe HU who actually did. While some data was able to be used for this indicator, the numerator for this measure was higher than the denominator for Illinois, likely due to providers who did not see a patient with SCD in more than a single encounter prescribing HU.

TABLE 29:

Midwest Region Aim 2 (Increase HU Prescription) Measures

PLAN (REFERENCE PERIOD)	MEASURE DATA (NUMERATOR/DENOMINATOR (%))				
	2a. Providers prescribing HU to pediatric SCD patients	**2b.** Providers prescribing HU to adult SCD patients	**2c.** Providers prescribing HU to any SCD patients	**2d.** Pediatric SCD patients filling HU prescriptions	**2e.** Adult SCD patients filling HU prescriptions
Illinois: Medicaid (7/1/2015-6/30/2016)	1058/38898 (3)	4188/38898 (11)	4693/38898 (12)	207/3166 (7)	355/3338 (11)
Indiana: Medicaid[a] (7/1/2015-6/30/2016)	N/A	N/A	N/A	111/440 (25)	129/601 (21)
Michigan: Medicaid (7/1/2015-9/30/2016)	N/A	N/A	N/A	97/907 (11)	283/1294 (22)
Ohio: Medicaid (10/2015-12/2015)	34/609 (<1)	84/5206 (<1)	84/5206 (<1)	264/748 (35)	202/831 (24)

[a]Provider denominator is number of providers who saw SCD patients, and the numerator is the number of those providers who saw an SCD patient 2 or more times in the past 12 months.
N/A-Data reported had a difference in measure definition or data quality issue.

TABLE 30:

Proportion of Providers Who Saw SCD Patients Two or More Times in the Past 12 Months prescribing HU

PLAN (REFERENCE PERIOD)	COMBINED MEASURE DATA (MEASURE 2A/B/C NUMERATOR/ MEASURE 1A/B/C NUMERATOR (%))		
	# of providers who prescribed HU at least once to a patient with SCD under 18 /# of providers who saw one or more patients with SCD under 18	# of providers who prescribed HU at least once to a patient with SCD 18 or over/# of providers who saw one or more patients with SCD 18 or over	# of providers who prescribed HU at least once to any patient with SCD/# of providers who saw any patients with SCD
Illinois: Medicaid (7/1/2015-6/30/2016)	N/A	N/A	N/A
Ohio: Medicaid (10/2015-12/2015)	34/156 (2)	84/455 (2)	84/544 (2)

N/A-Data reported had a difference in measure definition or data quality issue.

ILLINOIS

In the Illinois Medicaid sample, a relatively high proportion of providers in the sample had prescribed HU; however, a smaller proportion of patients with SCD had filled a prescription for HU. Although we cannot know with certainty, it is likely that either there were errors in data processing or patients were not filling their HU prescriptions. Another possible explanation is that there may be multiple providers writing prescriptions for the same cohort of patients on HU. Either way, this data varies from what is seen in other states and deserves additional consideration of plausible explanations for the variation being seen.

INDIANA

While data was provided for the provider measures for Indiana, several errors were identified in the data resources and timing of the project precluded re-running the data. For these reasons, data is not provided for Measures 2a/b/c. Data were available for HU prescription filling in Indiana and showed that a relatively low percentage had filled a prescription in the past 12 months. In Indiana, only 25 percent of pediatric patients with SCD and 21 percent of adults with SCD had filled a prescription for HU in the previous 12 months.

MICHIGAN

The provider measures for Aim 2 were not submitted for the data extraction of Michigan Medicaid data. Data were available for HU prescription filling in Michigan, however, and also showed that a relatively low percentage had filled a prescription in the past 12 months. Only 11 percent of children with SCD and 22 percent of adults with SCD had filled a prescription for HU. Given the much higher rate of HU use in adults in several states, further investigation into barriers to filling prescriptions among pediatric populations is warranted.

OHIO

The values seen in Ohio differ from those of other states in the Midwest, but more closely align with results seen in other regions, such as the Pacific and the Northeast. This data shows that less than one percent of providers are prescribing HU to their patients in either adult or pediatric populations. Among those who care for patients with SCD, two percent had prescribed HU. Another possible explanation for the low percentage of providers prescribing HU is that there are several pediatric and adult SCD centers in the state of Ohio.

Overall, approximately a third of pediatric patients (35%) and a quarter of adult patients (24%) have filled a prescription for HU in the past year. As has been described previously, it is difficult to assess whether these values are lower than best practices would suggest, as the number of eligible candidates for HU within this population is not known. However, the fact that there are states that have reached a higher percentage than what is described here, and the differential between pediatric and adult patients within this state, suggests there are opportunities for improvement.

Interpretation of Measurement Data

Data from the Midwest STORM region provided insight into prescribing behaviors from both the provider and patient perspectives. While these numbers do not capture every person in the region, they do clearly show that there is substantial variation, both among the number of providers writing HU prescriptions and the number of people with SCD who are receiving HU. Furthermore, the rate of HU use is much lower overall than the expected prevalence of SCD would suggest. Thus, there is a need for continued work in this area.

While there isn't as much data around provider behaviors, what data is available suggests that adult providers are more likely to write prescriptions for HU for their patients with SCD. There also doesn't appear to be a great deal of variation between adult and pediatric patients filling these prescriptions. While there is variation in the rate of filling prescriptions between states, greater consistency in measurement definitions and timing of data collection would allow us to make better comparison between states and across regions.

NORTHEAST REGIONAL COORDINATING CENTER: SINERGE

In the Northeast region, there are approximately 32,000 individuals with SCD. At the start of this grant, most patients, many of whom are adults, had limited access to hematology or oncology specialists and too few received the opportunity for HU therapy. SiNERGe approached the aim to increase uptake of HU use for patients with SCD through two main objectives. One was to build collaborative networks with CBOs to identify and reach out to SCD patients in the community. The second was to develop electronic decision-making and clinical support tools to increase uptake of HU using evidence-based guidelines and clinical protocols.

Building a Network of CBOs

SiNERGe worked to engage a regional CBO network, led by the William E. Proudford Sickle Cell Fund, Inc., to support and coordinate outreach, awareness, and education among patients, providers, policymakers, insurers and other key stakeholders who support HU use as a promising and effective disease-modifying treatment for SCD. These CBOs reached out in the community to identify and engage patients with SCD, sharing messages about the use of HU. Members of this network also contributed to the development, testing and dissemination of the shared decision-making tool described below.

HU Initiation Shared Decision-Making Tool

The purpose of this web-based instrument, currently in the final stages of development, is to encourage education and shared decision-making between patients and providers in discussions. It is designed for patients and providers to use together to support conversations and decisions related to starting HU therapy as a treatment option. The development process for this tool had two phases: a content specification phase and a design phase. The content specification phase has been concluded; it began with a literature review of decision aids and was modeled after a tool used to support oncology treatment decisions by providing information about the risk and benefits of each treatment option. Stakeholder involvement throughout the development process is key to the success of the final product, increasing user buy-in and leading to greater user satisfaction and implementation. Therefore, stakeholders have been engaged throughout the process to provide input on the tool, including pediatric and adult hematologists, CHWs, research coordinators, PCPs, nurses, and people with SCD. There have been multiple opportunities for usability and field-testing in each phase as well as ongoing input from patients, healthcare providers and scientific experts. The tool is now in the design phase, getting a graphic design makeover to make the tool more user-friendly and attractive for end users prior to launch in the Fall of 2017.

Data Collection Efforts

In the Northeast region, data collection efforts for administrative data requests were uneven across states. For example, New Jersey provided data for multiple time points, while many states provided data for only a single time period, or were not able to access their Medicaid data at all (Table 13 in Section 3). The descriptive review provided here features the most recent time period for each state or territory represented. Delaware, Puerto Rico, and the Virgin Islands did not provide any data for the SCDTDP data request. As mentioned in Section 3, Virginia data was received, but data was suppressed due to low numbers and differences in measures definitions. New York and West Virginia have data requests that are still pending, but due to time constraints were not available by the time of the drafting of this report.

On average, the Northeast data requests required more resources than the efforts of other regions. Analytic requests for this region often required a higher commitment of funds and coordination. This reflects in part a greater number of barriers related to the sharing of data, including legal review and higher personnel costs, as well as more significant cultural reluctance for using limited organizational resources to extend their services to external projects when compared to the culture of data sharing across other regions or states.

However, these barriers have been changing with shifting expectations nationally. Increasing numbers of initiatives are using administrative data to track population health, including the continued development of quality metrics that directly tie into administrative data sources. As this national shift continues, we should continue to see a growing acceptance and commitment of additional resources, technical assistance, and funding for extending the role of administrative data usage among Northeast states to support programmatic learning.

Table 11 in Section 3 shows the time periods for data submission. While all data covers some portion of the grant period, there remains a great deal of variation. New Jersey provided data for multiple recipients, which ranged from 2014 through the beginning of 2016. The table below shows the data from the most recent time point submitted for Quarter 1 of 2016. The MCO data from the District of Columbia only covered a full year look back for all three MCOs. Maryland submitted Medicaid data with a full year look back, from Feburary 2015 through January 2016. The period with the greatest degree of coverage across data sources is quarter three of 2015. As with all data provided in this report, interpretation of descriptive tables should be informed by the period for which data is available and presented. In addition, because there were also multiple data streams available for the District of Columbia, there is a unique opportunity for comparison across payer groups in a single jurisdiction as seen in Table 28 below.

TABLE 31:

Northeast Region Aim 2 (Increase HU Prescription) Measures

PLAN (REFERENCE PERIOD)	MEASURE DATA (NUMERATOR/DENOMINATOR (%))				
	2a. Providers prescribing HU to pediatric SCD patients	**2b.** Providers prescribing HU to adult SCD patients	**2c.** Providers prescribing HU to any SCD patients	**2d.** Pediatric SCD patients filling HU prescriptions	**2e.** Adult SCD patients filling HU prescriptions
District of Columbia: AmeriHealth[a] (9/1/2014-8/31/2015)	N/A	N/A	N/A	12/84 (14)	16/105 (15)
District of Columbia: Trusted[a] (9/1/2014-8/31/2015)	N/A	N/A	N/A	5/28 (18)	6/24 (25)
District of Columbia: HSCSN[a] (9/1/2014-8/31/2015)	107/3404 (3)	205/3404 (6)	279/3404 (8)	26/68 (38)	19/38 (50)
Maryland: Medicaid (2/1/2015-1/31/2016)	131/48881 (0)	251/48881 (1)	344/48881 (1)	240/925 (26)	237/1070 (22)
New Jersey: Horizon[b] (Jan 2016-Mar 2016)	13/193 (6)	20/193 (10)	31/193 (16)	25/196 (13)	27/160 (17)

[a] Provider denominator is of providers who see SCD patients, and then the numerator is of those providers, how many have seen an SCD patient two or more times in the past 12 months.
[b] Provider denominators were pulled as the pool of providers seeing pediatric, adult, and any SCD patients separately which led to different denominators for each provider measure.
N/A-Data reported had a difference in measure definition or data quality issue.

Measurement Summaries

In the Table 28 above, the data from the states and jurisdictions participating in the administrative data collection effort are summarized. The Trusted provider measures in the District of Columbia were removed due to a varying definition of provider than was used by other participants in the other jurisdictions' data requests. For the other data elements presented, the measures came from a common set of definitions across the various administrative data elements.

In addition, Table 32 on the next page combines data from Section 3 to display the number and percentage of providers who saw at least one patient with SCD two or more times during the measurement period and who also prescribed HU at least once. This measure estimates the proportion of providers who might be expected to prescribe HU who actually did. Similar to the Midwest Region, some data was able to be used for this indicator; but for some, the numerator for this measure was higher than the denominator, likely due to providers who did not see a patient with SCD in more than a single encounter prescribing HU.

TABLE 32:

Proportion of Providers Prescribing HU Out of Those Seeing SCD Patients Two or More Times in the Past 12 Months

PLAN (REFERENCE PERIOD)	COMBINED MEASURE DATA (MEASURE 2A/B/C NUMERATOR/ MEASURE 1A/B/C NUMERATOR (%))		
	# of providers who prescribed HU at least once to a patient with SCD under 18 /# of providers who saw one or more patients with SCD under 18	# of providers who prescribed HU at least once to an adult with SCD/# of providers who saw one or more adults with SCD	# of providers who prescribed HU at least once to any patient with SCD/# of providers who saw any patients with SCD
District of Columbia: AmeriHealth[a] (9/1/2014-8/31/2015)	N/A	N/A	N/A
District of Columbia: Trusted[a] (9/1/2014-8/31/2015)	N/A	N/A	N/A
District of Columbia: HSCSN[a] (9/1/2014-8/31/2015)	N/A	N/A	N/A
Maryland: Medicaid (2/1/2015-1/31/2016)	131/183 (72)	N/A	344/396 (87)
New Jersey: Horizon[b] (Jan 2016-Mar 2016)	13/23 (57)	20/55 (36)	31/75 (41)

[a]Provider numerators are higher than provider denominators.
N/A-Data reported had a difference in measure definition or data quality issue.

DISTRICT OF COLUMBIA

For the AmeriHealth data, the denominators of the provider measures were analyzed differently than in the measures specifications. Instead of including all providers in the denominator, the counts were limited to those providers caring for patients with SCD. Results for this measure are therefore not included in Table 32 above. However, among the 453 providers seeing pediatric patients with SCD in the AmeriHealth system, approximately 3 percent had a record of writing a prescription for HU in the past year. For providers treating adult patients with SCD, 5 percent had a record of writing a prescription of HU in the past year. For the AmeriHealth provider pool, 7 percent of providers treating patients with SCD had a record of writing a prescription for HU in the past year. Within the patient population in AmeriHealth, the percentage of patients filling a prescription were on the low-to-average side, with 14 percent of pediatric patients and 15 percent of adult patients having filled a prescription in the past year.

The Trusted system had measure definitions consistent with that of AmeriHealth and was also not included as part of Table 32 above. In addition, Trusted had a much smaller pool of providers in the District of Columbia that were serving patients with SCD. Among their total populations of providers (n=17), just under a third (29%) had prescribed HU in

the past year. For their patient population, a higher percentage had filled a prescription for HU compared to AmeriHealth, with 18 percent for pediatric populations and 25 percent for adult populations.

The final source of MCO data was for HSCSN, whose denominator was in alignment with definitions for other data sources. For the provider measures, the rate of prescribing was higher than found in other Medicaid data streams, but more closely aligned to what was seen from other MCO data streams. For pediatric populations, three percent of providers had written a prescription for HU in the past year, with double that amount, or six percent, of adult providers having written a prescription. The overall percentage of providers writing a prescription for HU was eight percent. Among the patient population, there was a definitive advantage with the percentage of adult patients filling a prescription (50%) compared to pediatric populations (38%). The percentage of adult patients filling a prescription for HU was the highest seen across the administrative data sources and is worth further investigation to understand if there are contextual factors that explain this high rate of filling a HU prescription in the past year by their adult patient population.

MARYLAND

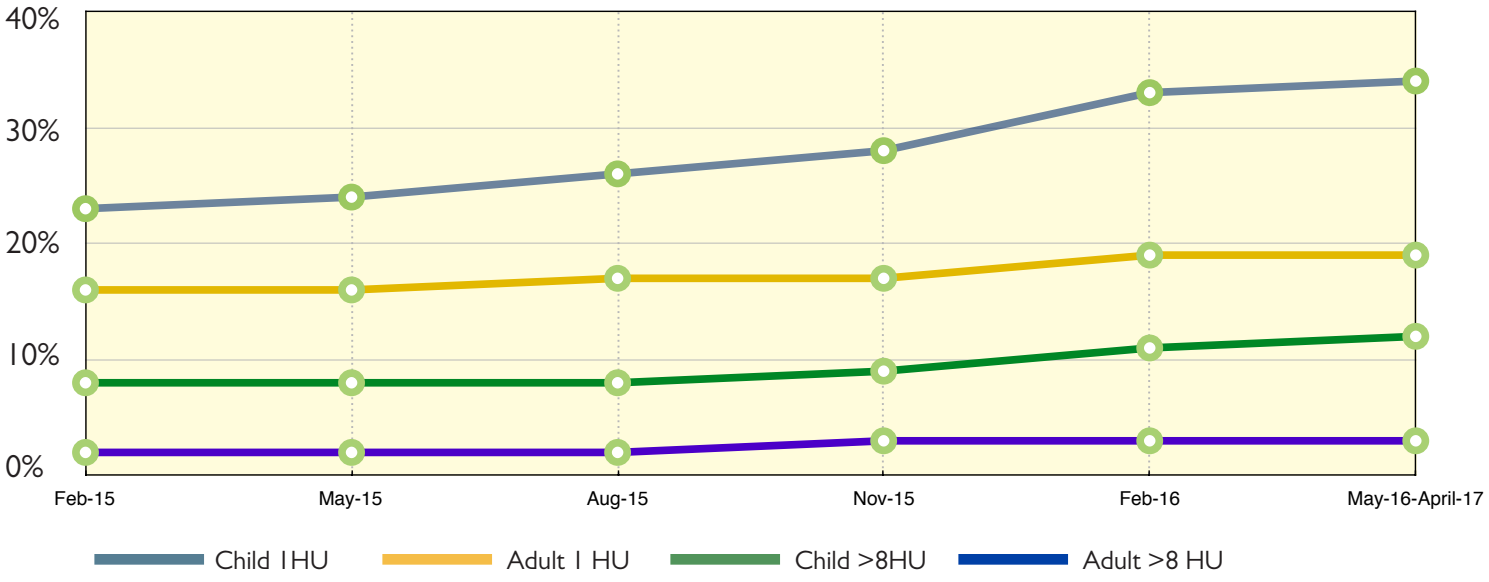
The Maryland Medicaid data showed that, as in many other states and regions, only one percent of providers had written a prescription for HU in the past year. While more providers working with adult populations (n=251) prescribed HU than those working with children (n=131), a similar proportion of patients had filled a prescription for HU for the two groups.

Overall, approximately one in four patients with SCD had filled a prescription within the past year. This percentage was slightly higher among the pediatric population (26%) as compared with the adult population (22%) and occurred at a similar rate to many other states in the region.

This chart shows data from a 12 month rolling period. Data shows patients with one or more HU prescription filled as well as those with 8 or more prescriptions filled, broken out by age.

FIGURE 3:

Increase in HU Use:
Maryland Medicaid included 1048 children and 1477 adults with SCD with claims 5/1/16-4/30/17



NEW JERSEY

In New Jersey, the rates of prescribing HU reported by the MCO were higher than for Medicaid provider data. Overall, 16 percent of providers had prescribed HU in the past year, with more of the adult providers (10%) prescribing HU compared with the pediatric providers (6%). However, only 13 percent of pediatric patients and 17 percent of adult patients had filled a prescription for HU in the past year.

INTERPRETATION OF MEASUREMENT DATA

As seen in the other regions, a very small number of providers are writing HU prescriptions in the Northeast. Further analysis is needed to know conclusively, but in several of the states, more MCO providers prescribed HU than in the larger Medicaid groups. In addition, it is likely that a large number of children and adults with SCD who are eligible for HU are not receiving this vital medication.

PACIFIC REGIONAL COORDINATING CENTER: PSCRC

The Pacific Sickle Cell Regional Collaborative (PSCRC) engaged in a range of ongoing efforts to increase the number of providers prescribing disease-modifying therapies, including HU. The SCDTDP clinicians closely reviewed the NHLBI guidelines and in Strategic Planning Meetings with other state leads, discussed how to refine the guidelines for clinical practice. Physical copies of the pocket guides for HU management developed by the American Society of Hematology were disseminated throughout the PSCRC and featured on PSCRC websites. This work informed additional efforts including provider trainings and a system to collect patient-level data about HU education and use via the MDS dataset and by direct queries to state leads. Tools were created to increase patient education on HU, and the effectiveness of the education was evaluted with pre-post surveys.

Quality Improvement & Data Collection Efforts to Increase Use of HU

In order to help patients with SCD manage their symptoms and improve their quality of life, the PSCRC worked with state leads across the region to engage in QI strategies for integrating HU assessment and prescription into their work. A driver diagram for increasing HU uptake and adherence was shared with clinical care teams to help them plan activities that aligned with the drivers. The NHLBI practice guidelines for SCD were distributed to each state partner and uploaded onto all SCDTDP grantee websites in the region. SCD care teams across all Pacific grantee states also received American Society of Hematology (ASH) pocket SCD treatment guides, which summarize the NHLBI SCD guidelines and protocols for HU use.

The PSCRC supported QI initiatives and collaborative learning within their region in a variety of ways over the course of this grant. These activities included webinars, in-person symposia, annual trainings, site visits with state partners, and the Project ECHO® telementoring knowledge transfer model. Each of these activities created opportunities to build provider capacity to treat patients with HU across state sites. Both primary and specialty care providers had opportunities for increasing knowledge by sharing their experiences with patient education on HU, decision-making tools, dosing protocols and medication management guidelines, among other topics.

To drive QI efforts, the PSCRC drafted an EHR template for tracking provision of education about HU, patient uptake of the medication, and related clinical and laboratory markers for the project. The PSCRC aims to have this form remain a part of EHR systems to support clinical decision-making and adherence tp guidelines.

Creation of Patient Education Materials About HU

Using patient surveys, the PSCRC identified gaps in knowledge and adult patient/parental concerns about HU as barriers to uptake of this treatment. Using this information, the PSCRC developed materials for adult patients and for parents of children with SCD to specifically address these issues. The materials were developed and tested with CBOs across the

SCDTDP regions. The final brochures were produced in English, Spanish, and French. Links to these materials are shared in the Model Protocol (Appendix, Section L) and Compendium of Tools and Materials, companion pieces of this report to Congress. The PSCRC also collaborated with the STORM region to evaluate the HU shared decision-making tools developed by the Cincinnati Children's Center for Education and Research in Therapeutics.

Support for Best Practices for Prescribing for HU

To facilitate sharing best practices related to managing SCD with HU, the PSCRC updated a series of presentations on HU and made them available for state partners to present to providers in their states. The PSCRC's ECHO® clinic was another forum for teaching best practices for SCD management to providers. The ECHO® curriculum includes didactic components as well as case studies that cover shared decision making with patients and clinical decision tools and protocols for prescribing HU. The Benioff Children's Hospital Oakland (BCHO) is implementing standardized documentation of provider-patient/family interactions about HU into their EHR system. The implementation of this standardized documentation is still in progress at this time.

Data Collection Efforts

In the Pacific region, data collection was enhanced by the previous experience of RCC team leads around using Medicaid data for SCD outcomes with the NHLBI's Registry and Surveillance System for Hemoglobinopathies (RuSH) initiative.[24, 25] This state-based initiative included California as one of the sites working to identify and partner with data sources, including Medicaid data. The relationship building and data infrastructure created during the RuSH initiative laid the groundwork, and understanding of SCD data was the foundation for the creation and spread of the SCDTDP measures defined and collected from administrative data sources throughout the Pacific region.

The Pacific Region ultimately successfully moved the administrative data requests forward in all participating states. In Arizona, the data was submitted but was not reported due to the size of the patient population. The participation by states for the administrative data collection effort was high for the Pacific with 70 percent of the participating states providing some data for the data request. See Table 17, Section 3, for a description of data submission by state and data source.

As was noted previously, there was considerable variation across the states in the time period for which data was pulled and submitted. However, the majority of states were able to pull data for the period between the third quarter of 2014 through the end of the second quarter of 2015. For the purposes of this report the data presented is based on the third quarter of 2015, as was done in Section 3.

Measurement Summaries

In the tables below are summaries of data provided from the Pacific Region, as well as state examples of how data was interpreted based on the data extraction from each state's administrative files. Table 33 presents data for the five core measures for this section by each state. In addition, Table 34 combines data from Section 3 to display the number and percentage of providers who saw at least one patient with SCD two or more times during the measurement period and who also prescribed HU at least once. This measure estimates the proportion of providers who might be expected to prescribe HU who actually did. For the Pacific region, this approximation could be useful as an additional source of information. However, in other regions, this indicator was not as useful, as the numerator for this value was higher than the denominator (likely due to providers who did not see a patient with SCD in more than a single encounter prescribing HU).

TABLE 33:

Pacific Region Aim 2 (Increase HU Prescription) Measures

PLAN (REFERENCE PERIOD)	MEASURE DATA (NUMERATOR/ DENOMINATOR (%))				
	2a. Providers prescribing HU to pediatric SCD patients	**2b.** Providers prescribing HU to adult SCD patients	**2c.** Providers prescribing HU to any SCD patients	**2d.** Pediatric SCD patients filling HU prescriptions	**2e.** Adult SCD patients filling HU prescriptions
California: MCO (9/14-9/15)	110/64859 (<1)	390/64859 (1)	455/64859 (1)	187/1176 (16)	277/1542 (18)
California: FFS (9/14-9/15)	N/A	N/A	N/A	42/297 (14)	91/677 (13)
Idaho: Medicaid (1/14-12/14)	+	123/8020 (2)	+	+	+
Nevada: FFS (9/14-8/15)	N/A	N/A	N/A	33/98 (34)	58/200 (29)
Oregon: Medicaid (9/14-8/15)	58/8020 (1)	123/8020 (2)	17/8020 (2)	20/46 (43)	16/43 (37)
Washington: MCO (9/14-8/15)	36/5815 (1)	67/5815 (1)	91/5815 (2)	39/108 (40)	42/105 (40)
Washington: FFS (9/14-8/15)	16/3314 (1)	43/3314 (1)	55/3314 (2)	13/38 (34)	22/75 (29)

[a] For these sources, the operational definition of "provider" included non-clinical staff such as ambulance services and home healthcare.
N/A-Data reported had a difference in measure definition or data quality issue.
+ -Data suppressed due to low numbers (n<5).

TABLE 34:

Proportion of Providers Prescribing HU Out of Those Seeing SCD Patients Two or More Times in the Past 12 Months

PLAN (REFERENCE PERIOD)	COMBINED MEASURE DATA (MEASURE 2A/B/C NUMERATOR/ MEASURE 1A/B/C NUMERATOR (%))		
	# of providers who prescribed HU at least once to a patient with SCD under 18 /# of providers who saw one or more patients with SCD under 18	# of providers who prescribed HU at least once to an adult with SCD/# of providers who saw one or more adults with SCD	# of providers who prescribed HU at least once to any patient with SCD/# of providers who saw any patients with SCD
California: MCO (9/14-9/15)	110/430 (25)	390/804 (48)	455/1172 (39)
California: FFS (9/14-9/15)	N/A	N/A	N/A
Idaho: Medicaid (1/14-12/14)	N/A	N/A	N/A
Nevada: FFS (9/14-8/15)	N/A	N/A	N/A
Oregon: Medicaid (9/14-8/15)	58/83 (70)	123/149 (83)	17/8020 (2)
Washington: MCO (9/14-8/15)	36/56 (64)	67/103 (65)	91/136 (67)
Washington: FFS (9/14-8/15)	16/26 (62)	43/72 (60)	55/92 (60)

N/A -data reported had a difference in measure definition or data quality issue.

CALIFORNIA

For California, provider data was only received from the California MCO data holders for measures 2a thru 2c. There were a small number of providers prescribing HU. This information is consistent with the small proportion of clinicians who saw patients with SCD reported in Aim1. However, when the denominator of patients seen with SCD is used (1d and 1e), a substantially higher and perhaps more appropriate rate is seen. In addition, a slightly higher number of providers prescribed HU to adult patients (1%) compared with those treating pediatric patients (<1%). Overall, approximately one percent of all providers wrote a prescription for HU in the past year, and among those who care for patients with SCD in a continuing capacity, 39 percent prescribed HU.

Approximately 15 percent of the pediatric population filled a prescription for HU within the past year (14% for FFS and 16% for MCO). Similarly, between 13 percent (FFS) and 18 percent (MCO) of adult patients filled a prescription for HU within the past year. Although not all patients with SCD are eligible for HU, this number is substantially lower than the expected rates based on the prevalence of SCT and rate of filling prescriptions seen in the MDS tables (Tables 35 and 36). In addition, among providers who saw patients with SCD, children were substantially less likely to be prescribed HU than adults (Table 34).

IDAHO

The low patient population does not allow for further description of the data extracted from the Idaho administrative data.

NEVADA

Similar to the state description of administrative data for Aim 1, the provider metrics for Nevada are not shown. The provider measures were found to be more than 2.5 standard deviations away from the mean, making the data outliers. As no explanation for the substantial deviation could be found, the data was removed from the descriptive tables above.

The number of patients with SCD filling a prescription for HU is more aligned with values found in other states in the region. Among pediatric patients, slightly more than a third (or 34%) report having filled a prescription for HU within the past year. That percentage is slightly lower for adult populations, where 29 percent report filling a HU prescription within the past year. These values are on par with the percentage of patients filling prescriptions for HU in Washington, but lower than the percentages seen in Oregon.

OREGON

As was previously described in Section 3, the denominator for Oregon is a forecasted estimate based on the assumption that the number of providers submitting a claim remained relatively constant across the period under consideration.

The number of providers prescribing HU in Oregon was similar to other states in the region. Overall, 2 percent of providers wrote prescriptions for HU within the past year, with more providers prescribing HU for adult patients (2%) compared with pediatric patients (1%). However, among regular providers who care for people with SCD, 78 percent had prescribed HU.

In Oregon, 20 of 46 pediatric patients (43%) with SCD had filled a prescription within the year. A smaller percentage of adult patients, 37 percent, had filled a prescription within the year.

WASHINGTON

In Washington, the percentage of providers writing a prescription for HU was similar to other states in the region. Overall, Washington Medicaid data showed two percent of providers had written a prescription for HU in the past year with an equal distribution of one percent each for pediatric and adult providers. These values mirror those seen in other states in the region. For providers seeing patients with SCD, an average of 61 percent had prescribed HU to these patients.

Among pediatric patients in Washington, more than a third of patients from each data source had filled a prescription for HU within the past year (34% FFS and 40% MCO). For the FFS data, the number of adults filling a prescription for HU was lower than in some places at 29 percent, while the percentage of adult MCO patients with SCD filling a prescription was the highest at 40 percent compared with other states in the region. To see additional HU Use data from the Pacific states please see Appendix, Section J.

Interpretation of Measurement Data

Across the PSCRC region, a similar percentage of providers was found to be writing prescriptions for HU, both within Medicaid providers in a state (MCO vs. FFS) and between states. However, considerable variation was seen for the proportion of providers who see SCD patients prescribing HU and for patients who actually received a prescription for HU. These findings clearly support an opportunity to improve the delivery of HU to SCD patients.

The percentage of patients filling a prescription for HU was found to be consistent, with between 30 and 40 percent of patients with SCD filling a prescription within the past year. Ideally, however, an estimated 70-80 percent of these patients should be prescribed HU — again underscoring the opportunity to improve this outcome in future projects.

MINIMUM DATA SET MEASURES RELATED TO HYDROXYUREA (HU) USE

The Minimum Data Set (MDS) activity was a voluntary effort of the RCCs to collect a common set of core measures related to how people with SCD are utilizing healthcare and their access to treatments like HU. Using local health registries and surveys, this data allowed for a more granular assessment of quality measures using data collected from clinical settings. The MDS measures are, in essence, local SCD registries where patient level data is collected and stored locally and aggregate data (summary data in the form of numerator/denominator and percentage) are shared centrally to the NCC. Participation in this data collection was a voluntary effort by RCCs, as these data elements were not part of the set of standardized administrative measures submitted as part of the OMB package. Despite this fact, the participation in the RCCs was quite high.

Heartland Iowa | Kansas | Missouri | Nebraska

Midwest Illinois | Indiana | Michigan | Minnesota | Ohio

Northeast Delaware | District of Columbia | Maryland | New Jersey | New York | Pennsylvania | Virginia | West Virginia

Pacific Alaska | Arizona | California | Idaho | Nevada | Oregon | Washington

The four RCCs worked collaboratively with the NCC over the course of several months to identify a number of common data elements that could be collected consistently across the states in each region and across the regions. After several rounds of discussion and revisions, a set of key measures was identified that focused on HU use (prescription filling behavior, reasons for not being on HU, and SCD genotype), as well as a set of measures focused on healthcare access and utilization (see Section 3 for more details). As previously mentioned in Section 3, the data was aggregated across states and regions using a cumulative average for regions that reported a snapshot of the data for each quarter. Additionally, for data that was reported on a rolling basis, an aggregate of the last reported quarter was used.

Data collection varied across the region, but most states were able to create a pool of patients from their MDS collection that covered the grant period. The tables below (Tables 35–37) indicate both the period for which patient data was pulled (in order to inform interpretation of the tables), provide estimates of the percentage of patients filling a prescription for HU in the past year, and show a profile of the SCD genotypes in each region. The genotype of people with SCD is important to understanding prescribing behavior for HU, as eligibility for HU depends on knowing the form of SCD that a patient has.

Those with HbSS, or Sickle Cell Anemia (SCA), who received a copy of the sickle cell gene from each parent, often have the most severe form of the disease. Patients may also receive a sickle cell gene from a parent with a beta thalassemia "0" gene, HbS-β^0 thalassemia, another form of anemia; they are also more likely to have a more severe form of SCA. The strength of the evidence for the use of HU for treatment and management of symptoms is highest for those people with SCA.[30] People with both the sickle cell gene and an abnormal "C" hemoglobin (HbSC) or the sickle cell gene and a gene for beta thalassemia + (HbS-β^0 +thal), are more likely to have milder forms of SCD, and the evidence for the use of HU is not as strong. There are also other rarer forms of SCD (HbSD, HbSE, HbSO), however, the prevalence of these is low.[31]

In Table 33, the population of people with SCD filling a prescription for HU ranges from a low of 42 percent (child) and 52 percent (adult) in the Northeast, to a high of 74 percent (child) and 79 percent (adult) in the Midwest region. The largest gap in the uptake of HU use between child and adult populations was in the Pacific, where 78 percent of children had filled a prescription for HU in the past year compared with only 63 percent of adults. It is encouraging that in most regions more than half of the population of those living with SCD (both pediatric and adult) were receiving HU given that the majority (ranging from 65 percent in the Heartland to 83 percent in the Pacific) of people with SCD in these regions have the more severe forms of SCA (HbSS and HbS-ß^0 thalassemia genotype).

TABLE 35:

Percentage of SCD Patient Population Prescribed HU in the Past 12 months

# OF PATIENTS PRESCRIBED HU (%)								
MEASURE	**HEARTLAND[a]**		**MIDWEST[b]**		**NORTHEAST[c]**		**PACIFIC[d]**	
SCD Population	Children n= 191	Adults n= 65	Children n= 192	Adults n= 36	Children n= 1669	Adults n= 3778	Children n= 492	Adults n= 197
# of Patients Prescribed HU (%)	116 (61)	38 (58)	147 (77)	23 (64)	702 (42)	1951 (52)	373 (76)	114 (58)

[a]Heartland data is Q2 2016-Q2 2017. [b]Midwest data is Q2 2017. [c]Northeast data is full calendar year 2015. [d]Pacific data is from Q1 2016-Q2 2017.

Most regions were able to collect information on the distribution of genotypes for the population of those with SCD in their region. As was stated previously, the majority of the population of those living with SCD has the most severe forms of SCA. However, in some regions (Heartland and Midwest and the pediatric population in the Northeast), between a fifth and a quarter of the population with SCD have the milder form of HbSC. In Table 36, the distribution of the patient population with SCD is described by genotype for each region for both adult and pediatric populations. The difference between the patient populations shown in Tables 35 and 36 is due to differences in states' ability to collect data across the measures for the MDS within a region. The Appendix, Section J describes the data collection by states within a region and the time period and measures for which they were able to collect data.

TABLE 36:
SCD Patient Population Distribution of SCD Genotypes

# OF PATIENTS WITH GENOTYPE (%)								
MEASURE	**HEARTLAND[a]**		**MIDWEST[b]**		**NORTHEAST[c]**		**PACIFIC[d]**	
	Children n= 302	Adults n= 104	Children n= 1789	Adults n= 383	Children n= 1669	Adults n= 3778	Children n=173	Adults n=155
HbSS	178 (59)	60 (58)	1292 (72)	239 (62)	1067 (64)	2572 (68)	131 (76)	114 (74)
HbSC	82 (27)	26 (25)	397 (22)	75 (20)	399 (24)	338 (9)	17 (10)	26 (17)
HbS-B+ Thal	18 (6)	7 (7)	42 (2)	42 (10)	108 (6)	217 (6)	9 (5)	8 (5)
HbSB⁰ Thal	17 (6)	7 (7)	29 (2)	27 (7)	43 (3)	196 (5)	15 (9)	6 (4)
Other	7 (2)	+	30 (2)	+	6 (0)	5 (0)	+	+

[a] Heartland data is from Q2 2016-Q2 2017. [b] Midwest data is Q2 2017. [c] Northeast data is for full calendar year 2015. [d] Pacific data is from Q1 2016-Q2 2017.
+-Data suppressed due to small numbers (n<5).

It was also of interest to each of the regions to gain a sense of the reasons why patients were not on HU. Because of the potential toxicity and the differing levels of evidence for the use of HU (dependent on the specific eligibility of a patient with SCD), the decision to use or not use HU should be a shared decision between families and providers.[9] Tracking the reasons for patients not being on HU may give some insight into whether patients are refusing HU, whether they are ineligible, or if states have sufficient information to understand the reasons for declining HU. For example, for the child population living with SCD in the Midwest, it is clear that the vast majority (100%) of patients are declining HU. Additionally, the Heartland population of children with SCD had a much higher number of children with SCD not on HU due to medical exclusion (73%) compared with the percentages seen for other age groups and for other regions.

TABLE 37:

Percent of Reasons SCD Patients Gave for Not Using HU

# OF PATIENTS GIVING REASON (%)					
MEASURE	**HEARTLAND[a]**		**MIDWEST[b]**	**PACIFIC[c]**	
SCD Population	Children n= 77	Adults n= 34	Children n=15	Children n= 160	Adults n= 91
Declined	16 (21)	8 (24)	15 (100)	45 (28)	29 (32)
Medical Exclusion	56 (73)	13 (38)	+	+	26 (29)
Other	+	+	+	11 (7)	6 (7)

[a] Heartland data is Q2-2016 - Q2-2017. [b] Midwest data is Q2-2017. [c] Northeast data is full calendar year 2015. [d] Pacific data is from Q1-2016 - Q2-2017.
[+-] Data suppressed due to small numbers (n<5).

All SCDTDP Regions Report Increases in HU Use

HEARTLAND:

- Among children, increased from 12% to 20%
- Among adults, increased from 14% to 17%

MIDWEST:

- Among all patients (pediatric & adult), increased from 48% to 69%
- Nearly 100% of all eligible patients now offered HU

NORTHEAST:

- Among children, increased from 23% to 34%
- Among adults, increased from 16% to 18%

PACIFIC:

- Among all patients, increased from 29% to 42%

Lessons Learned

As described above, the regional teams successfully implemented telementoring processes in multiple states and hosted a variety of activities to engage and educate clinicians with the goal of increasing the number of clinicians prescribing HU to patients with SCD.

While we had hoped to use the data from our Medicaid partners to regularly monitor progress during the project, ultimately, we were only able to capture cross-sectional views of quality at one time point per region. Nonetheless, we were able to assess these measures for a very large number of providers and patients. Approximately 336,698 providers and 21,791 patients are represented in the denominator populations for Aim 2 Measures. The activities within each region had many positive outcomes that hold promise if spread more widely. Equally important, our data clearly shows that:

- A relatively small number of providers are prescribing HU;
- Many providers who are seeing patients with SCD are not prescribing HU;
- Filling of prescriptions cannot be documented for many patients who are receiving prescriptions for HU; and
- Many patients with SCD who are eligible for HU are not getting the vital medication.

Key recommendations that could address future improvement in HU use are presented in Section 6 of this report.

Progress related to increasing access to HU and increasing the number of providers who prescribe or co-manage patients on HU was a key outcome of this program.

RCCs shared the following lessons learned from these efforts:

- Most providers lack knowledge, confidence and decision-making tools to prescribe HU.
- Medical education webinars, publications and creation of provider education tools and materials to support HU prescription and management increased provider comfort with prescribing HU.
- Specific tools and materials (e.g., brochures and roadmaps) directly related to HU's risks and benefits significantly helped increase the comfort level of providers around HU and their ability to explain these risks and benefits to their patients.
- Often the prescribers of HU are hematologists/oncologists rather than PCPs. Program efforts should focus on successful co-management between specialists and PCPs while also increasing knowledge of hematologists/oncologists in the overall care of people with SCD.
- For project results to be sustainable and best practices spread, providers need to be adequately reimbursed for caring for complex patients with SCD, many of whom have substantial social needs and declining health due to co-occurring complications of SCD with usual health problems of aging.
- Additional tools and interventions are needed to increase the number of providers prescribing HU.

Section 5: Provider Knowledge of Sickle Cell Care

The third aim of the SCDTDP was to increase the number of SCD patients receiving care from providers knowledgeable about treating SCD. Gaps in provider knowledge of SCD care increase the likelihood that patients with SCD will not get the right care at the right time. These gaps are particularly acute among providers caring for adults with SCD. Improvements in pediatric SCD care have led to patients living higher quality and longer lives; however, the systems of care for adults with SCD have not advanced as quickly.

As seen in Section 4, a very small proportion of providers currently care for patients with SCD and there is a critical lack of both specialists and PCPs for adults who understand SCD and how to monitor, manage, and treat its hallmark symptoms.

Provider knowledge about SCD is difficult to measure on a large, national scale and cannot be measured via administrative data. Thus, for this project we relied on existing reports, in-person interviews, and information gathered during meetings, webinars, and site visits to assess the ways that each region approached provider education. As with the other SCDTDP aims, the geographic and population needs within each region led to different approaches for building provider knowledge of SCD. Common approaches included implementing Project ECHO® clinics, planning in-person and virtual opportunities for SCD provider education, creating and sharing clinical decision tools and guidelines, writing journal publications, and presenting at conferences. These efforts are shown in the Table 36 on the next page and are described further following an overview of the NCC's role in supporting this work.

"The close affiliation with 'experts' (clinical and non-clinical) has been a tremendously worthwhile experience. It has provided an opportunity for real time feedback regarding care processes that has enriched my practice and boosted my confidence with providing care as a primary care provider. One unexpected outcome of participation was identifying a gap in immunization schedules that led to getting it corrected sooner than later. It also led to a full review of non-enrolled patients' immunization schedules to ensure that the same standards of care were being applied uniformly. In short, it's been an invaluable experience."

DONNA MCCURRY, FNP, TRUMAN MEDICAL CENTER, KANSAS CITY, MO

TABLE 38:
RCC Approaches to Provider Education

REGION	WEBSITE	WEBINARS & ONLINE CMES	IN-PERSON TRAINING	OTHER
Heartland	http://www.sicklecell.wustl.edu		Two annual in-person trainings with CME credits	
Midwest	http://sicklestorm.org/index.html		Six bi-annual regional learning sessions with all state partners	Development and testing of toolkits for HU clinical decision support for providers
Northeast	http://hopkinsmedicine.org/Medicine/sickle/	CBO Lead hosted 8 webinars with over 40 participants. JHUSOM hosted over 70 online CME telementoring sessions reaching over 100 providers	Six conference- calls & two in-person meetings in collaboration with CBOs	Grand rounds, symposiums, journal article publication
Pacific	http://pacificscd.org/pscrc-collaborative/	Five webinars in conjunction with the Sickle Cell Data Collection project of California Rare Disease Surveillance Program	Annual regional learning sessions with all state partners	Over 1456 providers trained through strategic planning and advanced treatment workshops; Technical assistance (TA) visits

ROLE OF NCC TO SUPPORT IMPROVING PROVIDER KNOWLEDGE

The NCC provided opportunities to bring regions together to share lessons learned, and materials and resources related to provider education strategies. The CoLab was available for all state and regional partners to share materials and provider education tools online. The NCC collated these materials and coordinated a Provider Education working group in the second and third years of the project. This group supported the development of the Model Protocol and Compendium of Tools and Materials.

The Model Protocol and Compendium of Tools and Materials are a complementary set of materials that document best practices and resources for meeting the aims of the SCDTDP program. Centered on the three aims of the project, these documents share best practices for building access to care, increasing use of HU therapy, and building provider knowledge about SCD. The Model Protocol and the Compendium of Tools and Materials are companions to the Congressional Report, with an audience that extends to providers, patients, researchers, policymakers, and others meeting the need for accessible, high quality SCD care on the ground.

The NCC also coordinated the Telementoring working group, which provided a space for the regional ECHO® programs to update each other on progress and share challenges and successes. This group provided input on the development of a one-page promotional document that highlighted the benefits of the TeleECHO™ approach for supporting and building knowledge among providers who have patients with SCD. This document also promoted each of the regional SCDTDP ECHO® programs to interested providers.

TELEMENTORING AND PROJECT ECHO® AND TELEMENTORING

Section 3 of this report describes the Project ECHO® model as an innovation in improving access to SCD care by increasing the number of knowledgeable providers. This section describes the approach that each region took to plan their curriculum and recruit providers to participate as spokes (i.e., the remote gathering points for participation in the sessions). While they each used the same basic format for TeleECHO® clinics, including de-identified case presentations and a brief didactic component on best practices in each session, they adapted the focus and frequency of their sessions based on their region's needs and resources. Members of the expert panel in each TeleECHO® clinic respond to case presentations through their own lens. The details of each clinic are displayed in Table 37 below.

TABLE 39:

Implementation of the Project ECHO® Model

REGION	MIDWEST (STORM)	NORTHEAST (SINERGE)	PACIFIC (PSCRC)	TOTALS
Start Date	March 2016	September 2015	October 2016	n/a
Frequency of Sessions	Monthly	Weekly	Monthly	n/a
SCD Focus	Lifespan	Adult care	Lifespan	n/a
# of Clinics Held[a]	16	72	7	95 sessions
# of Providers Participating	15 per clinic 50 unique participants	15 per clinic 135 unique participants	10 per clinic[b] 26 unique participants	10-15 per clinic 211 unique
# of Spokes (Remote Sites)	30	25	11	66 spokes

[a] as of July 31,2017

Two out of the three SCDTDP Project ECHO® clinics have a lifespan focus encompassing both pediatric and adult care, while the Northeast region focuses primarily on adult care. All focused their curriculum based on the NHLBI guidelines for the treatment of SCD[10]. Two of the regions offered CME credits for participants. Each of the clinics faced logistical challenges related to connecting with providers who were interested and available to participate on a regular basis. Providers faced challenges in finding time to participate. Each site determined the best time of day (typically lunchtime) that was most amenable to providers' schedules. Some of the sites began recording their sessions to be able to share with those who are interested but not able to join the live sessions.

The regions agree that a key component to having rich discussions that consider all aspects of patient care is the inclusion of a range of providers, including nurses, social workers, CHWs, specialists, and PCPs. The clinics have each created their own brochures and methods for recruiting participants, as well as case presentation forms to prepare for discussion during each session, systems for cataloguing case presentations, and participant evaluations. Another common challenge across sites was finding participants who were comfortable presenting cases for discussion during the clinic. They found that the longer participants have joined the sessions, the more comfortable and willing they became to volunteer to present a case and the richer the discussions. If none of the spokes volunteered to present a case, the hub site used a de-identified case they had prepared.

SiNERGe ECHO® Program

In 2015, SiNERGe became the first group to implement the Project ECHO® model for SCD. Johns Hopkins University School of Medicine (JHUSOM) is the hub and, as of July 2017, there are 25 spokes. The SiNERGe team led the telementoring workgroup, giving other regions the opportunity to learn from their experience launching and implementing their program. Their focus is on adult care. The ECHO® sessions run weekly and they have consistent participation with approximately 15 participants per session. The expert panel for this clinic includes a CHW, a psychiatrist with expertise in pain management, an adult SCD expert, a pediatric SCD expert, a PCP, and a primary care transition specialist.

When the program started, a local hospital's SCD care team was recruited to serve as the first spoke. A more formal arrangement was forged with the hospital administration. They attended regularly, which gave the hub the opportunity to recruit other spokes. The most successful means of recruitment has been by word of mouth and through personal connection. Efforts to contact potential providers via a "cold-call" email were not successful.

SCD PROVIDER EDUCATION: JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE TELEECHO™

- Over 90 hours of training in total
- 47% of participants have attended more than one session; of those, the average number of sessions attended is 11
- 66 cases shared and 41 didactic SCD-specific presentations

In 2017, Johns Hopkins Sickle Cell Disease ECHO® clinic has seen growth among participating spokes. There is more diversity of sites, including SCDTDP grantees and other providers from outside the region. Building on the success of this clinic, the group plans to kick off a Transition ECHO® for SCD, which will feature additional social services related to transitions of care in SCD. The Project ECHO® coordinator at Johns Hopkins will participate in a new hub training at the University of New Mexico to prepare for this launch.

STORM ECHO® Program

STORM's TeleECHO™ team was trained by the American Academy of Pediatrics (AAP) Superhub Project ECHO® team, and the first clinic launched in March 2016. Cincinnati Children's Medical Center is the hub and there are currently over 30 registered spokes consisting of 50 unique participants in nine states and three countries; and participation continues to grow. Participants have included pediatric and adult PCPs and hematologists, as well as pharmacists and trainees. Didactic presentations have included regional and national SCD experts presenting on topics such as pediatric and adult complications of SCD, newborn screening, psychosocial issues, HU therapy, abdominal complaints, renal complications, pain, retinopathy, transfusions, avascular necrosis, and home pain management plans. Post-session evaluation data has consistently shown that participants feel that the sessions improve their evidence-based knowledge about the management of SCD. Participants also agree that it is beneficial to feel that they part of a community of practice and 100 percent would recommend STORM TeleECHO™ to a colleague.

STORM was particularly successful with recruiting providers to participate in their TeleECHO™ clinic on a regular basis by leveraging existing partnerships through state partners. One example of this was collaborations with the AAP Section of Hematology/Oncology as well as the Illinois Primary Healthcare Association, who both included an article in their newsletters to recruit participation of PCPs. In 2017, STORM began offering free MOC credits for the American Board of Pediatrics as well as the American Board of Internal Medicine as an incentive for participation in the ECHO® clinic. The test of change was that providers would consider opportunities to earn more valuable MOC credits over more commonly available CME credits. Information about STORM TeleECHO™ registration is available on the STORM website (Table 38).[26]

"STORM TeleECHO™ has been a game-changer for my clinical team. Although I only have a few patients with sickle cell disease, TeleECHO™ has provided up-to-date research and guidelines to help increase my knowledge of sickle cell complications and increased my understanding about hydroxyurea. I like that I can easily access the program from my office, but yet it feels like I'm now part a network of providers that I wouldn't normally have access to...."

PRIMARY CARE PROVIDER, OHIO

PSCRC ECHO® Program

The PSCRC's Project ECHO® team launched monthly clinics in fall 2016. They use a centralized academic research center at BCHO or the Center for Inherited Blood Disorders (CIBD) as the host site to coordinate the video conference calls. The initial model separated pediatric care from adult care by having two separate calls for either adult or pediatric support. After consulting with the University of New Mexico Project ECHO™ team, and various other clinicians providing SCD Project ECHO® throughout the SCDTDP, the PSCRC shifted this model to include SCD across the lifespan (pediatric and adult care) in 2017.

Both adult and pediatric providers participate on a regular basis, including hematologists, NPs, hospitalists and PCPs from throughout the Pacific Region. The focus of the calls remains providing education grounded in the NHLBI evidence-based guidelines and the program saw measurable growth in participation in the second quarter of 2017. Participants reported this was an engaging way to introduce Project ECHO® to providers who generally do not see patients with SCD regularly. The team continues to work on recruiting new participants, especially PCPs, nurses, and social workers, to facilitate richer conversations on all aspects of SCD care. PCPs are the most challenging providers to recruit to Project ECHO® conferences. The PSCRC Project ECHO® team is currently in the process of a new recruitment campaign, with newly designed recruitment materials, educational websites, and various levels of follow-up contact, to keep and retain current participants as well as gain new participants.

The CIBD serves as the HRSA/CDC Western States Regional Hemophilia Network 's grantee and draws on this experience as co-lead of the PSCRC. In 2017, CIBD invited the Founder of Project ECHO® to serve as a plenary speaker at the HRSA/CDC Regional Hemophilia Network annual convention held in San Diego. PSCRC staff, including the SCDFC President/CEO attended, along with over 200 hemophilia healthcare providers, over 70 percent of whom also care for patients with SCD in their broader hematology practices. The Director of CDC's Division of Blood Disorders and the Director of the Division of Blood Diseases and Resources at NHLBI also attended the meeting, further building bridges between hemophilia and SCD care providers and creating new opportunities with Project ECHO®. This was a valuable opportunity to reach providers that PSCRC had not been able to connect with previously for SCD educational efforts. The meeting led to fruitful discussions and excitement about the possibility of synergizing hemophilia and sickle cell efforts around Project ECHO®.

Heartland Region Telementoring Activities

While experiences of the Northeast, Midwest, and Pacific regions showed Project ECHO® has some flexibility, a single model does not address the needs of all programs. While there are commonalities across the regions to help guide opportunities for collective impact, there are distinct differences in demographics, geography, culture, and priorities that require a variety of tactics across the SCDTDP initiative to improve provider knowledge. The Heartland assessed the TeleECHO® model and concluded it was not the best approach in their region. Telementoring or teleconsulting activities were more feasible for this region.

They offered a traditional ECHO to physicians in their area. The challenge was that providers wanted on demand education and consultation about cases. The clinicians didn't feel that it was a good use of their billable time to join a conference call on a monthly basis. The most consistent participation was from physicians who were the leads in their state or area of the state. They did review case presentations and offered expert opinions as requested. They also networked and shared institutional practices and roadmaps.

In Nebraska, a combined telemedicine/telementoring initiative was implemented to build capacity of local pediatricians and PCPs to help patients, who were often hundreds of miles away, manage their ongoing care between specialty care visits. The Heartland RCC also provided case management consultation with Centene, covering 19 states across the Midwest and Heartland. Combined, telemedicine and telementoring efforts bridged not just the miles and time barriers to care, but also improved the day-to-day management by increasing the knowledge base of patients and their local providers.

> The Heartland led a telementoring consultation practice with SCD care management teams through Centene (insurer/payer) covering 19 states.

WEBSITES

Each of the RCCs were tasked with building a website for their regional center to support the collaborative and collective work of the grantees and to provide local access to SCD resources and activities. The websites feature background information on the SCDTDP, resources for providers, details about the Project ECHO® clinics, information for patients and families, as well as a listing of partners and contact information for staff. Audiences of these websites included patients, families, providers, healthcare organizations, advocacy groups and CBOs.

TABLE 40:

Common Elements in RCC Websites

RCC WEBSITE NAMES LINKS	COMMON INFORMATION ELEMENTS
PCSRC: http://pacificscd.org/pscrc-collaborative/	Mission, vision, goals and objectives, leadership and partner listings with contact information
STORM: http://sicklestorm.org/index.html	Calendar with events and trainings
Heartland: https://sicklecell.wustl.edu/	Webinar series and/or Project ECHO® postings
SiNERGe: https://hopkinsmedicine.org/Medicine/sickle/	Resource listings for providers, patients, community groups, policymakers, healthcare leaders, etc.
	News and publications (events calendar, social media, press releases and videos)

EDUCATIONAL OPPORTUNITIES FOR PROVIDERS

All four regional centers employed multi-level approaches to provider education and learning across the range of SCD care domains, including acute care, preventive care, care coordination, transitions in care, HU use, and pain management. Opportunities included both in-person learning events, scholarly publications, and remote training (in addition to TeleECHO™ participation). Most of these events offered CME credits as an additional incentive.

In-person events ranged from large to small scale and included:

- Regional learning sessions, symposiums and conferences that brought together state grantees and a range of providers from states across regions
- Smaller in-person informational events, presentations and grand rounds sponsored by hospitals, provider organizations, professional societies, government agencies, academic medical centers, and CBOs

Educational webinars were a widely practiced approach across all of the regions. Webinars provided time efficient participation for all and remote participation for those geographically distant. For participants with limited availability, webinars were easily recorded and posted publicly for continual access and spread. Webinars were useful for focusing presentations and sharing examples on specific aspects of care with care teams. Links to various webinars are available on the regions' respective websites.

PSCRC: Workforce Development Focus

The purpose of PSCRC's healthcare workforce development initiative was to improve access to knowledgeable SCD care. They accomplished this by building a new cadre of healthcare professionals who are aware of SCD's prevalence, symptoms, and evidence-based treatment. This next generation of physicians, nurses, and NPs was encouraged to devote their careers to SCD and related catastrophic genetic blood disorders. Sites of this education included the medical schools at the University of California San Francisco and Davis and the nursing program at Samuel Merritt University in Oakland, California. The PSCRC region-wide initiatives to educate practicing physicians focused on their work in Project ECHO®, while state leads conducted grand rounds and mentored junior faculty and fellows.

State clinical leads also conducted numerous educational seminars to build the workforce throughout their local communities. In 2016, PSCRC leaders were invited to be plenary speakers on SCD at the Northwest Regional and US Conferences on African Immigrant and Refugee Health, the American Public Health Association, the National Convention of the Sickle Cell Disease Association of America, and American Society of Hematology. In 2017, PSCRC leaders presented on SCD at the National Minority Quality Forum's Sickle Cell Satellite, the Foundation for Sickle Cell Disease Research, and NAHN. The PSCRC leaders also presented national webinars on developing the Adult SCD Clinic at the MLK, Jr. Outpatient Center.

PSCRC team members hosted and contributed to many webinars focused on increasing provider education on SCD over the three years of this grant. This included five webinars in conjunction with the Sickle Cell Data Collection project of the California Rare Disease Surveillance Program.

Over 1,456 providers were trained through workshops and technical assistance from the PSCRC.

Throughout the life of this grant, over 1456 providers were trained through workshops and technical assistance from the PSCRC. The PSCRC hosted annual two-day meetings for state partners and providers. These conferences were forums for providers to receive updates on the latest treatment regimens and new SCD research, technical assistance for QI and data collection, and spread of best practices. The PSCRC also sponsored many smaller workshops, including joint workshops for families and providers on topics such as care transitions and cultural competence.

Improving Provider Knowledge of Sickle Cell Care

STORM: Provider Education and Evidence Based Practices

In addition to developing and disseminating educational materials, STORM worked on developing incentives for providers to treat patients with SCD. This involved providing CME workshops and webinars on treatment of SCD as well as opportunities to obtain the more coveted MOC credits. (MOC credits are required for board-certified providers to maintain their certifications.)

Between 2014 and 2015, STORM presented on their regional network model at several venues, including patient/provider conferences in Chicago and Indianapolis. Cincinnati Children's Hospital hosted several CME workshops, a symposium on HU therapy, and a national Hemoglobinopathy Counselor Training course. Between 2016 and 2017, each state in the Midwest region planned and implemented activities to increase provider knowledge of SCD; these are described further on the next page.

The Midwest awarded over 600 CME hours in 50+ events related to SCD.

Indiana gave 12 presentations on SCD to healthcare providers in-state.

Illinois provided SCD education to staff at Illinicare Health Corporation (an MCO), and developed a mandatory online education module for Registered Nurses managing SCD throughout the Order of Saint Francis (OSF) Healthcare System, comprised of 11 hospitals serving Illinois and Michigan.

Michigan STORM partners hosted two CME dinners for healthcare providers on the management of SCD and the use of HU with over 35 attendees. They also established a partnership with the Michigan Primary Care Association, which serves 39 Michigan health center organizations, and have been able to plan SCD "Lunch and Learns" for providers in health centers with higher populations of patients with SCD.

Minnesota provider education efforts included an SCD and equity talk in St. Cloud to over 75 providers, a presentation to over 30 providers through the Minnesota American Academy of Pediatrics, a presentation to over 50 providers through Blue Cross Blue Shield, presentations on Minnesota Medical Association's health equity webinars, and presentations at several organizational meetings, including the Association of Pediatric Hematology and Oncology Nurses and Minnesota Community Measurement.

Ohio partners hosted a symposium on cardiology in SCD for over 70 healthcare providers and an annual Hemoglobinopathy Counselor Training program for over 50 providers. They also gave a presentation on TeleECHO™ at a statewide meeting of the Ohio Association of Community Health Centers, educated staff at United Healthcare (MCO) about SCD, hosted a national webinar for providers about genotyping in SCD, and held a statewide PCP CME symposium.

In Wisconsin, STORM hosted a Sickle Cell Awareness Luncheon with the Froedtert Hospital's Adult Sickle Cell program and collaborated with ED partners to improve pain management protocols and to ensure that all patients seen for pain are discharged to home with a follow-up appointment with a provider knowledgeable about SCD.

The Heartland: Partnering for Provider Education

Over the three years of the SCDTDP grant, the Heartland sponsored annual conferences with CME credits for providers in the region with sessions and presentations themed around SCD clinical domains of care. Regional and state leads met monthly to build the course for a series of monthly webinars; advocacy and awareness raising efforts; and sharing of best practices.

Heartland clinical partners included multiple clinical institutions across each state as well as CBOs. These sites were charged with spreading best practices within their own institutions and with remote providers within their states. The Integrated Health Network (IHN), an HRSA-designated Health Center Controlled Network, organized education sessions and messaging for the participating safety net providers in the St. Louis metropolitan area. These sessions stemmed from round table meetings with physicians and leaders from federally qualified health centers and emergency rooms to discuss HU prescription practices as well as transitions of care for patients with SCD.

The Heartland had a 52% increase in the number of education sessions provided by partners

SiNERGe: Dissemination and Spread

The Northeast region's SiNERGe team defined providers beyond physicians to include nurses, allied health professionals, CHWs, social workers and other social service professionals. Through partnering with local CBOs advocating for and serving patients with SCD and their families, SiNERGe was able to extend its knowledge and efficacy-building efforts beyond traditional providers to include community stakeholders. In addition to provider education, the Northeast CBO Lead hosted and posted a series of eight webinars with over 40 individuals across stakeholder sectors participating. The series included an overview of SCD, pain management, use of HU, living with SCD (patient perspective), transitions in care from Pediatric to Adult, and nutrition for patients with SCD.

The SiNERGe team hosted a symposium with the Virgin Islands, both in St. Thomas and St. Croix. By convening this event territory wide, the team was able to provide education and spread of best practices in this remote location, bringing lessons learned in the United States to SCD stakeholders in the U.S. Virgin Islands. The symposium was open to medical providers as well as individuals living with SCD and their families. It was also attended by the Governor, Lieutenant Governor, and Commissioner of Health for the USVI. They discussed pediatric care, adult care, primary care, psychiatry, pain management, the use of Project ECHO® for SCD, and the role of CHWs in SCD care.

The SiNERGe team coordinated the publication of the Special Issue on Sickle Cell Disease in the Southern Medical Journal (September 2016, Volume 109 - Issue 9), including 24 articles published by over 30 different authors.

Another way that SiNERGe educated providers was to collaborate for two year's running with the Southern Medical Journal to produce a special issue focused on SCD. The issues covered a wide array of topics in SCD care, from clinical to psychosocial to programmatic. The journal's wide readership allowed for spreading knowledge and ideas not only to providers in the Northeast region, but also across the United States and its territories.

Lessons Learned

Due to the complexities, inherent in measuring knowledge in providers, we cannot know precisely how many providers actually improved their knowledge during this project. However, based on participant counts, attendance sheets, participant surveys, and other supporting information, we are able to demonstrate that a large number of providers were exposed to best practices and updated information related to SCD care. The TeleECHO™ program was very successful in multiple states and regions. Centralized and local educational efforts were well attended and rated highly by participants. But, as further explored in Section 6, much more work remains to be done to increase the number of SCD patients receiving care from providers knowledgeable about treating with SCD.

The primary lessons learned for this aim were that a number of activities and efforts are needed to create a networked approach to supporting providers who are not only willing to treat those with SCD, but appropriately trained to effectively manage this condition. RCCs identified the following lessons during this demonstration program:

Systems of Care

- It is essential to look beyond the healthcare delivery system to the public health system to create widespread, sustainable change and to mobilize evidence-based public health approaches.
- A list of knowledgeable providers who feel comfortable seeing patients with SCD is a critical resource enabling both patients and other providers to identify appropriate sites of care.
- It remains critically important to look beyond PCPs for educational efforts aimed at the healthcare system, and education should also be targeted beyond SCD specialists to include hospitalists for efforts such as Project ECHO®.
- Workforce development with the next generation of healthcare providers is a key entry point for educational efforts to gain maximum traction.

Patient and Stakeholder Engagement

- All SCD efforts should consider integration and partnerships within the wider blood disorders community to develop synergies between various project activities.
- While patient activation was not an explicit focus in the current cycle, patients remain essential partners in this work, and patient engagement is key to successfully developing materials and tools for providers.
- Project ECHO® is an innovative and well-poised vehicle for creating a community of providers who treat SCD, including hematologists and hospitalists.
- Network calls (telemedicine, case presentations) are critical tools that allow for active provider support and mentoring to discuss challenging cases and indications for certain treatments.
- The continuous incorporation of innovative education practices should be a standard practice.

While finding and adapting data to understand the impact of educational opportunities for providers remains elusive, significant groundwork has been laid to identify innovative practices to build the capacity of providers and connect patients to these providers.

Section 6: Recommendations

While significant progress has been made in both understanding and caring for patients affected by SCD in the past generation, much more remains to be done for this high need patient population to ensure equitable access to knowledgeable care, proven therapies and tailored forms of treatment. Throughout the three years of this SCDTDP initiative, NICHQ, serving as the National Coordinating Center, has worked closely with the Regional Coordinating Centers to support the regions' efforts in meeting the program's aims, as documented in the previous sections. The accomplishments of the grantees demonstrate that patients living with SCD and their families benefit when providers, CBOs and government agencies work collaboratively toward a shared aim of improving the health and quality of life of children and adults whose lives have been impacted by SCD.

Enormous opportunities remain, however, to improve the state of SCD care in the United States given that patients living with SCD have less access to comprehensive team care than people with other genetic disorders, such as hemophilia and cystic fibrosis.[27] **In addition to the learned experiences of the grantees, NICHQ regularly engaged with a diverse group of SCD experts with decades of combined experience to develop the series of recommendations outlined below that are focused on SCD initiatives, healthcare policy and clinical care.**

RECOMMENDATIONS FOR FUTURE SICKLE CELL INITIATIVES AND PROGRAMS

It's not a coincidence that patients living with SCD have benefited from better care coordination and access to disease-modifying therapies over the past century. Rather, these advancements are a result of deliberate and direct investments made to programs such as the SCD Treatment Demonstration Program and ongoing partnerships. However, despite the progress made in care that has allowed most children living with SCD to reach adulthood, systemic barriers still impede their ability to receive the comprehensive, coordinated care required to achieve their optimal health. As more people with SCD are surviving into adulthood, it remains imperative that demonstration programs designed to address and eliminate barriers to care continue. In addition, continuing to support the following recommendations would strengthen the investments made in SCD initiatives to date.

- Collect coordinated measures across aims and domains of focus, using standardized data definitions and collection methods, to follow and gain understanding of disease progression over time, including young adulthood and beyond
- Enhance the national focus on the use and coordination of sickle cell registries

- Develop standard SCD curricula and metrics of success around the application of the Extension for Community Healthcare Outcomes (ECHO®) model, a practice-guided medical education model, and other telehealth strategies for SCD care to:
    - Increase the amount of providers who are knowledgeable about treating SCD
    - Improve SCD outcomes by ensuring patients have some access to services even if they are not close to a sickle cell program or center
- Maintain improvement science as an integral component of SCD initiatives
- Sustain and provide resources to support interagency coordination and cooperation to amplify the impact and optimize the resources of federal SCD initiatives
- Support regionalization to sustain SCD healthcare systems' capacity building using evidence-based public health practices

HEALTHCARE POLICY RECOMMENDATIONS

The complications of managing the care and treatment of SCD can be all-consuming for patients and their families. Increased collaboration between all SCD stakeholders, including patients and families, as well as CBOs, is critical to enhance care coordination and patient and provider education. Involving key stakeholders as true partners in care will lead to better outcomes for patients across their lifespans. To continue to support transformation within the healthcare system, the following recommendations concern policies that when implemented would substantially improve the system of care supporting patients with SCD.

- Improve access to evidence-based SCD care through telehealth, telemedicine, telementoring, and other innovative models and enhance reimbursement for these services
- Incorporate standardized quality measures of access and care for patients with SCD into organizational performance measures, such as the Bureau of Primary Healthcare quality metrics[30]
- Ensure that all patients with SCD have consistent access to insurance so that they are able to get the care they need without interruption
- Provide system supports and adequate reimbursement for care transition that ensures seamless and comprehensive care from adolescence through young adulthood and beyond
- Adjust payment policies and enhance reimbursement rates to cover care coordination services that include CHWs to improve access to community resources, social services, mental healthcare, and clinical services, especially for Medicaid recipients
- Develop payment systems that support reimbursement of preventive care visits to both primary care and specialty care providers
- Ensure there are qualified healthcare professionals for both pediatric and adult SCD care by creating specific workforce training and student loan forgiveness programs for broader categories of physicians (e.g., hematologists), nurses, nurse practitioners and physician assistants

CLINICAL CARE RECOMMENDATIONS

One of the main objectives of the demonstration program was to increase the number of knowledgeable providers treating patients with SCD. Achieving this aim depends on a patient's continued access to comprehensive care (e.g. medical home) and enhancement of care management plans developed jointly by PCPs, specialists, hospitalists and other inpatient providers, together with patients and families. In addition, optimal healthcare systems support improved clinical outcomes for patients living with SCD by creating data and decision-making systems to track outcomes, support QI, and enable providers to ensure they are providing the best possible care and treatment across their patients' lifespan. The following clinical recommendations provide further insight into the improvements that ensure that those who treat SCD are adequately trained and supported by data-driven research, and provide a comprehensive system to meet the complex and changing needs of this patient population.

- Implement systems (e.g., EHR templates, order sets, tracking and feedback mechanisms) to track and increase rates of appropriate screening and preventative interventions (e.g., penicillin prophylaxis, immunizations, HU, transcranial Doppler screening)
- Address deficiencies in ED care of individuals with SCD experiencing acute pain crises by establishing pain protocols; providing and making widely available pain management plans; and using more easily administrable medications
- Implement data systems that enable management of the entire SCD population served through a clinical system or in a geographic area and track key processes and outcomes, including the use of effective therapies (e.g., HU), ED visits, hospitalizations, and readmissions
- Expand the evidence base related to the use of care plans and other care coordination tools for SCD patients.
- Ensure patient and family education regarding use of HU extends beyond a discussion of benefits and risks to include discussion of patient preferences and strategies for self-management support
- Ensure that healthcare systems address both psychosocial and medical needs of individuals with SCD and their families
- Ensure all facilities providing care for individuals with SCD incorporate the six core elements of transition where appropriate: having a transition policy, developing a process for tracking and monitoring transition-age youth, assessing and using transition readiness assessments, planning for transition, transferring care, and completing transfers
- Assess current practice patterns for screening of immigrants (including African, Caribbean, Hispanic and Middle Eastern immigrants) for SCD. Develop and/or refine screening processes and link identified individuals to systems of care based on this assessment
- Use systematic approaches to QI based on data collected and evidence assessment that involve patients and families in both the design and implementation
- Foster sufficient reimbursement for preventive clinical and social services (e.g., CHW)

CONCLUSIONS

The concerted efforts of SCDTDP have improved access to care, increased the use of Hydroxyurea among patients with SCD, and increased the number of providers knowledgeable about SCD. These efforts have led to the following accomplishments:

- At least 4 states across the country expanded access to care by opening new SCD clinics
- All 4 regions increased HU use among patients with SCD
- Over 200 providers engaged in SCDTDP TeleECHO™ initiatives
- Nearly 7,000 patients with SCD are contributing information to electronic health registries
- Nearly 11,000 patients with SCD are receiving care through SCDTDP regional networks, reflecting an increase of more than 3,000 from baseline

The recommendations described above were identified by RCCs and experts in the field as the key elements necessary to achieve the impact seen in the SCDTDP initiative, and to continue to expand and improve the efforts of future programs.

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The Appendix

Appendix Table Numbers

Section B: Administrative Measures Data Dictionary

Section C: Stakeholder Engagement

Section D: Minimum Data Set Dictionary

Section F: Communication Plan

Section I: Additional Data

Section J: Data Collection Tables

Appendix Figure Numbers

Section I Additional Data

A. Glossary

Action Period: A period in the Breakthrough Series model that falls between learning sessions, during which teams test and implement changes in their local settings. Teams are supported by experts, organizations and peers who share knowledge and experience through conference calls, webinars, visits, etc.

Acute chest syndrome: A complication of sickle cell disease in which a vaso-occlusive episode (see vaso-occlusive episodes) occurs in the pulmonary vasculature, the blood vessels of the lungs. Acute chest syndrome is characterized by fever, difficulty breathing and chest pain accompanied by a new pulmonary infiltrate on chest x-ray. This illness can be life-threatening.

Ambulatory care: Health care services such as preventive care, subspecialty and/or acute care that are provided on an outpatient basis. These services may include a personal health care consultation, treatment, or intervention.

Data dictionary: A set of information describing what type of data, including its format, structure and use, is collected within a database. It outlines the rules that data in a system need to comply with.

Day hospital: A hospital, or a specified area within a hospital, which provides an alternative to inpatient care for individuals with sickle cell disease. Services may include acute pain management, transfusions and/or primary care or subspecialty assessments depending on the location.

Electronic Health Record/Electronic Medical Record: A digital version of a patient's paper chart. These electronic charts are real-time, patient-centered records that are designed to make information available quickly and securely to authorized users.

ECHO® Model: A model that virtually links specialists at an academic center with primary care clinicians in local communities to develop primary care clinicians' skills to treat particular conditions. Using teleconferencing technology, primary care clinicians receive mentorship from specialists and participate in virtual ECHO® clinics to gain knowledge about complex health conditions.

Genotype: The alleles (different forms of a gene) which an individual has with respect to a particular characteristic. An individual inherits two alleles for each gene, one from each parent. For example, individuals with sickle cell anemia have inherited two copies of the gene for sickle cell hemoglobin. The major sickle cell genotypes are: sickle cell anemia (HbSS) and sickle cell beta zero thalassemia, which usually are associated with a moderate to severe clinical course, and sickle-hemoglobin C disease (Hb SC) and sickle cell beta plus thalassemia, which are characterized by mild to moderate clinical severity.

Hemoglobin: The protein in red blood cells that carries oxygen from the lungs to the rest of the body. In patients with sickle cell disease, a mutation in the hemoglobin gene produces slightly abnormal hemoglobin that can cause the red blood cells to become rigid and assume a sickle-like or crescent shape (whereas healthy red blood cells are round and flexible). The different genotypes of sickle cell disease (see genotype) result from differences in the exact mutation in the hemoglobin gene.

Hydroxyurea: A therapy approved by the Food and Drug Administration for the treatment of sickle cell disease. It is an orally administered chemotherapeutic drug historically used to treat a number of diseases, including some cancers. In patients with sickle cell disease, hydroxyurea reduces the extent to which blood cells assume a sickle shape, reducing the occurrence of sickle cell disease-related complications such as pain crises and acute chest syndrome

L-glutamine: A therapy recently approved by the Food and Drug administration for the treatment of sickle cell disease. L-glutamine oral powder is administered orally and can be prescribed to adults and children over five with sickle cell disease. This new treatment was approved in July 2017 and has been shown to reduce the acute complications of sickle cell disease.

Medical home: A medical home is not a building, house, hospital, or home healthcare service, but rather an approach to providing comprehensive primary care for children, adolescents and adults that is patient- and family-centered, comprehensive, coordinated, accessible and committed to quality and safety.

A. Glossary

Minimum Data Set: A standard set of data collected by local RCC-developed registries to allow the measurement of quality at the local level. The SCDTDP Minimum Data Set includes individual patient-level data from surveys and electronic health records.

Motivational interviewing: Motivational interviewing is a client-centered, directive therapeutic style to enhance readiness for change by helping clients explore and resolve ambivalence.

Parenteral analgesia: Pain medication administered through intravenous injection, through intramuscular injection or subcutaneously.

Prophylactic antibiotics: Antibiotics given on a daily basis to children less than 5 years of age with sickle cell disease to prevent infections such as blood stream infections.

Run chart: A graphical display of data plotted in some type of order, usually over time.

Satellite clinic: A healthcare facility affiliated with a larger entity, such as a hospital, that operates at a distant, stand-alone site.

Sickle cell disease: A group of inherited blood disorders characterized by an abnormality in the oxygen-carrying hemoglobin molecule in red blood cells, which causes them to become rigid, sticky and sickle-shaped under certain circumstances. Sickle cells are also fragile, often dying early and causing a shortage of red blood cells resulting in chronic anemia. Sickle cell disease is caused by inheriting two genes for sickle hemoglobin, one from each parent. There are several different genotypes of sickle cell disease. The disease causes a variety of serious health complications, including infection and stroke.

Sickle cell trait: An individual has sickle cell trait when he or she has inherited one gene for sickle hemoglobin and one gene for normal hemoglobin. An individual with sickle cell trait is a carrier for sickle cell disease, and can pass it on to a child, but usually does not have any of the symptoms of sickle cell disease.

Telehealth: The use of technologies and telecommunication to deliver long-distance medical and health services, including those of a clinical, educational or administrative nature.

Telementoring: The practice of long-distance mentorship between someone less experienced and someone more experienced through telecommunication.

Transcranial Doppler screening: A non-invasive radiologic ultrasound test that measures the velocity of blood flow through the brain's blood vessels. Transcranial Doppler screening is typically performed between 2 and 16 years of age in sickle cell patients to identify those individuals most at risk for stroke so that they can receive treatment that lowers their risk of stroke.

Vaso-occlusive episodes: Also known as pain crises, these are the hallmark manifestation of sickle cell disease. These unpredictable episodes of pain can occur as early as 6 months of age and occur throughout the lifespan – in childhood, adolescence and adulthood. Pain crises are caused when sickled blood cells get stuck in small blood vessels and block the flow of blood to tissues. They are the primary reason that patients with sickle cell disease seek medical attention at health care facilities.

TABLE 1:

Aim 1: Measure Specifications and Codes

AIM 1: INCREASE THE NUMBER OF PROVIDERS TREATING PERSONS WITH SICKLE CELL DISEASE	
Measure 1a: Number of providers in plan who saw at least one patient younger than 18 years of age with SCD two or more times during the past 12 months	
Denominator Population	Providers who had at least one claim submitted to the plan during the 12-month period ending with the reference month
Numerator Population	Providers from the denominator population who saw at least one patient with SCD who was less than 18 years old at the time of the visit for at least two non-emergent outpatient visits (Table 2) during the 12-month period ending with the reference month
Exclusions	Patients who also have a diagnosis of sickle cell trait (Table 3) should be excluded from denominator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied
Measure 1b: Number of providers in plan who saw at least one adult patient with SCD two or more times during the past 12 months	
Denominator Population	Providers who had at least one claim submitted to the plan during the 12-month period ending with the reference month
Numerator Population	Providers from the denominator population who saw at least one patient with SCD who was 18 years of age or older at the time of the visit for at least two non-emergent outpatient visits (Table 2) during the 12-month period ending with the reference month
Exclusions	Patients who also have a diagnosis of sickle cell trait (Table 3) should be excluded from denominator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied
Measure 1c: Number of providers in plan who saw any patient with SCD two or more times during the past 12 months	
Denominator Population	Providers who had at least one claim submitted to the plan during the 12-month period ending with the reference month
Numerator Population	Providers from the denominator population who saw any patient with SCD for at least two non-emergent outpatient visits (Table 2) during the 12-month period ending with the reference month
Exclusions	Patients who also have a diagnosis of sickle cell trait (Table 3) should be excluded from denominator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied

CONTINUED

TABLE 1: CONTINUED

Aim 1: Measure Specifications and Codes

AIM 1: INCREASE THE NUMBER OF PROVIDERS TREATING PERSONS WITH SICKLE CELL DISEASE	
Measure 1d: Number of children in plan with SCD who had at least 2 outpatient visits in the past 12 months	
Denominator Population	Patients less than 18 years old as of the end of the reference month who have ever had a diagnosis of sickle cell disease (Table 1) and who had at least one health care event (any claim) during the 12-month period ending with the reference month
Numerator Population	Patients from the denominator population who had at least two non-emergent outpatient visits (Table 2) during the 12-month period ending with the reference month
Exclusions	Patients who also have a diagnosis of sickle cell trait (Table 3) should be excluded from denominator.
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied
Measure 1e: Number of adults in plan with SCD who had at least 2 outpatient visits in the past 12 months	
Denominator Population	Patients who were 18 years old or older as of the end of the reference month who have ever had a diagnosis of sickle cell disease (Table 1) and who had at least one health care event (any claim) during the 12-month period ending with the reference month
Numerator Population	Patients from the denominator population who had at least two non-emergent outpatient visits (Table 2) during the 12-month period ending with the reference month
Exclusions	Patients who also have a diagnosis of sickle cell trait (Table 3) should be excluded from denominator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied

TABLE 2:

Aim 2: Measure Specifications and Codes

AIM 2: INCREASE THE NUMBER OF PROVIDERS PRESCRIBING HYDROXYUREA	
Measure 2a: Number of providers in plan who prescribed hydroxyurea to a child with SCD at least once during the past 12 months	
Denominator Population	Providers who submitted at least one claim to the plan during the 12-month period ending with the reference month
Numerator Population	Providers from the denominator population who had a patient under 18 years old and with a diagnosis of sickle cell disease (Table 1) who filled at least one hydroxyurea prescription during the 12-month period ending with the reference month
Exclusions	Providers whose patients also have a diagnosis of sickle cell trait (Table 3) should be excluded from numerator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied.
Measure 2b: Number of providers in plan who prescribed hydroxyurea to an adult with SCD at least once during the past 12 months	
Denominator Population	Providers who submitted at least one claim to the plan during the 12-month period ending with the reference month
Numerator Population	Providers from the denominator population who had a patient over 18 years old and who have a diagnosis of sickle cell disease (Table 1) and who filled at least one hydroxyurea prescription during the 12-month period ending with the reference month
Exclusions	Providers whose patients also have a diagnosis of sickle cell trait (Table 3) should be excluded from numerator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied
Measure 2c: Number of providers in plan who prescribed hydroxyurea at least once during the past 12 months	
Denominator Population	Providers who submitted at least one claim to the plan during the 12-month period ending with the reference month
Numerator Population	Providers from the denominator population who had any patient with a diagnosis of sickle cell disease (Table 1) who filled at least one hydroxyurea prescription during the 12-month period ending with the reference month
Exclusions	Providers whose patients also have a diagnosis of sickle cell trait (Table 3) should be excluded from numerator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied

CONTINUED

TABLE 2: CONTINUED

Aim 2: Measure Specifications and Codes

AIM 2: INCREASE THE NUMBER OF PROVIDERS PRESCRIBING HYDROXYUREA	
Measure 2d: Number of children with SCD who filled a prescription for hydroxyurea at least once during the past 12 months	
Denominator Population	Patients less than 18 years old as of the end of the reference month who have ever had a diagnosis of sickle cell disease (Table 1) and who had at least one health care event (any claim) during the 12-month period ending with the reference month.
Numerator Population	Patients from the denominator population who filled at least one hydroxyurea prescription during the 12- month period ending with the reference month
Exclusions	Patients who also have a diagnosis of sickle cell trait (Table 3) should be excluded from denominator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied
Measure 2e: Number of adults with SCD who filled a prescription for hydroxyurea at least once during the past 12 months	
Denominator Population	Patients 18 years of age or older as of the end of the reference month who have ever had a diagnosis of sickle cell disease (Table 1) and who had at least one health care event (any claim) during the 12-month period ending with the reference month
Numerator Population	Patients from the denominator population who filled at least one hydroxyurea prescription during the 12-month period ending with the reference month
Exclusions	Patients who also have a diagnosis of sickle cell trait (Table 3) should be excluded from denominator
Reporting Outputs	Denominator and numerator counts and percentage
Reporting Interval	Monthly
Comments	Claims include those paid, suspended, pending or denied

TABLE 3:

Codes to Identify Sickle Cell Disease

CONDITION	ICD-9	ICD-10
Hb S beta-thalassemia	282.41, 282.42	D57.40, D57.41
Hb SS-disease (Sickle Cell Anemia)	282.6, 282.61, 282.62	D57 Sickle cell disorders D57.0 Sickle cell anemia with crisis D57.1 Sickle cell anemia without crisis
Hb SC-disease	282.63, 282.64	D57.20, D57.21
Hb SD-disease	282.68, 282.69	D57.80, D57.81
Hb SE-disease	282.68, 282.69	D57.80, D57.81

TABLE 4:

Codes to Identify Outpatient Care

DESCRIPTION	CPT	ICD-9
Office or Other Outpatient Services	99201-99205, 99211-99215, 99241-99245	
Preventive Medicine	99381-99385, 99391-99395, 99401-99404, 99411-99412, 99420, 99429	
General Medical Examination		V20.2, V70.0, V70.3, V70.5, V70.6, V70.8

TABLE 5:

Excluded Sickle Cell-Related Codes

CONDITION	ICD-9	ICD-10
Hb S (Sickle)-Carrier (Sickle Cell Trait)	282.5	D57.3

TABLE 6:

Sickle Cell Treatment Demonstration Program — Medicaid Data Request

MEASURE CONCEPTS	
Provider	NPI codes, other de-identified provider ID
Provider Location*	Provider group practice location, etc.
Patient	Monthly reporting: age as of last day of reference month Quarterly reporting: age as of last day of reference quarter Age at time of visit Patient-filled prescription
Geographical Area	Zip codes (5-digit or 3-digit) for practice
Visit Type	Non-emergent or outpatient visit - see specifications in Tab 3
Reference Month	Monthly reports: that month Quarterly reports: last month of quarter
Claims	Paid claims (confirming whether states can also do pending, suspended, and/or denied)
Outcomes	Visit: outpatient; exclude ER or inpatient visits Medication Prescription: filled prescriptions for Hydroxyurea

* This measure can be rolled into geographical measure.

TABLE 7:
National Drug Code Directory

PROPRIETARY NAME	DOSAGE FORM NAME	APPLICATION NUMBER	PACKAGE DESCRIPTION	PRODUCT NDC	STRENGTH	PRODUCT TYPE NAME	NON-PROPRIETARY NAME	ROUTE NAME	MARKET CATEGORY NAME	LABELER NAME	SUBSTANCE NAME	PHARM CLASS	DEA	START DATE	END DATE
Hydroxyurea	Capsule	ANDA075143	30 Capsules in 1 Bottle, Plastic (54868-4773-0)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075143	100 Capsules in 1 Bottle, Plastic (54868-4773-1)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075143	50 Capsules in 1 Bottle, Plastic (54868-4773-2)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075143	60 Capsules in 1 Bottle, Plastic (54868-4773-3)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075143	40 Capsules in 1 Bottle, Plastic (54868-4773-4)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075340	100 Capsules in 1 Bottle (60429-265-01)	60429-265	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Golden State Medical Supply, Inc.	Hydroxyurea	N/A	N/A	Frbruary 24/1999	N/A
Hydroxyurea	Capsule	ANDA075340	100 Blister Packs in 1 Box, Unit-Dose (68084-28401) > 1 Capsule in 1 Blister Pack (68084-284-11)	68084-284	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	American Health Packaging	Hydroxyurea	N/A	N/A	August 12/2008	N/A
Hydrea	Capsule	NDA016295	100 Capsules in 1 Bottle (0003-0830-50)	0003-0830	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	NDA	E.R. Squibb & Sons, L.L.C.	Hydroxyurea	N/A	N/A	June 1/2009	N/A
Droxia	Capsule	NDA016295	60 Capsules in 1 Bottle (0003-6335-17)	0003-6335	200 mg/1	Human Prescription Drug	Hydroxyurea	Oral	NDA	E.R. Squibb & Sons, L.L.C.	Hydroxyurea	N/A	N/A	June 1/2009	N/A

CONTINUED

TABLE 7: CONTINUED

National Drug Code Directory

PROPRIETARY NAME	DOSAGE FORM NAME	APPLICATION NUMBER	PACKAGE DESCRIPTION	PRODUCT NDC	STRENGTH	PRODUCT TYPE NAME	NON-PROPRIETARY NAME	ROUTE NAME	MARKET CATEGORY NAME	LABELER NAME	SUBSTANCE NAME	PHARM CLASS	DEA	START DATE	END DATE
Droxia	Capsule	NDA016295	30 Capsules in 1 Bottle (0003-6336-17)	0003-6336	300 mg/1	Human Prescription Drug	Hydroxyurea	Oral	NDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	June 1/2009	N/A
Droxia	Capsule	NDA016295	60 Capsules in 1 Bottle (0003-6337-17)	0003-6337	400 mg/1	Human Prescription Drug	Hydroxyurea	Oral	NDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	June 1/2009	N/A
Hydroxyurea	Capsule	ANDA075143	100 Capsules in 1 Bottle (0555-0882-02)	0555-0882	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	October 19/1998	N/A
Hydroxyurea	Capsule	ANDA075143	100 Capsules in 1 Bottle (42291-321-01)	42291-321	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	July 19/2003	N/A
Hydroxyurea	Capsule	ANDA075340	100 Capsules in 1 Bottle (49884-724-01)	49884-724	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	February 24/1999	N/A

TABLE 8:
Sub-metrics by Measure for Aim 1

AIM 1: INCREASE THE NUMBER OF PROVIDERS TREATING PERSONS WITH SICKLE CELL DISEASE	
Measure 1a: Number of providers in plan who saw at least one patient younger than 18 years of age with SCD two or more times during the past 12 months	
	Number of providers in plan seeing patients ages <1 with SCD (broad definition) twice in past 12 months
	Number of providers in plan seeing patients ages <1 with SCD (narrow definition) twice in past 12 months
	Number of providers in plan seeing patients ages 1-4 yrs with SCD (broad definition) twice in past 12 months
	Number of providers in plan seeing patients ages 1-4 yrs with SCD (narrow definition) twice in past 12 months
	Number of providers in plan seeing patients ages 5-12 yrs with SCD (broad definition) twice in past 12 months
	Number of providers in plan seeing patients ages 5-12 yrs with SCD (narrow definition) twice in past 12 months
	Number of providers in plan seeing patients ages 13-17 yrs with SCD (broad definition) twice in past 12 months
	Number of providers in plan seeing patients ages 13-17 yrs with SCD (narrow definition) twice in past 12 months
Measure 1b: Number of providers in plan who saw at least one adult patient with SCD two or more times during the past 12 months	
	Number of providers in plan seeing patients ages 18-21 with SCD (broad definition) yrs twice in past 12 months
	Number of providers in plan seeing patients ages 18-21 yrs with SCD (narrow definition) twice in past 12 months
	Number of providers in plan seeing patients ages 21+ yrs with SCD (broad definition) twice in past 12 months
	Number of providers in plan seeing patients ages 21+ yrs with SCD (narrow definition) twice in past 12 months
Measure 1c: Number of providers in plan who saw any patient with SCD two or more times during the past 12 months	
	Number of providers in plan seeing patients with SCD (broad definition) in past 12 months
	Number of providers in plan seeing patients with SCD (narrow definition) in past 12 months
Measure 1d: Percentage of children in plan with SCD who had at least two outpatient visits in the past 12 months.	
	Number of patients in plan <1 yr with SCD (broad definition) who had two outpatient visits in past 12 months
	Number of patients in plan <1 yr with SCD (narrow definition) who had two outpatient visits in past 12 months
	Number of patients in plan 1-4 yrs with SCD (broad definition) who had two outpatient visits in past 12 months
	Number of patients in plan 1-4 yrs with SCD (narrow definition) who had two outpatient visits in past 12 months
	Number of patients in plan 5-12 yrs with SCD (broad definition) who had two outpatient visits in past 12 months
	Number of patients in plan 5-12 yrs with SCD (narrow definition) who had two outpatient visits in past 12 months
	Number of patients in plan 13-17 yrs with SCD (broad definition) who had two outpatient visits in past 12 months
	Number of patients in plan 13-17 yrs with SCD (narrow definition) who had two outpatient visits in past 12 months
Measure 1e: Number of adults in plan with SCD who had at least two outpatient visits in the past 12 months.	
	Number of patients ages 18-21 yrs with SCD (broad definition) who had two outpatient visits in past 12 months
	Number of patients ages 18-21 yrs with SCD (narrow definition) who had two outpatient visits in past 12 months
	Number of patients aged 21+ yrs with SCD (broad definition) who had two outpatient visits in past 12 months
	Number of patients aged 21+ yrs with SCD (narrow definition) who had two outpatient visits in past 12 months

CONTINUED

TABLE 9: CONTINUED

Sub-metrics by Measure for Aim 2

AIM 2: INCREASE THE NUMBER OF PROVIDERS PROVIDING HYDROXYUREA	
Measure 2a: Number of providers in plan who prescribed hydroxyurea to a child with SCD at least once during the past 12 months	
	Number of providers in plan who prescribed hydroxyurea to a patient <1 yr with SCD (broad definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient <1 yr with SCD (narrow definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient 1-4 yrs with SCD (broad definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient 1-4 yrs with SCD (narrow definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient 5-12 yrs with SCD (broad definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient 5-12 yrs with SCD (narrow definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient 13-17 yrs with SCD (broad definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient 13-17 yrs with SCD (narrow definition) at least once during the past 12 months
Measure 2b: Number of providers in plan who prescribed hydroxyurea to an adult with SCD at least once during the past 12 months	
	Number of providers in plan who prescribed hydroxyurea to a patient aged 18-21 yrs with SCD (broad definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient aged 18-21 yrs with SCD (narrow definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient aged 21+ yrs with SCD (broad definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to a patient aged 21+ yrs with SCD (narrow definition) at least once during the past 12 months
Measure 2c: Number of providers in Plan who prescribed hydroxyurea at least once during the past 12 months	
	Number of providers in plan who prescribed hydroxyurea to patients with SCD (broad definition) at least once during the past 12 months
	Number of providers in plan who prescribed hydroxyurea to patients with SCD (narrow definition) at least once during the past 12 months

CONTINUED

TABLE 9: CONTINUED

Sub-metrics by Measure for Aim 2

AIM 2: INCREASE THE NUMBER OF PROVIDERS PROVIDING HYDROXYUREA	
Measure 2d: Number of children with SCD who filled a prescription for hydroxyurea at least once during the past 12 months	
	Number of patients with SCD (broad definition) ages 1-4 who filled a prescription for hydroxyurea at least once during the past 12 months
	Number of patients with SCD (narrow definition) ages 1-4 who filled a prescription for hydroxyurea at least once during the past 12 months
	Number of patients with SCD (broad definition) ages 5-12 who filled a prescription for hydroxyurea at least once during the past 12 months
	Number of patients with SCD (narrow definition) ages 5-12 who filled a prescription for hydroxyurea at least once during the past 12 months
	Number of patients with SCD (broad definition) ages 13-17 who filled a prescription for hydroxyurea at least once during the past 12 months
	Number of patients with SCD (narrow definition) ages 13-17 who filled a prescription for hydroxyurea at least once during the past 12 months
Measure 2e: Number of adults with SCD who filled a prescription for hydroxyurea at least once during the past 12 months	
	Number of patients with SCD (broad definiton) aged 18-21 yrs who filled a prescription for hydroxyurea at least once during the past 12 months
	Number of patients with SCD (narrow definiton) aged 18-21 yrs who filled a prescription for hydroxyurea at least once during the past 12 months
	Number of patients with SCD (broad definiton) aged 21+ yrs who filled a prescription for hydroxyurea at least once during the past 12 months
	Number of patients with SCD (narrow definiton) aged 21+ yrs who filled a prescription for hydroxyurea at least once during the past 12 months

TABLE 10:

Sickle Cell Treatment Demonstration Program
Data Request — Sample Data Form — Measure 1a

MEASURE TYPE (PROVIDER, LOCATION, ZIP3, ZIP5, OR STATE)	POPULATION ID (BASED ON MEASURE TYPE)	REFERENCE PERIOD	REFERENCE PERIOD START DATE	REFERENCE PERIOD END DATE
Provider	Zip3 = 019 or State = MD	Month-Year for monthly measures (10-2014) Quarter- Year for quarterly measures (Q1-2014)	Date reference period begins (06/11/1997)	Date reference period ends (11/30/2004)

NUMERATOR COUNT	DENOMINATOR COUNT	SYSTEM DATE	DATA SOURCE
# Providers from the denominator population who saw at least one patient with SCD who was less than 18 years old at the time of the visit for at least two non-emergent outpatient visits during the 12-month period ending with the reference month	# Providers who had at least one claim submitted to the plan during the 12-month period ending with the reference month	Date report was run (11/30/2004)	CMS data, Managed Care Plan data, etc.)

TABLE 11:

November 3-4, 2014 SCDTDP Data Summit – Participant List

NAME	ROLE	AFFILIATION
William Adams	Pediatrician, informatics researcher	Boston Medical Center
Michele Ako	Research intern, pediatric hematology	Northeast Coordinating Center
Nina Anderson	Primary care provider	Northeast Coordinating Center
Mary Brown	President & CEO of the Sickle Cell Disease Foundation of California	SCDAA
Emily Clermont	Senior project manager	NICHQ
Alice Cohen	Hematologist	Northeast Coordinating Center
Ben Cooper	Data manager	Heartland Sickle Cell Disease Network
Denise Dougherty	Federal partner	AHRQ
Jim Eckman	Hematologist	Emory University School of Medicine
Patricia Finnerty	Improvement advisor	NICHQ
Jonathan Goldsmith	Federal partner	FDA
Althea Grant	Epidemiologist	CDC
Carlton Haywood	Epidemiologist, clinical researcher, patient with SCD	The Johns Hopkins School of Medicine
Charlie Homer	Pediatrician, former CEO of NICHQ	NICHQ
Mary Hulihan	Health sciences researcher	CDC
Alan Ikeda	Pediatric hematologist	Pacific Sickle Cell Regional Collaborative
Donnell Ivy	Project officer	HRSA
Trish Kavanagh	Pediatrician	Boston Medical Center
Allison King	Pediatric hematologist	Heartland Sickle Cell Disease Network
Norma Lerner	Federal partner	NHLBI
Michael Lu	Associate administrator	HRSA
Tammy Nordheim	Project manager	Sickle Cell Treatment and Outcomes Research in the Midwest (STORM)
Diane Nugent	Pediatric hematologist	Pacific Sickle Cell Regional Collaborative
Suzette Oyeku	Pediatrician, NCC medical director	NICHQ/ Children's Hospital at Montefiore
Susan Paulukonis	Epidemiologist	Pacific Sickle Cell Regional Collaborative

CONTINUED

TABLE 11: CONTINUED

November 3-4, 2014 SCDTDP Data Summit – Participant List

NAME	ROLE	AFFILIATION
Madelyn Reyes	Federal partner	HRSA
Yaffa Rubinstein	Federal partner	NIH
Kay Saving	Pediatric hematologist	Sickle Cell Treatment and Outcomes Research in the Midwest (STORM)
Joan Scott	Genetic Service Branch Chief	HRSA
Avery Seefeld	Project manager	NICHQ
Lisa Shook	Health services researcher	Sickle Cell Treatment and Outcomes Research in the Midwest (STORM)
Kim Smith-Whitley	Pediatric hematologist	The Children's Hospital of Philadelphia
Rosalyn Stewart	Pediatrician	Northeast Coordinating Center
Bonnie Strickland	Retired	HRSA
John Strouse	Pediatric hematologist	Northeast Coordinating Center
Christina Turgel	Federal partner	HRSA
Kate Vaughan	Associate director	NICHQ
Nicole Verdun	Federal partner	FDA
Ellen Werner	Program director	NHLBI
Lauren Whiteman	Program coordinator, analyst	Northeast Coordinating Center

TABLE 10:
On Monday, August 15, 2016 over 92 members of the public came together at the National Institutes of Health to discuss how to leverage measurement and data to improve sickle cell disease treatment nationally.

SCDTDP: Leveraging 10 Years of Measurement & Data

Monday, August 15, Building 10, National Institutes of Health
Public meeting: 9:00 am-3:30 pm (Rooms 3 & 4)
Closed meeting of the SCDTDP Oversight Steering Committee: 3:30–4:30pm (Room 6)

August 15, 2016, SCDTDP Measurement & Data Gathering Agenda

TIME	SESSION DESCRIPTION	SPEAKERS
9:00-9:30 am	**CHECK-IN**	
9:30-9:45 am	**Welcome & Overview of the Day**	Suzette Oyeku, MD, MPH Donnell Ivy, MD, MPH Ellen Werner, PhD, MA
9:45-10:45 am	**Morning Session 1** **SCDTDP Regional Coordinating Center Report Out** In this opening session, the SCDTDP Regional Collaborative Centers (RCCs) will share updates on their progress, challenges and lessons learned in meeting the three aims of the SCDTDP.	John J. Strouse, MD, PhD Rosalyn Stewart, MD, MS, MBA Lisa Shook, MA, MCHES Marsha Treadwell, PhD Allison King, MD, PhD
10:45-10:55 am	**BREAK**	
10:55 am-12:00 pm	**Morning Session 2** **SCDTDP Data: Lessons Learned** This panel presentation shares an overview of the collective data and measurement approach that the SCDTDP grantees are employing across 23 states and 4 regions. This overview includes multiple measurement approaches, successes, challenges and lessons learned thus far.	Lauren N. Whiteman, MPH Lisa Shook, MA, MCHES Marsha Treadwell, PhD Allison King, MD, PhD Suzette Oyeku, MD, MPH
12:00-1:00 pm	**LUNCH**	
1:00-2:00 pm	**Afternoon Session 1** **Prioritizing Sickle Cell Disease Domains for Provider Education** Participants will break out into working groups of 5-6 people and use a matrix tool to prioritize domains of SCD provider education. In the second part of this breakout, participants will assess the potential for measurement and data collection across these domains to report out.	Facilitator: Suzette Oyeku, MD, MPH
2:00-2:10 pm	**BREAK**	
2:10-3:10 pm	**Afternoon Session 2** **Leveraging a Decade of SCDTDP Work to Move Forward** The final session for the day has participants leveraging the previous session content and exercises. Participants will break out into groups of 5-6 people for an in-depth strategic review of the domains prioritized in the previous session across a series of questions. Output from this session will be used to inform recommendations for the future of SCD measurement, and identify opportunities for continued SCD measurement and data efforts.	Facilitator: Scott Berns, MD, MPH, FAAP
3:10-3:20 pm	**WRAP UP & NEXT STEPS FROM THE DAY**	
3:20-3:30 pm	**ADJOURN/BREAK FOR THOSE ATTENDING OSC MEETING**	
3:30-4:30 pm	**CLOSED MEETING:** **SCDTDP OVERSIGHT STEERING COMMITTEE QUARTERLY MEETING**	

TABLE 12:
SCDTDP Oversight Steering Committee Members

NAME	POSITION AND AFFILIATION	ROLE IN OSC
Jim Eckman, MD	Professor Emeritus, Hematology and Oncology, Emory University School of Medicine	OSC Chair/ Faculty Member
Keith Marsolo, PhD	Associate Professor, Division of Biomedical Informatics, Cincinnati Children's Hospital Medical Center	OSC member
Senator Gladys Robinson	Deputy Minority Leader, North Carolina Senate	OSC member
Carlton Haywood, PhD, MA	Faculty, Johns Hopkins Berman Institute of Bioethics; Associate Faculty, Welch Center for Prevention, Epidemiology, and Clinical Research; Assistant Professor, Division of Hematology at the Johns Hopkins School of Medicine	OSC member
Lanetta Jordan, MD, MPH, MSPH	Associate Professor, Department of Epidemiology and Public Health Sciences at the University of Miami Miller School of Medicine; Senior Medical Advisor, Centers for Disease Control and Prevention	OSC member
Mary Brown	President & CEO, Sickle Cell Disease Foundation of California	OSC member
Kim Smith-Whitley, MD	Clinical Director of the Division of Hematology and Medical Director of the Sickle Cell Clinical Program, Children's Hospital of Philadelphia; Associate Professor of Pediatrics, Children's Hospital of Philadelphia	OSC member
Mary Hulihan, DrPH	Health Scientist, Centers for Disease Control and Prevention	OSC member
Althea Grant, PhD, MPH	Chief, Epidemiology and Surveillance Branch, Division of Blood Disorders (DBD), National Center on Birth Defects and Developmental Disabilities, Office of Noncommunicable Diseases, Injury and Environmental Health	OSC member
Ellen Werner, PhD	Program Director at National Heart, Lung, and Blood Institute/NIH	OSC member
Allison King, MD, MPH, PhD	Heartland Sickle Cell Disease Network Team Lead	Regional PI
Diane Nugent, MD	Pacific Sickle Cell Regional Collaborative Team Co-Lead	Regional PI
Marsha Treadwell, PhD	Pacific Sickle Cell Regional Collaborative Team Co-Lead	Regional PI
Eliott Vichinsky, MD	Pacific Sickle Cell Regional Collaborative Team Co-Lead	Regional PI
Rosalyn Stewart, MD, MBA, MS	Sickle cell Improvement across the NorthEast ReGion through Education (SiNERGe) Team Co-Lead	Regional PI

CONTINUED

TABLE 12: CONTINUED

SCDTDP Oversight Steering Committee Members

NAME	POSITION AND AFFILIATION	ROLE IN OSC
John J. Strouse, MD, PhD	Sickle cell Improvement across the NorthEast ReGion through Education (SiNERGe) Team Co-Lead	Regional PI
Lisa Shook, MA	Sickle Treatment and Outcomes Research in the Midwest (STORM) Team Lead	Regional PI
Jean Raphael, MD	Attending Physician, Texas Children's Hospital; Assistant Professor, Pediatrics, Section of Academic General Pediatrics, Baylor College of Medicine	Faculty Member
Bill Adams, MD	NCC Informatics Director; Associate Professor, Pediatrics, Boston University School of Medicine	Faculty Member
Talana Hughes, MPH	Executive Director, Sickle Cell Disease Association of Illinois	Faculty Member
Patricia Kavanagh, MD	Assistant Professor of Pediatrics, Boston University School of Medicine	Faculty Member
Scott Berns, MD, MPH	National Coordinating Center Principal Investigator	Faculty Member, NCC Staff
Suzette Oyeku, MD, MPH	National Coordinating Center Medical Director	Faculty Member, NCC Staff
Sabrina Selk, ScD	National Coordinating Center Project Director	NCC Staff
Camie Berardi, MPA	National Coordinating Center Senior Project Manager	NCC Staff
Barbara Lambiaso, MSW, MPH	National Coordinating Center Project Manager	NCC Staff
Edward Donnell Ivy, MD, MPH	Health Resources and Services Administration Medical Officer	HRSA Staff
Andrea Williams	Health Resources and Services Administration Project Officer	HRSA Staff
Joan Scott, MS	Deputy Director, Division of Services for Children with Special Health Needs, Health Resources and Services Administration	HRSA Staff

TABLE 13:
MDS 1 (Hydroxyurea use) Percent of Patients 9 Months or Older Prescribed Hydroxyrea

AGE	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
9 Months to Less Than 18 Years Old	Count of SCD patients ≥9 months and < 18 years of age as of last day of the measurement period who are eligible candidates for hydroxyrea	Count of SCD patients ≥9 months and < 18 years of age as of last day of the measurement period who have an active prescription for hydroxyrea	Eligible candidates for hydroxyurea include individuals >=9 months of age and up with SS or Sb0thal that have had ≥ 3 sickle cell-associated moderate to severe pain crises in 12 months, pain that interferes with daily activities or quality of life, history of severe and/or recurrent chest syndrome, symptomatic chronic anemia that interferes with daily activities or quality of life Excluding individuals receiving chronic transfusion therapy (i.e., transfusions that are usually repeated every 3 or 4 weeks as defined by NHLBI guidelines)
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percenteage	Quarterly	N/A
18 and Over	Count of SCD patients 18 years of age and over as of last day of the measurement period who are eligible candidates for hydroxyrea	Count of SCD patients 18 years of age and over as of last day of the measurement period who have an active prescription for hydroxyrea	Eligible candidates for hydroxyurea include individuals >=9 months of age and up with SS or Sb0thal that have had ≥ 3 sickle cell-associated moderate to severe pain crises in 12 months, pain that interferes with daily activities or quality of life, history of severe and/or recurrent chest syndrome, symptomatic chronic anemia that interferes with daily activities or quality of life Excluding individuals receiving chronic transfusion therapy (i.e., transfusions that are usually repeated every 3 or 4 weeks as defined by NHLBI guidelines)
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	N/A

TABLE 14:

MDS 2 (Not using Hydroxyurea) Reasons Patients are Giving for Not Using Hydroxyurea

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Declined	Count of eligible SCD patients that are not being prescribed hydroxyurea	Count of eligible SCD patients that declined a hydroxyurea prescription	Eligible candidates for hydroxyurea include individuals ≥9 months of age and up with SS or Sb0thal that have had ≥ 3 sickle cell-associated moderate to severe pain crises in last 12 months, pain that interferes with daily activities or quality of life, history of severe and/or recurrent chest syndrome, symptomatic chronic anemia that interferes with daily activities or quality of life Excluding individuals receiving chronic transfusion therapy (i.e., transfusions that are usually repeated every 3 or 4 weeks as defined by NHLBI guidelines)
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Reasons that qualify as Declined: • Hydroxyurea was offered to the patient/family, but they were not interested • Hydroxyurea was previously prescribed but was discontinued due to Patient Family Preference
Medical Exclusion	Count of eligible SCD patients that are not being prescribed hydroxyurea	Count of eligible SCD patients not using hydroxyurea due to medical exclusions	Eligible candidates for hydroxyurea include individuals ≥ 9 months of age and up with SS or Sb0thal that have had ≥ 3 sickle cell-associated moderate to severe pain crises in last 12 months, pain that interferes with daily activities or quality of life, history of severe and/or recurrent chest syndrome, symptomatic chronic anemia that interferes with daily activities or quality of life Excluding individuals receiving chronic transfusion therapy (i.e., transfusions that are usually repeated every 3 or 4 weeks as defined by NHLBI guidelines)
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Reasons that qualify as medical exclusion: • Patient has no overt clinical indication that warrants use of hydroxyurea • Empiric treatment has not been indicated • Concerns about whether patient/family will be adherent with medication treatment • Concerns about whether patient/family will be adherent with the monitoring protocol (e.g., lab work) • Hydroxyurea was previously prescribed but had to be discontinued due to medical side effects

CONTINUED

TABLE 14: CONTINUED

MDS 2 (Not using Hydroxyurea) Reasons Patients are Giving for Not Using Hydroxyurea

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Other Reasons	Count of eligible SCD patients that are not being prescribed hydroxyurea	Count of eligible SCD patients not using hydroxyurea for other reasons	Eligible candidates for hydroxyurea include individuals ≥9 months of age and up with SS or Sb0thal that have had ≥ 3 sickle cell-associated moderate to severe pain crises in last 12 months, pain that interferes with daily activities or quality of life, history of severe and/or recurrent chest syndrome, symptomatic chronic anemia that interferes with daily activities or quality of life Excluding individuals receiving chronic transfusion therapy (i.e., transfusions that are usually repeated every 3 or 4 weeks as defined by NHLBI guidelines)
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Reasons that quality as Other: • Hydroxyurea may be indicated for this patient, however, it has not yet been introduced (e.g., Doctor could not previously prescribe because patient was not eligible yet) • Hydroxyurea was previously prescribed but had to be discontinued best patient driven example: "patient was prescribed medication but has not filled prescription," best provider driven example: "the medication was not effective for the patient") • Other Reason(general) Please annotate what the reasons are based on qualifying descriptions above.
Unknown	Count of eligible SCD patients that are not being prescribed hydroxyurea	Count of eligible SCD patients not using hydroxyurea for unknown reasons	Eligible candidates for hydroxyurea include individuals ≥9 months of age and up with SS or Sb0thal that have had ≥ 3 sickle cell-associated moderate to severe pain crises in last 12 months, pain that interferes with daily activities or quality of life, history of severe and/or recurrent chest syndrome, symptomatic chronic anemia that interferes with daily activities or quality of life Excluding individuals receiving chronic transfusion therapy (i.e., transfusions that are usually repeated every 3 or 4 weeks as defined by NHLBI guidelines)
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Unspecified; no documentation for reason in medical records (e.g., no response from patient)

TABLE 15:

MDS 3: (Has a Primary Care Provider) Percentage of SCD patients who have a Primary Care Provider (PCP)

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Under 18	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of SCD patients under 18 years of age as of last day of the measurement period that has seen a Generalist PCP (e.g., Family physician, Pediatrician, Internist, General PCP) in the last 24 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
18 and Over	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of SCD patients 18 years of age and over as of last day of the measurement period that have seen a Generalist PCP (e.g., Family physician, Pediatrician, Internist, General PCP) in the last 24 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records

TABLE 16:
MDS 4: (Genotype) Distribution of SCD Genotypes

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Sickle Cell Disease (SS)	Count of SCD patients	Count of SCD patient with genotype Sickle Cell Disease (SS) documented	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams should annotate whether aggregate data was lab confirmation, patient reported, or unknown
Sickle Hemoglobin C Disease (SC)	Count of SCD patients	Count of SCD patients with genotype Sickle Hemoglobin C Disease (SC) documented	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams should annotate whether aggregate data was lab confirmation, patient reported, or unknown
Sickle Beta-Plus Thalassemia	Count of SCD patients	Count of SCD patient with genotype Sickle Beta-Plus Thalassemia documented	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams should annotate whether aggregate data was lab confirmation, patient reported, or unknown
Sickle Beta-Zero Thalassemia	Count of SCD patients	Count of SCD patients with genotype Sickle Beta-Zero Thalassemia documented	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams should annotate whether aggregate data was lab confirmation, patient reported, or unknown

CONTINUED

TABLE 16: CONTINUED

MDS 4: (Genotype) Distribution of SCD Genotypes

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Other	Count of SCD patients	Count of SCD patient with genotype "other" documented	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams should annotate whether aggregate data was lab confirmation, patient reported, or unknown
Don't Know	Count of SCD patients	Count of SCD patient with unknown genotype	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams should annotate whether aggregate data was lab confirmation, patient reported, or unknown

TABLE 17:

MDS 5a (ED/Day Hospital Visits) Average Number of ED/Day Hospital Visits for Pain that Do Not Result in a Hospital Admission per SCD Patient in the Past 12 Months

UNDER 18	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
0 Visits	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of 0 ED/Day hospital visits for SCD patients under 18 years of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records
1 Visits	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of one ED/Day hospital visits for SCD patients under 18 years of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records
2 Visits	Denominator and numerator counts and percentage	Count of 2 ED/day hospital visits for SCD patients under 18 years of age as of the last day of the measurement period in the last 12 months	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records

CONTINUED

TABLE 17: CONTINUED

MDS 5a (ED/Day hospital Visits) Average Number of ED/Day Hospital Visits for Pain that Do Not Result in a Hospital Admission per SCD Patient in the Past 12 Months

UNDER 18	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
3 Visits	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of 3 ED/Day hospital visits for SCD patients under 18 year of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records
4+ Visits	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of 4+ ED/Day hospital visits for SCD patients under 18 year of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records

CONTINUED

TABLE 17: CONTINUED

MDS 5a (ED/Day Hospital Visits) Average Number of ED/Day Hospital Visits for Pain that Do Not Result in a Hospital Admission per SCD Patient in the Past 12 Months

18 AND OVER	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
0 Visits	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of 0 ED/Day hospital visits for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records
1 Visits	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of one ED/Day hospital visit for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records
2 Visits	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of 2 ED/Day hospital visits for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentag	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records

CONTINUED

TABLE 17: CONTINUED

MDS 5a (ED/Day Hospital Visits) Average Number of ED/Day Hospital Visits for Pain that Do Not Result in a Hospital Admission per SCD Patient in the Past 12 Months

18 AND OVER	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
3 Visits	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of 3 ED/Day hospital visits for SCD patients 18 year of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records
4+ Visits	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of 4+ ED/Day hospital visits for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	For pain defined as a visit due to a general pain Teams can annotate whether information was taken from patient report or electronic medical records

TABLE 18:

MDS 5b: (Day Hospital Visits) Average Number of Day Hospital Visits That Did Not Result in a Hospital Admission per SCD Patient in The Past 12 Months

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Under 18	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of Day hospital visits for SCD patients under 18 years of age as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
18 and over	Count of SCD patients 18 years of age and older as of last day of the measurement period	Count of Day Hospital visits for SCD patients 18 years of age and older as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records

TABLE 19:
MDS 5c: (SCD-Related ED/Day Hospital Visits) Average Number of SCD-Related ED/Day Hospital Visits per SCD Patient in the Past 12 Months

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Under 18	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of hospital admissions for SCD patients under 18 years of age as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	SCD-related defined as a visit due to a pain crisis Teams can annotate whether information was taken from patient report or electronic medical records
18 and Over	Count of SCD patients 18 years of age and older as of last day of the measurement period	Count of hospital admissions for SCD patients 18 years of age and older as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	SCD-related defined as a visit due to a pain crisis Teams can annotate whether information was taken from patient report or electronic medical records

TABLE 20:

MDS 6a: (Hospital Admission) Average Number of Hospital Admissions per SCD Patient in Past 12 Months

UNDER 18	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
0 Admissions	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of 0 hosptial admissions for SCD patients under 18 years of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
1 Admissions	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of one hosptial admissions for SCD patients under 18 years of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
2 Admissions	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of 2 hosptial admissions for SCD patients under 18 years of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records

CONTINUED

TABLE 20: CONTINUED

MDS 6a: (Hospital Admission) Average Number of Hospital Admissions per SCD Patient in Past 12 Months

UNDER 18	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
3 Admissions	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of 3 hosptial admissions for SCD patients under 18 years of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
4+ Admissions	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of 4+ hosptial admissions for SCD patients under 18 years of age as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records

CONTINUED

TABLE 20: CONTINUED

MDS 6a: (Hospital Admission) Average Number of Hospital Admissions per SCD Patient in Past 12 Months

18 AND OVER	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
0 Admissions	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of 0 hosptial admissions for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
1 Admissions	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of one hosptial admission for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
2 Admissions	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of 2 hosptial admissions for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records

CONTINUED

TABLE 20: CONTINUED

MDS 6a: (Hospital Admission) Average Number of Hospital Admissions per SCD Patient in Past 12 Months

18 AND OVER	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
3 Admissions	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of 3 hosptial admissions for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
4+ Admissions	Count of SCD patients 18 years of age and over as of last day of the measurement period	Count of 4+ hosptial admissions for SCD patients 18 years of age and over as of last day of the measurement period in the last 12 months	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records

TABLE 21:
MDS 6b: (Hospital Admissions) Average Number of Hospital Admissions per SCD Patient in the Past 12 Months

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Under 18	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of hospital admissions for SCD patients under 18 years of age as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
18 and Older	Count of SCD patients 18 years of age and older as of last day of the measurement period	Count of hospital admissions for SCD patients 18 years of age and older as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records

TABLE 23: MDS 6c: (SCD-related Hospital Admissions) Average Number of SCD-Related Hospital Admissions per SCD Patient in the Past 12 Months

	DENOMINATOR POPULATION	NUMERATOR POPULATION	EXCLUSIONS
Under 18	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of SCD related hospital admissions for SCD patients under 18 years of age as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	SCD-related defined as a admission due to a pain crisis Teams can annotate whether information was taken from patient report or electronic medical records
18 and Older	Count of SCD patients 18 years of age and older as of last day of the measurement period	Count of SCD related hospital admissions for SCD patients 18 years of age and over as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	SCD-related defined as a admission due to a pain crisis Teams can annotate whether information was taken from patient report or electronic medical records

TABLE 23:

MDS 7b: (ED Visits) Average Number of ED Visits that Did Not Result in a Hospital Admission per SCD Patient in the Past 12 Months

	DENOMINATOR POPULATION	NUMERATOR POPULATION	COMMENTS
Under 18	Count of SCD patients under 18 years of age as of last day of the measurement period	Count of ED visits for SCD patients under 18 years of age as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patient report or electronic medical records
18 and Older	Count of SCD patients 18 years of age and older as of last day of the measurement period	Count of ED visits for SCD patients 18 years of age and older as of last day of the measurement period	N/A
	REPORTING OUTPUTS	**REPORTING INTERVAL**	**COMMENTS**
	Denominator and numerator counts and percentage	Quarterly	Teams can annotate whether information was taken from patent report or electronic medical records

Sickle Cell Treatment Demonstration Program

TABLE 24:

Codes to Identify Sickle Cell Disease

CONDITION	ICD-9	ICD-10
Hb S Beta-thalassemia	282.41, 282.42	D57.40, D57.41
Hb SS-disease (Sickle Cell Anemia)	282.6, 282.61, 282.62	D57 Sickle cell disorders D57.0 Sickle cell anemia with crisis D57.1 Sickle cell anemia without crisis
Hb SC-disease	282.63, 282.64	D57.20, D57.21
Hb SD-disease	282.68, 282.69	D57.80, D57.81
Hb SE-disease	282.68, 282.69	D57.80, D57.81

TABLE 25:

Codes to Identify Outpatient Care

DESCRIPTION	CPT	ICD-9
Office or Other Outpatient Services	99201-99205, 99211-99215, 99241-99245	
Preventive Medicine	99381-99385, 99391-99395, 99401-99404, 99411-99412, 99420, 99429	
General Medical Examination		V20.2, V70.0, V70.3, V70.5, V70.6, V70.8

TABLE 26:

Excluded Sickle Cell-Related Codes

CONDITION	ICD-9	ICD-10
Hb S (Sickle)-Carrier (Sickle Cell Trait)	282.5	D57.3
General Medical Examination		V20.2, V70.0, V70.3, V70.5, V70.6, V70.8

TABLE 27:
National Drug Code Directory

PROPRIETARY NAME	DOSAGE FORM NAME	APPLICATION NUMBER	PACKAGE DESCRIPTION	PRODUCT NDC	STRENGTH	PRODUCT TYPE NAME	NON-PROPRIETARY NAME	ROUTE NAME	MARKET CATEGORY NAME	LABELER NAME	SUBSTANCE NAME	PHARM CLASS	DEA	START DATE	END DATE
Hydroxyurea	Capsule	ANDA075143	30 Capsules in 1 Bottle, Plastic (54868-4773-0)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075143	100 Capsules in 1 Bottle, Plastic (54868-4773-1)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075143	50 Capsules in 1 Bottle, Plastic (54868-4773-2)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075143	60 Capsules in 1 Bottle, Plastic (54868-4773-3)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075143	40 Capsules in 1 Bottle, Plastic (54868-4773-4)	54868-4773	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	April 11/2003	N/A
Hydroxyurea	Capsule	ANDA075340	100 Capsules in 1 Bottle (60429-265-01)	60429-265	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Golden State Medical Supply, Inc.	Hydroxyurea	N/A	N/A	Frbruary 24/1999	N/A
Hydroxyurea	Capsule	ANDA075340	100 Blister Packs in 1 Box, Unit-Dose (68084-284-01) > 1 Capsule in 1 Blister Packs (68084-284-11)	68084-284	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	American Health Packaging	Hydroxyurea	N/A	N/A	August 12/2008	N/A
Hydrea	Capsule	NDA016295	100 Capsules in 1 Bottle (0003-0830-50)	0003-0830	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	NDA	E.R. Squibb & Sons, L.L.C.	Hydroxyurea	N/A	N/A	June 1/2009	N/A
Droxia	Capsule	NDA016295	60 Capsules in 1 Bottle (0003-6335-17)	0003-6335	200 mg/1	Human Prescription Drug	Hydroxyurea	Oral	NDA	E.R. Squibb & Sons, L.L.C.	Hydroxyurea	N/A	N/A	June 1/2009	N/A

TABLE 27: CONTINUED

National Drug Code Directory

PROPRIETARY NAME	DOSAGE FORM NAME	APPLICATION NUMBER	PACKAGE DESCRIPTION	PRODUCT NDC	STRENGTH	PRODUCT TYPE NAME	NON-PROPRIETARY NAME	ROUTE NAME	MARKET CATEGORY NAME	LABELER NAME	SUBSTANCE NAME	PHARM CLASS	DEA	START DATE	END DATE
Droxia	Capsule	NDA016295	30 Capsules in 1 Bottle (0003-6336-17)	0003-6336	300 mg/1	Human Prescription Drug	Hydroxyurea	Oral	NDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	June 1/2009	N/A
Droxia	Capsule	NDA016295	60 Capsules in 1 Bottle (0003-6337-17)	0003-6337	400 mg/1	Human Prescription Drug	Hydroxyurea	Oral	NDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	June 1/2009	N/A
Hydroxyurea	Capsule	ANDA075143	100 Capsules in 1 Bottle (0555-0882-02)	0555-0882	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	October 19/1998	N/A
Hydroxyurea	Capsule	ANDA075143	100 Capsules in 1 Bottle (42291-321-01)	42291-321	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	July 19/2003	N/A
Hydroxyurea	Capsule	ANDA075340	100 Capsules in 1 Bottle (49884-724-01)	49884-724	500 mg/1	Human Prescription Drug	Hydroxyurea	Oral	ANDA	Physicians Total Care, Inc.	Hydroxyurea	N/A	N/A	February 24/1999	N/A

E. Program Evaluation

SUMMARY

OVERVIEW

NICHQ conducted a program evaluation of the SCDTDP's ability to achieve its stated aims. Qualitative data collected in semi-structured interviews provided background information that highlights the "why" behind the "what." The story of what enabled success and what hindered progress for whom, how and why. Participants' perspectives were used to evaluate, suggest changes, and make recommendations to the project and to describe stakeholders' experiences. Interviews took place at two points during the project. The methods and results for each are described below.

MIDPOINT EVALUATION

The midpoint evaluation involved semi-structured interviews with a representative from each of the RCCs as well as several state teams. State partners were selected to represent a range of geographical locations and a variety of challenges and successes in key areas including data capacity, telementoring, provider education, and HU. The interviews took place between June and August 2016 and focused on project activities, successes and challenges faced at the regional and state level, and needs related to spread and sustainability.

The results of these interviews highlighted teams' challenges and achievements related to building infrastructure for data collection and building networks for reaching more providers with SCD educational activities and resources. Many explained that the amount of time and effort related to building infrastructure was much greater than anticipated and, as a result, they did not expect to see quantitative evidence related to achieving the project aims until the final year of the project. Participants also described the impact of their efforts on patient access that may not be reflected quantitatively. This included the value of community health workers, the early successes of telementoring activities, and the demand for adult providers. These results informed the NCC's coordination of events and communications in the final year of the project and provided qualitative information to describe the teams' experiences towards reaching the project aims.

SUMMATIVE EVALUATION

The summative evaluation involved semi-structured interviews with individuals who participated in SCDTDP educational opportunities representing three out of the four regions. The interviews took place between May and June 2017. The goals of these interviews were to 1) learn more about what motivated individuals to participate in events or opportunities related to learning about SCD care, and 2) gather qualitative data about the value of these activities. The interviews provided insight into participants' positive experiences with Project ECHO®. Many participants highlighted the need for more buy-in from PCPs to learn to manage or co-manage their SCD and several suggested adding SCD management to medical school curriculum. These results provided additional support for the recommendations developed with OSC members, faculty members, and the RCCs through the SCDTDP between 2014 and 2017.

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: State Partners

Thank you for taking the time out of your schedule to participate today! My name is [interviewer], and I'm an evaluator at NICHQ.

As I wrote in my invitation, this interview is part of the evaluation of SCDTDP. The purpose of the evaluation is to see what is and is not working well to achieve the project's aims, specifically, to increase the number of providers knowledgeable about sickle cell disease, the number of providers treating individuals with sickle cell disease, and the number of providers prescribing hydroxyurea. Your participation in this evaluation will help us to make recommendations for improving the program in order to increase patient access to SCD treatment.

This interview should last about 45 minutes. Your participation is completely voluntary; you can decline to answer any questions, and can end the call at any time.

I'll be taking notes throughout the discussion to make sure we don't miss anything you have to say. I would also like to record our session today to ensure we capture your responses correctly in our notes, but NICHQ evaluation researchers are the only ones who would ever listen to the tape. Do I have your consent to record the interview?

- [If yes]: Thank you!
- [If no]: Certainly. We will not record the interview.

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: State Partners

QUESTION	NOTES
1. What has been your state's biggest success in the project to-date in terms of the project's aims to increase the number of providers knowledgeable about SCD, the number of providers treating patients with sickle cell disease, and/or the number of providers prescribing hydroxyurea? **Probes:** • What is the biggest challenge your state has overcome to-date? How was it overcome? • What is the biggest challenge your state still faces? • What might help to remove the barriers posed by those challenges?	
2. Please describe how providers in your state treat individuals living with SCD. What models of care are being used? **Probes:** • What care do patients living with SCD receive? • Which kinds of providers typically see patients with SCD? • Which settings are individuals being treated in? Pediatrics, Emergency Medicine, Adult Primary Care, Specialists? • What do clinicians do? • What are the pros & cons of the care that is being provided in your state?	
3. Over the past year, has anything changed about the number of providers who prescribe hydroxyurea? **Probes:** • Over the past year, has anything changed about how providers prescribe hydroxyurea? • How do providers within your state educate patients about hydroxyurea?	
4. To what extent, if any, have patients in your state demonstrated improved knowledge and/or understanding regarding hydroxyurea?	
5. To what extent, have patients living with SCD in your state experienced changes in access to care since the start of this project in September 2014? **Probes:** • To what extent, if at all, has the number of providers treating SCD increased? • To what extent, if at all, have providers' caseloads increased?	
6. In what ways are regional coordinating centers affecting provider education and knowledge regarding SCD in your state?	
7. What could help your state to accomplish more? **Probe:** • That's great, is there content or technical assistance that would help facilitate your state accomplishing more?	

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: RCC Leads

Thank you for taking the time out of your schedule to participate today! My name is [interviewer], and I'm an evaluator at NICHQ.

As I wrote in my invitation, this interview is part of the evaluation of SCDTDP. The purpose of the evaluation is to see what is and is not working well to achieve the project's aims, specifically, to increase the number of providers knowledgeable about sickle cell disease, the number of providers treating individuals with sickle cell disease, and the number of providers prescribing hydroxyurea. Your participation in this evaluation will help us to make recommendations for improving the program in order to increase patient access to SCD treatment.

This interview should last about 45 minutes. Your participation is completely voluntary; you can decline to answer any questions, and can end the call at any time.

I'll be taking notes throughout the discussion to make sure we don't miss anything you have to say. I would also like to record our session today to ensure we capture your responses correctly in our notes, but NICHQ evaluation researchers are the only ones who would ever listen to the tape. Do I have your consent to record the interview?

- [If yes]: Thank you!
- [If no]: Certainly. We will not record the interview.

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: RCC Leads

QUESTION	NOTES
1. What has been your region's biggest success in the project to-date in terms of the project's aims (to increase the number of providers knowledgeable about SCD, the number of providers treating patients with sickle cell disease, and/or the number of providers prescribing hydroxyurea)? **Probes:** • What is the biggest challenge your region has overcome to-date? How was it overcome? • What is the biggest challenge your region still faces? • What might help to remove the barriers posed by those challenges?	
2. Since the start of this project in September 2014, how do you think the number of providers in your region who are knowledgeable about and prescribe hydroxyurea has changed? **Probe:** • How have your region's states changed over the past year?	
3. What impact has the National Coordinating Center's activities had on your region's ability to collaborate with other regional coordinating centers? **Probes:** • For example, what impact has the SCDTDP Collaboratory (or CoLab) had on your level of collaboration with other RCCs? • What project activities have worked well for improving collaboration among regional coordinating centers? Why? • What do you think has contributed to their success? • What project activities have not worked well? Why?	
4. Have NICHQ processes and HRSA support had an impact on your regional coordinating center's efforts? **Probes:** • What has been the impact of any technical assistance, communication, or project management support you've received? • What has been most impactful?	
5. To what extent have patients living with SCD in your state experienced changes in access to care since the start of this project in September 2014? **Probes:** • To what extent, if at all, has the number of providers treating SCD increased? • To what extent, if at all, have providers' caseloads increased?	
6. What could help your region accomplish more? **Probes:** • That's great, is there content or technical assistance that would help facilitate your accomplishing more? • What suggestions do you have to help create overall project improvement?	

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: Providers Who Participated

Thank you for taking the time out of your schedule to participate today! My name is [interviewer], and I'm an evaluator at NICHQ.

As written in the invitation, this interview is part of the evaluation of the Sickle Cell Disease Treatment Demonstration Program. This primary aim of the project is to increase the access and quality of care for patients living with Sickle Cell Disease. There are three primary strategies used to achieve this goal, including: increase the number of providers treating persons with SCD; increase the number of providers prescribing hydroxyurea and increase the number of patients receiving care from knowledgeable providers.

This interview will focus on our efforts to engage providers around caring for patients with SCD, and increasing resources for providers about SCD treatments and the importance of prescribing hydroxyurea. You will be asked about how you were engaged by the SCDTDP programmatic efforts and what worked or didn't work from your perspective. Your participation in this evaluation interview will help us make recommendations for program and policy solutions that will build provider capacity to care for SCD patients and in turn increase patient access to high quality SCD treatment.

This interview should last about 45 minutes. Your participation is completely voluntary; you can decline to answer any questions and can end the call at any time without negative consequences.

I will be taking notes throughout the discussion to make sure we don't miss anything you have to say. I would also like to record our session today to ensure we capture your responses correctly in our notes. NICHQ evaluation researchers are the only ones who would ever listen to the recording. Do I have your consent to record the interview?

- o [If yes]: Thank you!
- o [If no]: Certainly. We will not record the interview.

As promised in the confidentiality statement, none of the information you provide will be linked to your name. Would you feel comfortable with the information you share being associated with your state/region? This may better enable SCDTDP to assist your region/state and/or provide a better understanding of your state/region circumstances.

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: Providers Who Participated

QUESTION	NOTES
1. What is your specialty? (e.g. Internal Medicine, Pediatrics, Hematology)	
2. How many individuals with sickle cell disease do you currently care for?	
3. How comfortable are you with your ability to provide care to patients with SCD?	
4. What resources/tools do you currently use if you have questions about the management of care for individuals with SCD? (For example, NHLBI Expert Panel Report on the Management of SCD)	
5. How did you hear about the continuing medical education (CME) opportunities or other SCD educational activities in your state/region?	
6. In what ways, did you participate in the SCD continuing medical education activities or other SCD educational activities? **Examples:** • Attended TeleECHO® clinics • Utilized SCD education tools (e.g., toolkits) • Attended In-person trainings for CME credit (e.g., grand rounds, symposiums)	
7. What motivated you to participate in the SCD continuing medical education or other SCD educational activities in your state/region? **Probes:** • What did you hope to achieve by participating? • Were you looking for a solution to a problem or were you more broadly interested in expanding your knowledge or expertise around SCD?	
8. Please describe any other benefits for participating that you discovered as you became involved in SCD education activities that you did not initially anticipate?	
9. In what ways has SCD education efforts met or failed to meet your expectations and/or needs?	
10. Has participating in SCD educational opportunities made you more inclined to treat more patients with SCD? Why or why not?	
11. Has participating in SCD educational opportunities made you more inclined to prescribe hydroxyurea to your eligible SCD patients? Why or why not?	

CONTINUED

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: Providers Who Participated CONTINUED

QUESTION	NOTES
12. How would you rate the overall success of the SCD continuing medical education opportunities or other SCD educational activities in your state/region using a scale from one to ten, where one is complete failure and ten is a total success? Why did you rate these efforts as you did? **Probes:** • Quality of group discussions • Relevance of topics • Usability of tools/resources	
13. What challenges or barriers did you experience, if any, that kept you from participating in the SCD education efforts at the level you would have liked to participate? **Examples:** • Lack of incentives • Political climate/legislation at national/state level? (political factors, limited time and finances, organizational structure of health department, data capacity and sharing, demographic and geographic factors) • Aspects of the healthcare system (e.g., provider networks, recruiting providers, reimbursement for time/training, health insurance • Aspects of the SCD Education efforts? • Aspects of your team? (team turnover) • Aspects of SCD? (e.g., rare disease)	
14. Based on the challenges/barriers that you identified, what do you think can be done to address them? *(For interviewer: use examples above if no challenges/barriers were given)*	
15. What other approaches/solutions, if any, do you think might have encouraged more providers to participate in SCD continuing medical education opportunities?	
16. What else do you feel is important to share about SCD continuing medical education or other SCD educational activities that we haven't already covered? What areas of SCD continuing medical education opportunities warrant more attention?	

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: Providers Who Did Not Participated

Thank you for taking the time out of your schedule to participate today! My name is [interviewer], and I'm an evaluator at NICHQ.

As written in the invitation, this interview is part of the evaluation of the Sickle Cell Disease Treatment Demonstration Program. This primary aim of the project is to increase the access and quality of care for patients living with Sickle Cell Disease. There are three primary strategies used to achieve this goal including: increase the number of providers treating persons with SCD; increase the number of providers prescribing hydroxyurea; and to increase the number of patients receiving care from knowledgeable providers.

This interview will focus on our efforts to engage providers around caring for patients with SCD, and increasing resources for providers about SCD treatments and the importance of prescribing HU. You will be asked about how you were engaged by the SCDTDP programmatic efforts and what worked or didn't work from your perspective. Your participation in this evaluation interview will help us make recommendations for program and policy solutions that will build provider capacity to care for SCD patients and in turn increase patient access to high quality SCD treatment.

This interview should last about 45 minutes. Your participation is completely voluntary; you can decline to answer any questions and can end the call at any time without negative consequences.

I will be taking notes throughout the discussion to make sure we don't miss anything you have to say. I would also like to record our session today to ensure we capture your responses correctly in our notes. NICHQ evaluation researchers are the only ones who would ever listen to the recording. Do I have your consent to record the interview?

- [If yes]: Thank you!
- [If no]: Certainly. We will not record the interview.

As promised in the confidentiality statement, none of the information you provide will be linked to your name. Would you feel comfortable with the information you share being associated with your state/region? This may better enable SCDTDP to assist your region/state and/or provide a better understanding of your state/region circumstances.

- [If yes]: Thank you!
- [If no]: Certainly. We will not use your state/region name

SCDTDP MIDPOINT EVALUATION

Stakeholder Interview Guide: Providers Who Did Not Participated CONTINUED

QUESTION	NOTES
1. What is your specialty? (e.g. Internal Medicine, Pediatrics, Hematology)	
2. How many individuals with Sickle Cell Disease (SCD) do you currently care for?	
3. How comfortable are you with your ability to provide care to patients with SCD?	
4. Are you open to seeing more SCD patients? If no, why not?	
5. Are you open to prescribing hydroxyurea (HU) to your eligible SCD patients? If no, why not?	
6. What resources do you currently use if you have questions about the management of individuals with SCD?	
7. Have you heard about SCD continuing medical education opportunities or other SCD educational activities in your state/region? If so, how? **Examples:** • TeleECHO® groups • SCD education tools (e.g., toolkits) • In-person trainings for CME credit (e.g. grand rounds, symposiums)	
8. To what extend did you consider participating in SCD educational opportunities or other SCD educational activities?	
9. What were the challenges/barriers, if any, that kept you from participating in these SCD educational opportunities or other SCD educational activities? **Examples:** • Lack of incentives • Political climate/legislation at national/state level? (political factors, limited time and finances, organizational structure of health department, data capacity and sharing, demographic and geographic factors) • Aspects of the healthcare system (e.g., provider networks, recruiting providers, reimbursement for time/training, health insurance • Aspects of the SCD Education efforts? • Aspects of your team? (team turnover) • Aspects of SCD? (e.g. rare disease)	
10. Based on the challenges/barriers that you identified, what do you think can be done to address them? *(For interviewer: use examples above if no challenges/barriers were given)*	
11. What other approaches/solutions, if any, do you think might have made you and/or other providers participate in SCD educational opportunities or other SCD educational activities? **Prompt:** What kind of incentive(s) would motivate you and other providers to join (e.g., CME?)?	
12. What else do you feel is important to share about the SCD educational opportunities or other SCD educational activities that we haven't already covered? What areas of SCD warrant more attention?	

JANUARY 29, 2015

Sickle Cell Disease Treatment Demonstration Program Communication Strategy

Developed by Cindy Hutter

Contents

Sickle Cell Disease Treatment Demonstration Program Communication Strategy

INTRODUCTION

The following communication strategy has been developed for the Sickle Cell Disease Treatment Demonstration Program (SCDTDP). The strategy aims to enable the National Coordination Center for the SCDTDP to provide more effective bi-directional communication with SCDTDP grantees, the Oversight Steering Committee and HRSA, as well as disseminate the project results and resources to stakeholders external to the project. The communication strategy was informed by 13 interviews with a mix of internal and external project stakeholders (Appendix A) and participation in the American Society of Hematology's (ASH) Sickle Cell Disease Implementation Stakeholder Meeting.

SITUATIONAL ANALYSIS

The first year of the SCDTDP focused on setting a measurement strategy and putting the necessary infrastructure in place. This included establishing the database and hosting a monthly webinar to provide updates to regional leads about the database development and a forum for regional leads to share their progress.

Feedback from participants and stakeholders revealed that the scope of NICHQ's year one work was too narrow to support HRSA's ultimate goals for the program. Consequently, NICHQ's role for project year two has been adjusted a bit to reflect this feedback. While NICHQ facilitated the SCDTDP, by scope design, many of the traditional supports provided by NICHQ in previous iterations of this project were missing. The biggest loss was the coordination of mutual reinforcing activities through a learning collaborative model, which facilitates continuous communication between grantees. Project stakeholders, both internal and external, have expressed a deep need for better connection with other participants, new mechanisms for collaboration and a stronger facilitating presence.

As the second year of the SCDTDP begins, a greater emphasis will be put on creating a more collaborative-like atmosphere. It's anticipated that by supporting and better connecting the regional coordinating centers—along with their state partners—that all participants can better learn from each other, accelerate improvement and enhance external dissemination opportunities.

PROJECT OBJECTIVES

The following are the key project communication objectives:

- Improve collaboration between stakeholders internal to the project through multiple venues and across regional and national levels
- Develop and implement a plan for disseminating project results to stakeholders external to the government and project participants

F. Communication Plan

OPPORTUNITIES AND THREATS

It is important to understand the opportunities and threats for this project in order to create a sound communication strategy.

OPPORTUNITIES

- **Desire to Collaborate:** Many stakeholders at both the regional and state level expressed interest in learning more about what other SCDTDP participants are doing and a desire to better "connect the dots" to better understand the link between the collective work and what the data are showing.

- **Wide Reach:** Between the regional coordinating centers, state level partners, community-based organizations, federal partners, SCD clinical experts and patient representatives participating in the SCDTDP, there is a wide reach for promoting results and resources from the project.

- **Strong Regional Leadership:** Regional coordinating center leads—many of whom participated in the former SCDTDP project—are having much success in running their own versions of regional mini-collaboratives. This lends itself to a strong underpinning of the SCDTDP work moving forward.

- **Small Community:** While sickle cell disease is the most common genetic condition identified through newborn screening in the U.S., the sickle cell community—providers, patients and families, etc. —is still a relatively small one, making it possible to develop more targeted communications.

- **Web Presence:** The regional coordinating centers have developed their own websites, which are serving as information hubs for those regions.

THREATS

- **Lack of Leadership:** In the sickle cell field, there is no one identified leader that doctors or patients and families immediately think to turn to for resources or other materials. While there are several government, philanthropic, and academic entities with information related to sickle cell disease, there is no central clearinghouse or authority for providers, patients, public health programs, etc.

- **Information Dispersion:** There is much information, including resources and tools related to SCDTDP, that lives in many places. This can be over burdensome and confusing to the external stakeholder seeking information about SCD resources. It also creates a lot of redundancies and duplication of efforts when multiple regional coordinating centers are developing, posting and sharing the same materials that could instead be housed at a central location.

- **Few Incentives:** There are few incentives to engage physicians in learning more about SCD treatment guidelines, such as those released by NIH/NHLBI, making the aim of this project around education a challenge. This is also coupled with the limited additional funding for SCD care, and potential impact on physicians' time providing care for individuals with a complex chronic condition in a resource-constrained environment.

F. Communication Plan

PROPOSED STRATEGIES

OBJECTIVE 1:

Improve collaboration between stakeholders internal to the project through multiple venues and across regional and national levels

- **Establish an online collaboration and data hub (known as SCDTDP Collaboratory) for all SCDTDP participants, and potential requests from those outside of SCDTDP**
  - Educate stakeholders of its purpose and utility
  - Drive all project communications through the SCDTDP Collaboratory

- **Improve and increase the amount of internal communication to facilitate inter-regional sharing**
  - Establish technical working groups that cut across regions facilitating conversations and cross-regional sharing
  - Establish monthly webinars for regional leads; quarterly webinars for state leads; twice yearly all-participant calls
  - Re-envision all-SCDTDP participant (regional, state, OSC, etc.) monthly emails that focus on outcomes—what teams are working on—with a contact name to follow up and report outs on data collection as well as one feature story about a team/participant and the successes or challenges s/he faces

- **Centralize resources in support of developing a compendium of tools, resources and best practices**
  - Identify and centralize common education pieces (e.g., a hydroxyurea brochure, pocket cards) to reduce redundancies by regional centers
  - Identify best practices/tools to approach state officials for funding or insurance entities/payers for reimbursement processes and develop tactical plans for local customization

F. Communication Plan

PROPOSED STRATEGIES

OBJECTIVE 2:

Develop and implement a strategy for disseminating project results to stakeholders external to the government and this project

In coordination with ongoing governmental efforts — i.e., HRSA, Centers for Medicare and Medicaid Services (CMS), Agency for Healthcare Research and Quality (AHRQ), National In stitutes of Health (NIH), Centers for Disease Control and Prevention (CDC), etc.), diverse stakeholders (e.g., ASH, Sickle Cell Disease Association of American (SCDAA), etc. — and existing campaigns and efforts (e.g., Get Connected platform):

- **Identify a central hub for SCDTDP information**
  - Conduct an environmental scan of all existing websites and ListServs related to SCD
  - Propose to key stakeholders (via ASH meeting) one central hub and coordinate links from various sites to the hub

- **Establish a national SCD guidelines/resources awareness campaign with a three-pronged approach: Patient/Family-focused, Physician-focused (inclusive of hematologists, hospitalists, PCPs, emergency physicians and community health centers, academic medical centers,) and SCD Treatment Center staff) and general audience**
  - Support patient/family education campaigns
    - Outreach to patient-focused organizations (e.g., SCDAA)
    - Support regions and state partners to host community-based patient education events
    - Support adaptation and dissemination of existing apps/tools to increase self-awareness about conditions (AHRQ Report)
  - Support provider education campaigns (including PCPs, specialty providers, nurse practitioners, physicians assistants, etc.)
    - Present at conferences; grand rounds; resident lectures; regional meetings
    - Input SCD guidelines into UpToDate, Dynamed and other e-textbooks that clinicians consult
    - Support the creation of an online CME course
    - Support the creation of a certificate in treatment of rare diseases that could position doctors to get a higher reimbursement rate from payers
    - Outreach to national medical directors, program directors, and others who oversee teaching and curricula about SCD to ensure knowledge of and compliance with treatment guidelines
  - General audience campaign
    - Leverage Sickle Cell Awareness Month for a public relations and social media campaign
    - Develop and promote short video series with existing or new patient vignettes (e.g, http://www.nytimes.com/interactive/2011/03/02/health/healthguide/te_sicklecell.html?_r=0)
  - Provide trainings for SCDTDP teams about how to promote their resources
  - Partner with other stakeholders/organizations to tap their audiences to disseminate SCDTDP resources

F. Communication Plan

REVISED SUMMARY

In this communications strategy document, we have provided a brief but cogent explanation of how to improve communication and collaboration between SCDTDP participants, as well as enhance external dissemination opportunities. We are confident that the structures, systems, and staffing that we currently have in place at the National Coordinating Center will be able to support enhanced work around the opportunities outlined under Objective 1: *Improve collaboration between stakeholders internal to the project through multiple venues and across regional and national levels.* Many of the opportunities are ongoing or recently launched, and we look forward to enhanced communication with our internal stakeholders through the activities outlined.

The opportunities listed under Objective 2: *Develop and implement a strategy for disseminating project results to stakeholders external to the government and this project, include all suggestions that came out of the stakeholder interviews.* These activities vary in the level of feasibility and impact, so we have developed a prioritization matrix (Appendix B) to help guide discussion on which activities to focus our resources. Our team will work with the SCDTDP Oversight Steering Committee and HRSA to determine the best implementation strategy going forward.

ADDENDUM: DISSEMINATION PLAN FOR CONGRESSIONAL REPORT AND FINAL DELIVERABLES

The delivery and dissemination of final deliverables is a key activity of the SCDTDP NCC. To that end, the NCC has worked with RCC teams, the OSC and HRSA to highlight audiences that will both both receive, review and continue to disseminate the report forward. The NCC will work closely with key stakeholders and audiences shown in the table below, as well as NICHQ internal marketing team to ensure electronic dissemination across multiple modes including Internet, social media, electronic newsletters.

TABLE 28:
Audiences and Products for Dissemination

	CONGRESSIONAL REPORT	EXECUTIVE SUMMARY	MODEL PROTOCOL	IMPACT STATEMENT
Congress	*	included as section in report		*
SCDTDP Grantees	*			
Federal Agencies				
Allied Organizations	(SCDAA)			
Physician Specialty Societies				
Provider Groups				
Data Quality Organizations				

* Indicates printed copy.

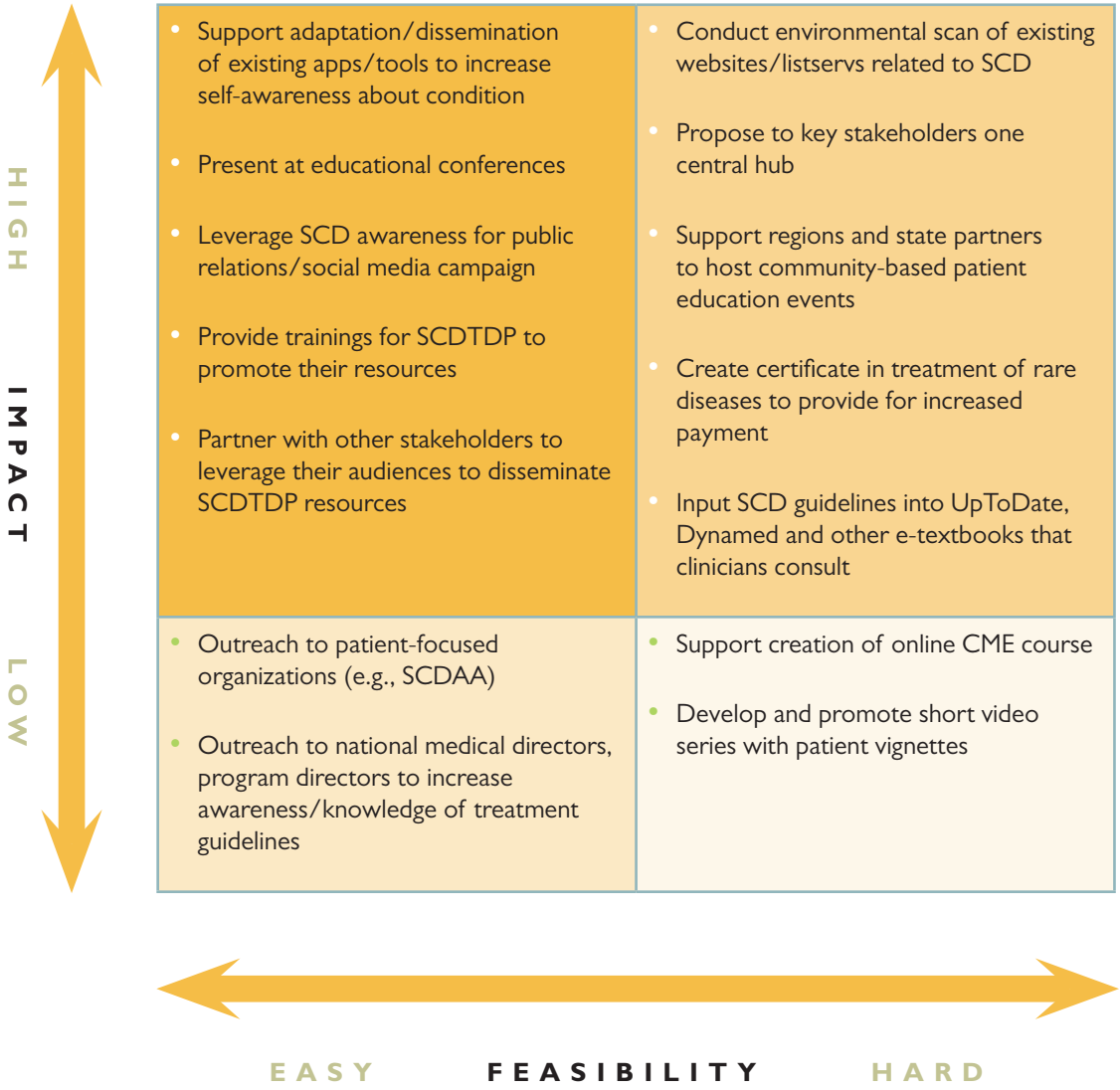
APPENDIX A

List of interviewees

- **Alice Cohen, MD, FACP** Director, Division of Hematology/Oncology; Training Program Director, Hematology/Oncology, Director, Hemophilia and Thrombosis Treatment Center; Northeast Region State Partner
- **Allan Platt PA-C, MSc** Emory University, Organizer of the Sickle Cell Disease ListServ; External stakeholder
- **Allison King, MD, MPH, PhD** Assistant Professor of Pediatrics, Washington University; SCDTDP Heartland Region Principle Investigator
- **Ari Hoffman, MD** Hospitalist, Assistant Clinical Professor Dept. of Medicine, University of California, San Francisco; External stakeholder
- **Diane Nugent, MD** Chair, Hematology, CHOC Children's; SCDTDP Program Manager
- **Kay Savings, MD** Professor of Pediatrics, University of Illinois at Chicago; Midwest Region State Partner
- **Lanetta Jordan, MD, MPH, MSPH** Associate Professor of Epidemiology and Public Health Sciences, University of Miami; SCDTDP OSC Member
- **Lisa Shook, MA, MCHES** Cincinnati Children's Hospital Medical Center; SCDTDP Midwest Region Principle Investigator
- **Marsha Treadwell, PhD** Pediatric Hematologist, Children's Hospital Oakland; SCDTDP Pacific Region Principle Investigator
- **Regina Abel, PhD** Staff Scientist, Program in Occupational Therapy, Washington University School of Medicine; SCDTDP Heartland Region Program Manager
- **Ron Brathwaite, MD** Runs SCD clinic at Loma Linda University Medical Center; External stakeholder
- **Rosalyn Stewart, MD, MS, MBA** Associate Professor of Medicine; SCDTPD Northeast Region Co-Principle Investigator
- **Yvonne Carrol, RN** Director of Patient Services for the Department of Hematology at St. Jude Children's Research Hospital; External stakeholder

APPENDIX B

Prioritization Matrix for Objective 2 of Communication Strategy



NICHQ
National Institute for Children's Health Quality

SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROJECT

2017 COMPENDIUM OF TOOLS AND MATERIALS

The National Coordinating Center for the Sickle Cell Disease Treatment Demonstration Program was supported by the Health Resources and Services Administration's Contract HHSH520201400026C.

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www.NICHQ.org

G. Compendium of Tools and Materials

Table of Contents

G. Compendium of Tools and Materials

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 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.

Source: NICHQ
Published: 2017

Sickle Cell Disease and Project ECHO®

Connecting Providers and Experts to Improve Care, Outcomes and Costs

People with sickle cell disease suffer from episodes of sudden, excruciating pain prompting emergency room visits and frequent hospitalizations. Delayed treatment deprives tissues of oxygen, can exacerbate pain and cause organ damage. Good preventive care and treatment can reduce pain episodes, and unnecessary emergency room visits and hospitalizations, particularly for adults.

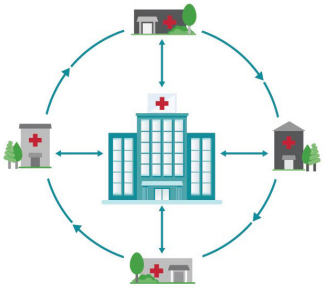
In the United States, nearly 100,000 people have this inherited red blood cell disorder, yet there is a shortage of knowledgeable healthcare providers.

This is unacceptable. Patients need convenient and consistent access to high quality sickle cell care. There is a way to make that a reality.

Project ECHO® (Extension for Community Healthcare Outcomes) is an internationally recognized telementoring innovation that builds clinician knowledge in diagnosing and treating complex disorders. Project ECHO connect local clinicians with experts from sickle cell centers to learn skills necessary to deliver high quality sickle cell disease care using this proven telementoring model.

Moving Knowledge, Not Patients

Through telementoring, ECHO creates access to high-quality specialty care in local communities.



Hub and spoke knowledge-sharing networks create a learning loop:

Community providers learn from specialists.

Community providers learn from each other.

Specialists learn from community providers as best practices emerge.

Through a federal Sickle Cell Disease Treatment Demonstration Program, sickle cell disease expert centers throughout the U.S. have provided Project ECHO telementoring since 2014. This has helped to:

- close the gap in quantity of knowledge providers, especially for adults with sickle cell disease that not only need care for the disease, but whole patient care;
- improve patient health outcomes;
- enhance healthcare delivery;
- and reduce costs.

There is still a need for more providers to serve the sickle cell disease population. Learn more about joining Project ECHO by contacting your regional sickle cell coordinating center.

Northeast Region: Sickle Cell Disease TeleECHO Clinic Conference Series, hosted by Johns Hopkins University (DC, MD, NJ, NY, VA, PA, DE, WV, Virgin Islands, Puerto Rico) bailey.house@jhu.edu **Midwest Region:** STORM TeleECHO (IL, IN, MI, MN, OH, WI) storm@cchmc.org **Pacific Region:** Western States Telementoring Collaborative for Sickle Cell Disease (AK, AZ, CA, ID, HI, OR, NV, WA) jennkim@mail.cho.org General info: https://echo.unm.edu

Project ECHO®

NICHQ National Institute for Children's Health Quality

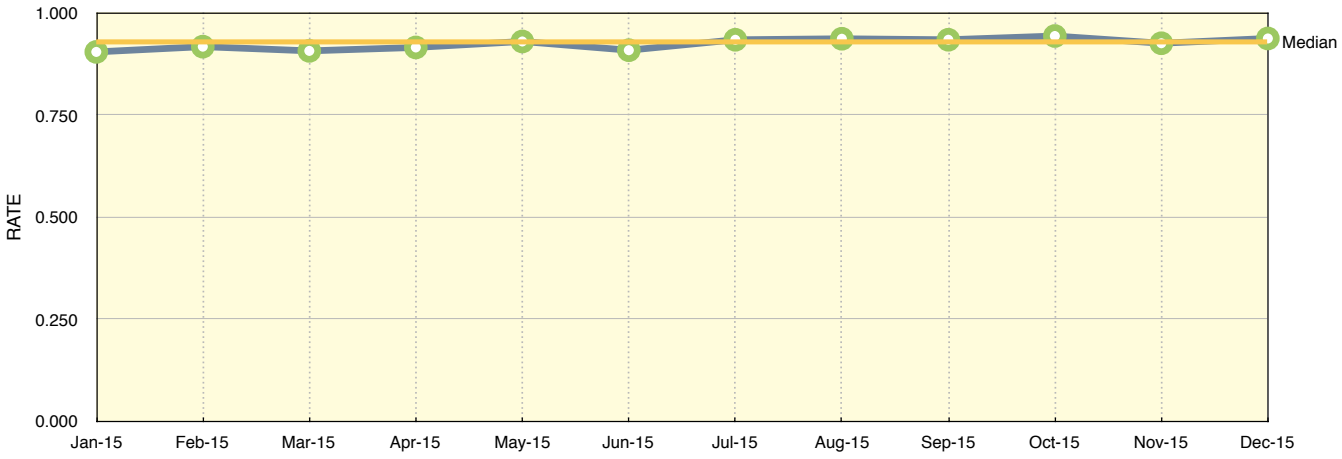
I. Additional Data

RUN CHARTS: DATA RECEIVED FOR MULTIPLE TIME POINTS

When data was received for multiple time periods, we are able to create run charts that allow us to track progress across time. For most states participating in the SCDTDP initiative, it was not feasible to provide data across multiple time periods. Ohio, however, has a long history of using Medicaid data for quality improvement, and in their data request they were able to provide monthly data from January to December of 2015 as can be seen in Figures 1 through 4. A greater emphasis on collecting data across multiple time points has the opportunity to strengthen data collection as teams build out their minimum data set cohorts and will be useful for learning and tracking progress in their work and outcomes across time. Run charts provide information on how a measure changes across time and provides guidance on whether there are random or non-random patterns in the data. Understanding the variation in measures across time allows for better understanding of whether changes seen are improvements. Run charts and, when appropriate, Shewhart charts, provide a probability-based set of rules that detect change in measures being collected over time that is unlikely to be due to simple random variation.[1]

FIGURE 1:

Monthly Ohio Medicaid Data for 2015 of the Percentage of Pediatric Patients with Two or More Outpatient Visits within the Past 12 Months



[1]Perla RJ, Provost LP and Murray SK. The run chart: a simple analytical tool for learning from variation in healthcare processes. BMJ Qual Saf. 2011;20:46e51.

FIGURE 2:

Monthly Ohio Medicaid Data for 2015 of the Percentage Adult Patients with Two or More Outpatient Visits within the Past 12 Months

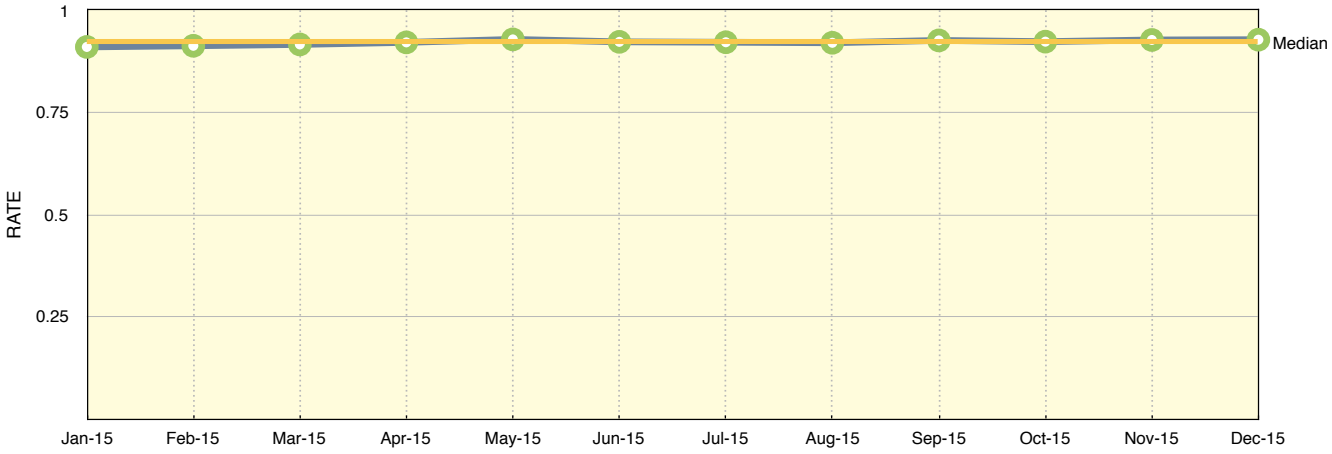


FIGURE 3:

Monthly Ohio Medicaid Data for 2015 of the Percentage of Pediatric Patients Filling a Hydroxyurea Prescription at Least Once within the Past 12 Months

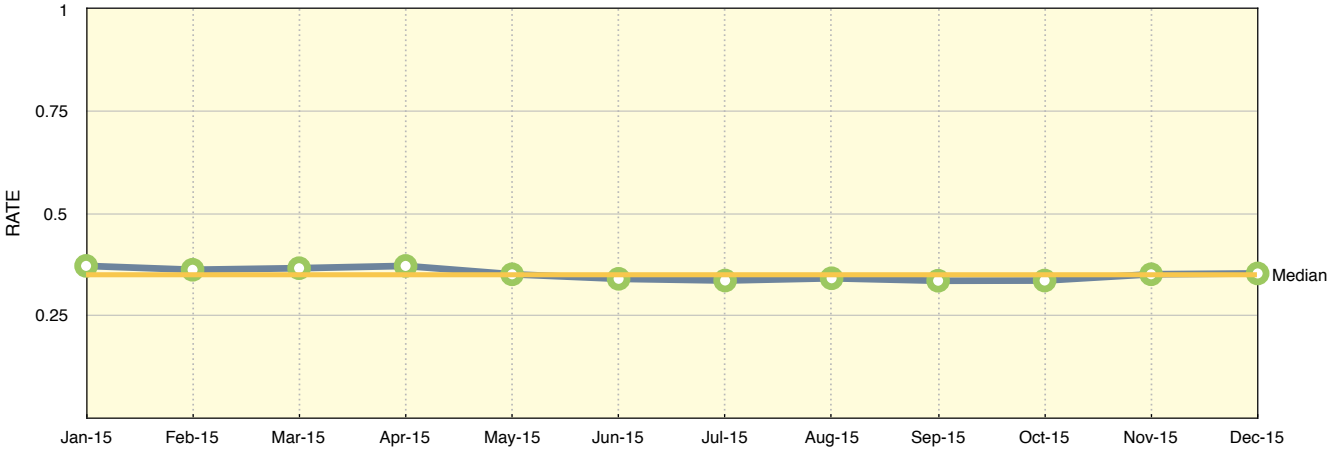
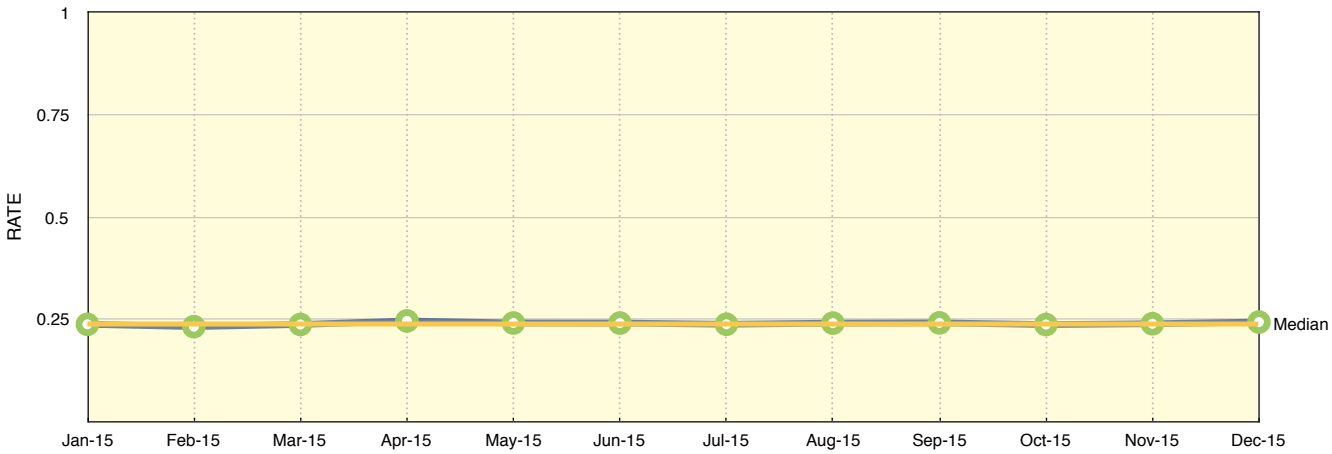


FIGURE 4:

Monthly Ohio Medicaid Data for 2015 of the Percentage of Adult Patients Filling a Hydroxyurea Prescription at Least Once within the Past 12 Months



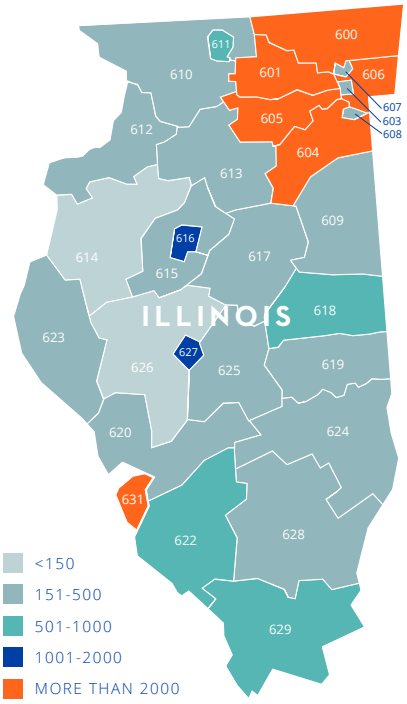
GEO-CODED MAPS

In addition to data being provided across multiple time periods, some teams were also able to submit administrative data from their Medicaid offices that was geocoded to a three digit zip code area. An example from Illinois is highlighted for some of the administrative measures in Figures 5 through Figure 9 below. This information allowed for the creation of maps that demonstrate the population density of patients living with SCD in local areas, as well as density of providers seeing patients with SCD on a regular basis (defined as 2 or more times for the same patient within a 12-month period). The data represented in these charts reflects a number of key metrics in a way that allows the reader to visually assess where there are the largest number of patients being seen regularly and whether patients in a geographic area are using hydroxyurea. Access to geo-coded data has tremendous potential to inform teams' efforts and provide information on the care of patients in the areas supported by the SCDTDP initiative.

FIGURE 5:

Provider Population in Illinois

07/01/2015 -06/30/2016



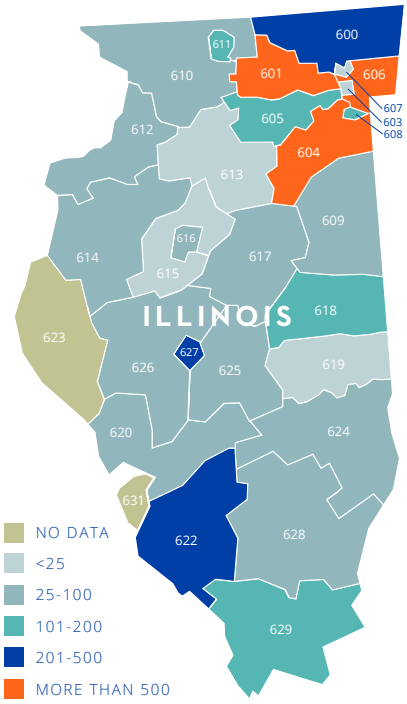
ZIP CODES	POP
600	2654
601	2900
602	1047
603	170
604	2248
605	2834
606	9610
607	129
608	179
609	254
610	329
611	620
612	398
613	154
614	138
615	183
616	1263
617	257
618	946
619	195
620	364
622	567
623	326
624	215
625	283
626	111
627	1295
628	352
629	535
631	3056

Note: Zip codes starting with 602 are considered part of section 600 on this map.

FIGURE 6:

SCD Patient Population in Illinois

07/01/2015 -06/30/2016



ZIP CODES	POP
600	314
601	517
602	32
603	20
604	1012
605	167
606	2788
607	21
608	135
609	64
610	52
611	113
612	34
613	16
614	28
615	19
616	89
617	98
618	149
619	7
620	95
622	243
623	N/A
624	47
625	74
626	31
627	83
628	88
629	168
631	N/A

*Please note populations for Zip Codes 619 only reflect adult patient populations

*N/A data not reported

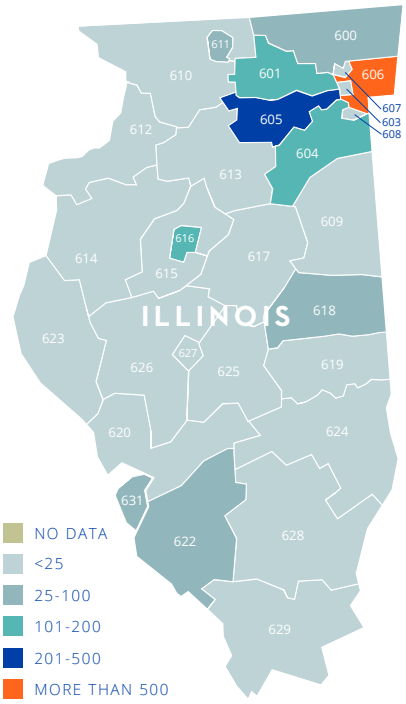
Note: Zip codes starting with 602 are considered part of section 600 on this map.

I. Additional Data

FIGURE 7:

Number of Providers Seeing SCD Patients 2 or More Times in the Past 12 Months in Illinois

07/01/2015 -06/30/2016



Note: Zip codes starting with 602 are considered part of section 600 on this map.

ZIP CODES	POP
600	77
601	179
602	33
603	8
604	105
605	284
606	688
607	+
608	16
609	16
610	+
611	32
612	0
613	0
614	+
615	12
616	117
617	0
618	71
619	+
620	+
622	32
623	0
624	+
625	12
626	+
627	22
628	0
629	18
631	62

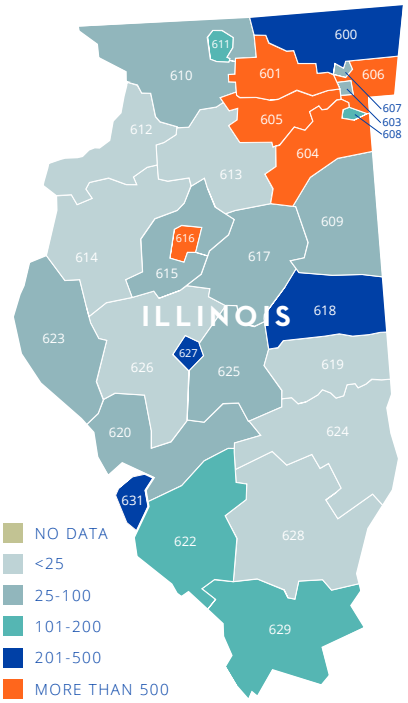
* + data suppressed due to small numbers (<5)

N/A data not reported

FIGURE 8:

SCD Patients Filling HU Prescriptions in the Past 12 Months in Illinois

07/01/2015 -06/30/2016



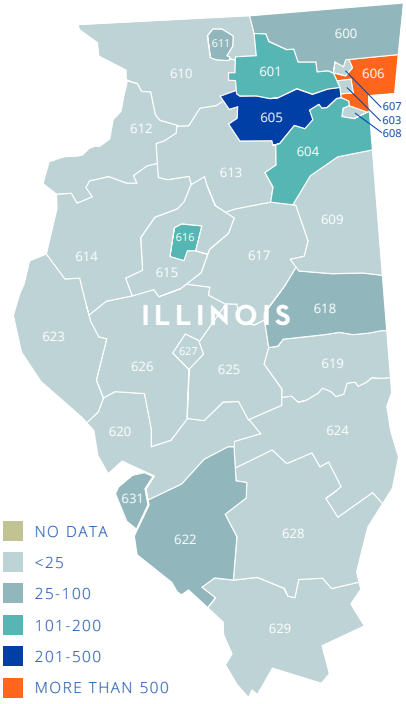
Note: Zip codes starting with 602 are considered part of section 600 on this map.

ZIP CODES	POP
600	399
601	780
602	130
603	47
604	556
605	1235
606	3777
607	12
608	77
609	36
610	56
611	122
612	18
613	8
614	16
615	51
616	548
617	63
618	269
619	6
620	48
622	167
623	94
624	14
625	57
626	8
627	233
628	10
629	108
631	497

FIGURE 9:

SCD Patients with Two or More Outpatients Visits in the Past 12 Months in Illinois

07/01/2015 -06/30/2016



Note: Zip codes starting with 602 are considered part of section 600 on this map.

ZIP CODES	POP
600	77
601	179
602	33
603	8
604	105
605	284
606	688
607	+
608	16
609	16
610	+
611	32
612	0
613	0
614	+
615	12
616	117
617	0
618	71
619	+
620	+
622	32
623	0
624	+
625	12
626	+
627	22
628	0
629	18
631	62

* + data suppressed due to small numbers (<5)

N/A data not reported

MINIMUM DATA SET DEFINITIONS IN ADMINISTRATIVE DATA SOURCES

There were also opportunities to learn from data collection when the minimum data set measures were applied across administrative data sources. An example of this is the data request submitted on behalf of the Heartland to Centene, a large MCO that was able to provide SCD specific measures for 12 states as described below. Two of the states, Kansas and Missouri, were part of the Heartland region that submitted the request. The data request to Centene was matched to the minimum data set measures, which provides a unique opportunity to compare the minimum data set measures across states in a number of regions for Centene, and also allows for consideration of data from different sources using a common set of metrics.

TABLE 28:

Centene MCO Data Submitted by the Heartland Region

STATE	MEASURE (NUMERATOR/DENOMINATOR (%))							
	Members with an HU Fill		Members with a PCP Visit		Members with an ER Visit		Members with an IP Visit	
	Pediatric	Adult	Pediatric	Adult	Pediatric	Adult	Pediatric	Adult
Kansas	+	8/45 (18)	27/43 (63)	26/45 (58)	16/43 (37)	22/45 (49)	6/43 (14)	14/45 (31)
Missouri	22/105 (21)	+	51/105 (49)	13/30 (43)	45/105 (43)	11/30 (37)	23/105 (22)	6/30 (20)
Florida	66/390 (17)	55/322 (17)	186/390 (48)	162/322 (50)	143/390 (38)	168/322 (50)	71/390 (18)	101/322 (31)
Georgia	63/334 (19)	5/163 (3)	185/334 (55)	54/163 (33)	99/334 (30)	55/163 (34)	33/334 (10)	26/163 (16)
Illinois	20/72 (28)	35/176 (20)	44/72 (61)	119/176 (68)	35/72 (49)	91/176 (52)	13/72 (18)	56/176 (32)
Indiana	16/116 (14)	17/122 (14)	48/116 (41)	58/122 (48)	26/116 (22)	50/122 (41)	6/116 (5)	20/122 (16)
Louisiana	89/435 (20)	79/330 (24)	261/435 (60)	194/330 (59)	140/435 (32)	177/330 (54)	51/435 (12)	101/330 (31)
Mississippi	83/344 (24)	74/278 (27)	213/344 (62)	188/278 (68)	111/344 (32)	153/278 (55)	33/344 (10)	86/278 (31)
Ohio	32/116 (28)	21/201 (10)	52/116 (45)	103/201 (51)	36/116 (31)	96/201 (48)	11/116 (10)	37/201 (18)
South Carolina	37/173 (21)	28/172 (16)	70/173 (41)	83/172 (48)	49/173 (28)	78/172 (45)	17/173 (10)	32/172 (19)
Texas	50/213 (24)	43/290 (15)	92/213 (43)	140/290 (48)	63/213 (30)	134/290 (46)	23/213 (19)	68/290 (23)
Wisconsin	+	7/31 (23)	+	15/31 (48)	+	11/31 (36)	+	6/31 (19)

+ Data suppressed due to low number (n<5).
* Data from the Heartland Region is highlighted in blue.

TABLE 29:

Missouri Medicaid Data Submitted by the Heartland Region, 2013-2016

STATE/YEAR	MEASURE (NUMERATOR/DENOMINATOR (%))							
	Members with an HU Fill		Members with a PCP Visit		Members with an ER Visit		Members with an IP Visit	
	Pediatric	Adult	Pediatric	Adult	Pediatric	Adult	Pediatric	Adult
MO/2013	61/498 (12)	133/575 (23)	459/498 (92)	516/575 (90)	303/498 (61)	446/575 (77)	221/498 (44)	228/575 (40)
MO/2014	85/510 (17)	145/625 (23)	317/510 (62)	467/625 (75)	317/510 (62)	467/625 (75)	223/510 (44)	265/625 (42)150
MO/2015	105/503 (21)	171/632 (27)	459/503 (91)	514/632 (81)	284/503 (56)	441/632 (70)	188/503 (37)	230/632 (36)
MO/2016	136/523 (26)	185/703 (26)	469/523 (90)	569/703 (80)	311/523 (59)	489/703 (70)	194/523 (37)	268/703 (38)

TABLE 30:

Increase in HU Use: Pacific: Increase in % of Adult and Pediatric Patients on HU

STATE	# Patients with SCD seen in the last 12 months	# Patients with SCD seen in the last 12 months on Hydroxyurea	% Change from baseline in previous 12 months
Alaska	12	2	0
Arizona	78	31	48%
California	715	276	30%
Idaho	14	10	10%
Nevada	170	95	86%
Oregon	41	12	17%
Washington	260	136	20%
Totals	1290	562	30%

TABLE 31:
Administrative Data Set

MEASURES			STATES/RCCS COLLECTING MEASURE
Aim 1	**A**	Providers seeing pediatric patients	• Northeast: all states • Midwest: all states • Heartland: all states • Pacific: all states
	B	Providers seeing adult patients	
	C	Providers seeing any SCD patients	
	D	Pediatric patients with outpatient visits	• Northeast: all states • Midwest: IL, IN, MI • Heartland: all states • Pacific: all states
	E	Adult patients with outpatient visits	
Aim 2	**A**	Providers Prescribing HU to pediatric patients with SCD	• Northeast: all states • Midwest: all states • Heartland: all states • Pacific: all states
	B	Providers prescribing HU to adult patients with SCD	
	C	Providers prescribing HU to any SCD patient	
	D	Pediatric patients filling HU prescriptions	• Northeast: all states • Midwest: IL, IN, MI • Heartland: all states • Pacific: CA-Fee For Service, OR
	E	Adult patients filling HU prescriptions	

TABLE 32:

Timepoints/Data Quality and Usability

REGION	STATES	TIME POINT	DATA QUALITY/USABILITY
Northeast	MD DC: Amerihealth DC: Trusted NJ: Horizon (waiting on updated data)	MD: Q1 2016* DC: Amerihealth- Q3 2015 DC: Trusted- Q3 2015	• Data from only one timepoint • Cannot compare across states in the region • Multiple data sources for one state may mean an overlap (e.g., counting someone twice)
Midwest	IN MI IL: (includes: IN, IA, WI, IL, MO)	IN- Q2 2015* MI- Q3 2015* IL- Q3 2015, Q4 2015, Q1 2016, Q2 2016	• Access to 3-digit zip codes • Multiple data points • Different data sources for the same state • Includes patients who live in the Heartland states but get services in Midwest states
Heartland	KS MCO	KS- Q4 2014*	• Data from only one timepoint
Pacific	CA: MCO CA: FFS OR (waiting for updated data for 2016) ID NV WA:FFS WA: MCO	OR- Q3 2014; Q3 2015* ID- Q4 2014* NV- Q3 2015* WA:FFS- Q3 2015* WA: MCO- Q3 2015*	• Majority of states have data from Q3 2015 • OR denominator is an estimate for 2015 and 2016 • Multiple data sources for one state may mean an overlap (e.g., counting someone twice)

* Data ends in this quarter, may be annual data.

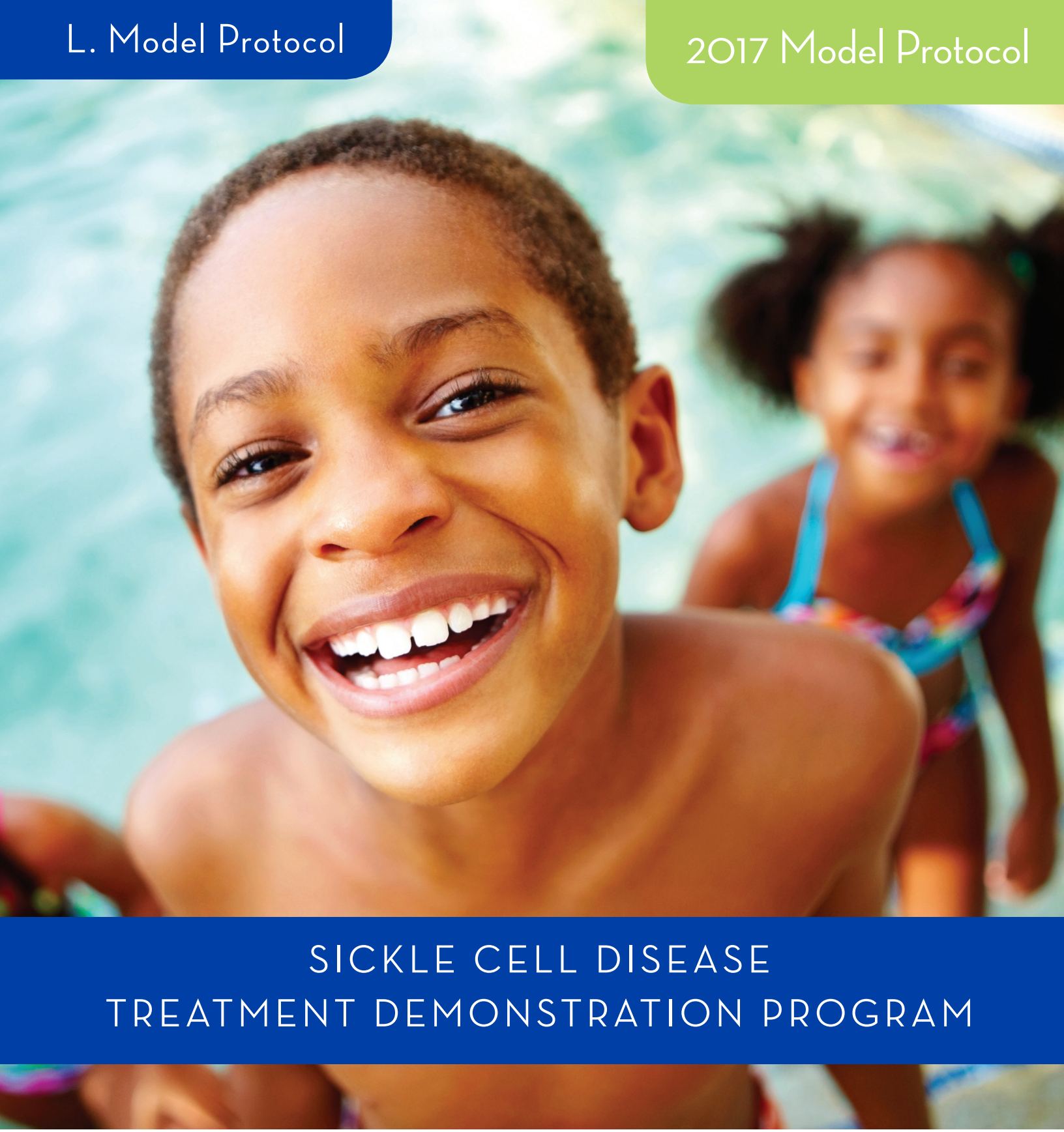
TABLE 33:

Minimum Data Set

MEASURES	RCCS/STATES COLLECTING IT	DATA QUALITY ISSUES/ USABILITY
MDS 1: Hydroxyurea Use	• All states	
MDS 2: Reasons for Not using HU	• Midwest • Heartland • Pacific	• Some regions are not collecting reasons for not using HU
MDS 3: Has a PCP	• All states	• Having a PCP vs. seeing a PCP in the last 24 months
MDS 4: Genotype	• All states	
MDS 5: ED/Day Hospital Visits	• Midwest • Heartland • Pacific	• Regions are collecting measures 5 & 6 differently and cannot be compared across regions
MDS 6: Hospital Admissions	• Midwest • Heartland • Pacific	

L. Model Protocol

2017 Model Protocol



SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROGRAM

NICHQ National Institute for Children's Health Quality

The National Coordinating Center for the Sickle Cell Disease Treatment Demonstration Program was supported by the Health Resources and Services Administration's Contract HHSH520201400026C.

Introduction

Between 2014 and 2017, the Health Resources and Services Administration (HRSA) funded four Regional Coordinating Centers (RCCs), representing 29 states and territories across the country, which coordinated collaborative efforts to improve the health and quality of life of children and adults with sickle cell disease (SCD). This initiative was known as the Sickle Cell Disease Treatment Demonstration Program (SCDTDP). The National Institute for Children's Health Quality (NICHQ) served as the National Coordinating Center (NCC) during this period, guiding the national work of the SCDTDP across regions.

The SCDTDP built upon and expanded the work begun during the successful Working to Improve Sickle Cell Healthcare (WISCH) initiative (2010-2014) to develop and refine clinical and system protocols to ensure that all patients with SCD receive the highest quality of care. The WISCH project culminated in 2014 with the development of a resource compendium designed to help with spread of critical resources. This compendium linked providers to key tools and resources designed to facilitate the provision of high quality care for children and adults living with SCD and sickle cell trait (SCT).

Building upon strategies to improve care developed during this past work, the four RCCs —

- Sickle Cell Improvement in the Northeast Region through Education (SiNERGe);
- Sickle Treatment and Outcomes Research in the Midwest (STORM);
- Heartland Sickle Cell Disease Network; and
- Pacific Sickle Cell Regional Collaborative (PSCRC)

— are spreading and implementing new and existing clinical and system protocols in efforts to improve access to care, increase use of disease-modifying therapies, and increase the number of providers knowledgeable about SCD and SCT.

This Model Protocol includes the resources, strategies and best practices that sites used to meet the following three aims of the SCDTDP 2014-2017 grant:

- Improve access to care by increasing the number of providers treating patients with SCD
- Increase use of Hydroxyurea (HU)
- Increase the number of patients with SCD that are receiving care from providers knowledgeable about treating SCD

To access an electronic copy of the 2017 Model Protocol and all of the links contained therein, please visit: www.nichq.org/resources/Model-Protocol-2017.

Introduction

The purpose of this Model Protocol is to give providers, community-based organizations, public health agencies, academic institutions, healthcare organizations, policy-makers, and others guidance on the best of the promising practices and strategies developed during the SCDTDP initiative. This tool was developed to support the spread and implementation of clinical guidelines and development of systems that can collectively improve the care provided 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 centers for excellence, regional centers of collaborative learning, and experts from across the nation. Guiding this process was the SCDTDP Provider Education Working Group tasked with the development of this Model Protocol. These strategies work best within collaborative teams using collective feedback and with tailoring by the key stakeholders that comprise the system. While these change ideas have been tested and implemented across communities and regions, it is recommended that quality improvement principles be employed when implementing these strategies in new settings. Using quality improvement principles to apply and test these ideas in a new environment can better ensure that local care needs will be met.

This Model Protocol is organized into four sections reflecting the broader aims of the project:

- Improving Access to Care
- Increasing Use of Hydroxyurea
- Increasing Provider Education
- Developing Local Electronic Health Registries

Each of these sections includes:

- An overview narrative
- A table listing strategies, rationale and resources

Improving Access to Care

The Institute of Medicine defines access to care as "the timely use of personal health services to achieve the best possible health outcomes."[1]

There are three components to achieving access to care:

- Obtaining entry into the health care system
- Getting access to health care sites that can provide needed services
- Identifying providers who meet the person's needs and can develop a therapeutic relationship based on shared communication and trust[2]

There are wide-ranging barriers to accessing quality care for individuals with SCD. This protocol will focus on the second and third components of achieving access to care. SCD is a serious genetic condition that, while rare, can have a significant impact on affected individuals and their families. Those living with SCD can have acute painful episodes and are at high risk for complications such as infection or stroke. These complications can have a severe impact on both the quality of life and overall lifespan for those living with SCD. Centers of excellence have been established to provide coordinated care that meets current clinical guidelines. However, these centers are often not accessible to individuals who reside in areas that are far away from large academic health systems, such as rural communities, preventing them from benefitting from new and innovative technology and improved treatment options that could help them live longer. In particular, adults with SCD have significant difficulties accessing quality primary and specialty care. The reasons for these disparities are numerous and include a shrinking workforce of knowledgeable providers able to care for individuals with SCD. Primary care providers frequently have limited numbers of sickle cell patients on their respective patient panels, which diminishes opportunities to increase expertise in caring for individuals with SCD. To increase access to care, SCDTDP RCCs used a multidimensional approach as part of their strategy to increase access to quality care for both children and adults with SCD.

For example, RCCs focused on creating integrated care networks that partner 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 community-based organizations (CBOs) that support children, adolescents, adults and families with SCD in their homes and communities. In addition, providers and CBOs are working closely together to employ community health workers to identify and connect individuals to both primary and specialty care. These strategies help to create a bridge to additional supports for families affected by SCD and to extend the reach of clinical sites within the communities they serve.

Improving Access to Care

In rural areas where geographic barriers challenge care access, state and regional partners set up satellite centers of care, leveraging telehealth and telementoring strategies to grow the capacity of rural physicians to manage routine SCD care. With on-call supports and case study telementoring calls with specialists, rural providers become a local access point for patients to receive coordinated care.

Grantees are also collectively working to improve transitions from pediatric to adult care for individuals living with this condition. In many regions, CBOs and health care institutions are helping to develop adolescents' life skills and capacity to self-manage aspects of their condition with specialized training curricula. Provider organizations are central to the creation of systems-level changes and resources to facilitate transitions from pediatric to adult care. In areas where there is a dearth of providers available to care for individuals with SCD, regional and local collaboratives are also reaching out to local governments, health systems, and communities to promote the need for more providers, especially adult providers, knowledgeable about caring for individuals with SCD.

Along with established strategies to increase the number of providers and institutions delivering SCD care, RCCs also acknowledged 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 ensure appropriate reimbursement and payment arrangements are in place to support providers' ability to improve access to quality care. For example, reimbursement policies that cover care coordination between specialists and primary care providers can facilitate care coordination, resulting in better disease management and quality of life for patients.

These following lessons learned sum up key opportunities for improving access to care by increasing numbers of providers treating patients with SCD.

- Facilitate connections between CBOs and health care providers to ensure outreach and health care access for individuals with SCD and their families (e.g., enrolling patients with Get Connected™)
- Leverage community health workers to help identify and connect individuals 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 primary care providers and hematologists 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 leveraging telehealth technologies

TABLE 1:
Recommended Strategies to Increase Access to Quality Care

STRATEGY	RATIONALE	RESOURCES
Creation of Sickle Cell Programs	SCD advocates in California, leveraging existing data, made the case for why a new SCD treatment facility was needed to meet the medical home needs of adults living with SCD in South Los Angeles, California.	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.
Provider Outreach and Engagement	There are a limited number of providers with expertise in the care of individuals with SCD, specifically adults. As individuals with SCD can live longer with specialized care, providers need to be knowledgeable about this condition and recommendations for primary and specialty care for this population.	Illinois Provider Engagement Survey (contact storm@cchmc.org for information) Primary Care Providers' Comfort Levels in Caring for Patients with Sickle Cell Disease Enhancing Access to Care for Sickle Cell Disease in South Carolina
Enhancement of SCD and SCT awareness in the community and health care institutions	Patients are more likely to access quality care when they become aware of the care that they need and know where they can find it. Similarly, communities affected by SCD can better advocate for access to quality 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 specialty providers.	*What You Should Know about Sickle Cell Trait* English French Spanish (handout) *Sickle Cell Trait Toolkit* (website) *Cincinnati Children's: Sickle Cell Trait* (website) *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)
Enhancement of family and school personnel awareness about management of SCD at home and in school settings	It is essential that caregivers at home and in school be knowledgeable about SCD, related symptoms, available treatments, and necessary accommodations for children with SCD. Resources educating parents and teachers about SCD management can help children and adolescents receive the appropriate care and referral outside of a clinical setting.	*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)

CONTINUED

TABLE 1: CONTINUED

Recommended Strategies to Increase Access to Quality Care

STRATEGY	RATIONALE	RESOURCES
Support to adolescents with SCD transferring from pediatric to adult care	Now that individuals with sickle cell disease are living well into early and late adulthood, transferring from pediatric to adult care can be fraught with multiple challenges related to changes in insurance, care providers and care settings. Consequently, young adults navigating the transition from pediatric to adult care require training in disease self-management and general life skills. Most of the functional life of young adults with SCD takes place at home, in school, and in the community[3]. Consequently, it is important for clinicians to teach young adults how to maintain healthy habits in these environments.	*What You Should Know About Sickle Cell Disease: Nine Steps to Living Well with Sickle Cell Disease in College* (handout)
Implementation of an SCD-specific transition curriculum	This comprehensive curriculum covers all ages of the transition period (12-21 years of age) and includes recommendations of educational content for providers, patients and parents. It is organized into three main sections by age group, each consisting of three domains: medical, social, and academic. Use of the entire curriculum will ensure that all topics are covered throughout the transition planning process. Each domain includes guidelines for topics, suggested methodologies, and techniques to measure efficacy. The curriculum can be used as a resource in both the medical and the community setting, and would be especially effective in organizing the work in partnerships.	Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolescents with Sickle Cell Disease: Suggested Topics, Methods, and Efficacy Measurements Heartland Life Skills and SCD Self-Management Curriculum (For information, visit Heartland Sickle Cell Disease Network website, https://sicklecell.wustl.edu/)

Increasing Use of Hydroxyurea

Until July 2017, Hydroxyurea (HU) was the only Food and Drug Administration (FDA) approved therapy for sickle cell disease.[4-6,7] This medication results in a decrease in sickle cell-related complications such as pain crises, acute chest syndrome, and associated emergency department visits and hospitalizations.[8] HU can improve the quality of life for patients by reducing the frequency of these complications of SCD[9,10,11] and has been found to lower the costs associated with care for individuals 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.[8]

Promising strategies have been employed to increase HU use, but they have varied greatly from region to region and provider to provider.[8] Many individuals and their parents are unaware of the drug or its potential benefits, as their provider does not discuss HU with them. Or they may be reluctant to use disease-modifying therapies.[12,13] However, these barriers can be addressed by increasing both provider and patient knowledge. To facilitate conversation between patients and providers, several tools have been developed by professional societies such as the American Society of Hematology (ASH). These tools leverage the National Heart, Lung, and Blood Institute (NHLBI) evidence-based clinical guidelines for use of HU in sickle cell care.[7]

Electronically shared decision-making tools, as well as print materials, can help providers communicate with patients to enhance patients' understanding of clinical benefits, side effects, and long-term consequences of HU use. Shared decision-making tools function to walk the patient and provider through the various considerations related to SCD treatment and have been demonstrated to empower patients through increasing knowledge of evidence-based treatment options, increasing their understanding of risk, and decreasing decisional conflict.[14] Shared decision-making tools also help providers feel more comfortable initiating conversations. An expert panel from NHLBI encourages shared decision-making with all patients with SCD. In addition, RCCs have been testing clinical decision-making tools that utilize the evidence- based guidelines and expert panel review on both paper and electronic medical records. Clinical decision tools support provider knowledge and self-efficacy, increasing the quality of care received by patients. Clinical decision tools can also aid in the collection of data around decisions and processes that allow for further improvement of the care system to meet the needs of children and adults with SCD.

Print materials such as brochures and flyers with infographics also facilitate treatment conversations between physicians and patients by outlining key treatment information and considerations. An advantage of these resources is that they can then be taken home by the patient and reviewed with family members.

TABLE 2:
Recommended Strategies to Increase Use of Hydroxyurea

STRATEGY	RATIONALE	RESOURCES
Evidence-based guidelines and protocols for clinical practice support	These guidelines were generated using a systematic process, including literature review and grading of the evidence to address specific clinical questions developed by an expert panel.[5,15]	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 Indiana Hydroxyurea Prescribing Guidelines Hydroxyurea for Sickle Cell Disease: Indications, Dosing and Monitoring (from Midwest/Cincinnati Children's Hospital)
Enhancement of patient awareness of HU and shared decision-making tools	Hydroxyurea is an under-utilized treatment for sickle cell disease. This stems from both patient and provider unfamiliarity with its effectiveness and use, and beliefs related to harmful side effects.[16] To increase acceptance and adherence to HU, patients and families need access to accurate information about their treatment options, which can be provided through brochures, flyers, and shared decision-making tools.[17]	Midwest RCC shared decision-making eTool (contact storm@cchmc.org for information) Northeast adult patient shared decision/ initiation eTool (contact SiNERGe team, 443-287-0608 for information) 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
Enhancement of physician awareness of disease-modifying therapy initiation and dosing materials	Primary care physicians, especially those that treat few or no people with SCD, need resources to stay up to date on current SCD treatment guidelines. Pocket guides or guideline documents that outline initiation and dosing of hydroxyurea are useful for physicians who may need a quick reference tool in the clinical setting. Continuing medical education webinars are another resource for primary care physicians who seek to increase their knowledge about hydroxyurea.	Hydroxyurea Treatment for Adults (CME webinar) American Society of Hematology's Hydroxyurea and Transfusion Therapy (pocket guide) Boston Medical Center Pediatric Hydroxyurea Dosing Guidelines SiNERGe Webinar - Helping Patients Adhere to Hydroxyurea Therapy SiNERGe WEBINAR: A Conversation about Hydroxyurea Part 2

Increasing Provider Education

As more and more individuals with SCD are surviving into adulthood, there is a growing need for more adult providers to be engaged in caring for individuals with sickle cell disease. While there are geographic areas where the numbers of sickle cell patients are concentrated, there will continue to be a growing need across the country for more primary care providers and specialists who are trained to effectively manage sickle cell disease, particularly in the adult population. There will also continue to be patients with SCD who live in remote areas, where it will be harder to reach providers with significant expertise in sickle cell care. Innovative models of telehealth and telemedicine are needed to ensure access to quality care to help address both of these issues.

The RCCs employed multiple tactics to address the need to educate both primary care and specialty providers about SCD and the key dimensions of care. Table 3 shares the range of topics reviewed along with resources and protocols used over the course of the grant period. More traditional provider education methods include presentations at symposiums, grand rounds, and national professional society meetings, as well as disseminating information through publications. These methods provided opportunities to build engagement and awareness and enhance knowledge across broader audiences of providers. More focused training efforts, such as quality improvement learning sessions and continuing medical education training, offered opportunities for more in-depth learning about relevant content. Finally, innovative methods like the Extension for Community Healthcare Outcomes (ECHO) model, an innovative way of training providers through case reviews and webinars leveraging remote telehealth technology, presented additional opportunities for more in-depth learning applied directly to practice.

SCDTDP RCCs started their own ECHO models based on the standards set by Project ECHO® which uses telehealth technology to dramatically improve capacity of providers and increases access to specialty care for rural and underserved populations. This low-cost, high-impact intervention is accomplished by using web technology to link expert inter-disciplinary specialist teams with primary care clinicians through TeleECHO® clinics, which allows experts to mentor primary care clinicians, provide feedback on difficult patient cases, and share expertise via monthly case presentations and didactic educational sessions. Three SCDTDP RCCs initiated Project ECHO® replications to support an increase of knowledgeable providers and access to high quality care. While Project ECHO® has not been used in the past with rare diseases such as SCD, it is a promising approach that will continue to be refined.

SCDTDP PROJECT ECHO® REPLICATION PROGRAMS
These are SCDTDP replications of Project ECHO® (Extension for Community Healthcare Outcomes). Visit these websites to register, participate, and access curricula and session recordings.
Northeast Region John's Hopkins Sickle Cell TeleECHO® Clinic Conference Series
Midwest Region STORM TeleECHO®
Pacific Region Western States Tele-Mentoring Collaborative for SCD
Sickle Cell Disease and Project ECHO® (information sheet)
Project ECHO®

TABLE 3:

Recommended Topics to Target for Improving Provider Knowledge

TOPICS	RESOURCES
Screening for SCD	CDC Hemoglobinopathies: Current Practices for Screening, Confirmation and Follow-up (guidelines)
Pain Management	Illinois SCDTDP Pain Chart Indiana Pediatric Sickle Cell Pain Pathway Wong-Baker FACES Pain Rating Scale©2016 Living with the Pain of SCD I (webinar) Living with the Pain of SCD II (webinar) Chronic Opioid Therapy & Sickle Cell Disease (webinar) SCD: What the Internist Needs to Know (CME webinar) NHLBI Evidence-Based Management of Sickle Cell Disease (guidelines) Management of Acute Complications of Sickle Cell Disease (pocket guide) Health Maintenance and Management of Chronic Complications of Sickle Cell Disease (pocket guide) Acute Complications of SCD (CME webinar) 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) Massachusetts SCDNBSP Intranasal Fentanyl handout California SCDTDP ED Protocol for IN Fentanyl Sickle Cell Pain in the Emergency Department: A Guide to Improving Care
Medical Home/Care Coordination	Ethical and Health Policies in SCD (CME webinar) Individual Care Plans: • Patient Needs Assessment • SMART Phrase: ◦ Care Coordination Screening Tool ◦ Care Coordination Checklist Older Adults and Sickle Cell Disease
Preventive Care	NHLBI Evidence-Based Management of Sickle Cell Disease (report)
Transitions from Pediatrics to Adult Care	Making a Smooth Transition from Pediatric to Adult SCD Care: Eliminating Barriers, Enhancing Resources Part I & II (webinar) Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolescents with Sickle Cell Disease: Suggested Topics, Methods, and Efficacy Measurements

Developing 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. Leveraging the considerable experience available from the previous SCD project, the RCCs first identified and clearly defined a core set of quality measures that both aligned with the specific programs and goals of the current project and aligned with existing quality metrics, such as those developed by the WISCH initiative and the PhenX Toolkit (Table 4). Taking these steps ensured that the teams focused on metrics that aligned with their specific regional programmatic goals as well as the aims of the larger national initiative. The measures that were found to be consistent across all regions included: SCD phenotype, whether patients are currently on HU, reasons for not being on HU, hospital admissions and outpatient ED visits, and whether patients were over or under 18. Other measures such as use of transcranial doppler, vaccination status, demographics, being seen by a primary care provider, pain frequency, lab test results, chronic transfusion therapy status and adverse events, were not consistently collected by all RCCs.

Agreement on a common set of core quality measures was followed by the development of measure specifications and common data elements. After data elements were identified, each region focused on developing the necessary infrastructure and research compliance to establish a local registry. This included both executing a data use agreement with all participating sites and clinics, as well as moving through Institutional Review Board (IRB) consideration that would determine whether a waiver of consent or informed consent would be needed. Operationalization of the actual registries at each site required identification of a low-cost, easy to use, web-enabled data collection and reporting system for each region. Most of the RCCs used REDCap, a publically available, free-license, data management system developed at Vanderbilt University. The system is widely available in academic healthcare settings and universities and is easy to use. While a few sites were able to develop approaches that allowed the automatic extraction and loading of data from electronic health records, most RCCs continued to perform manual review of EHR records and manual data entry.

Data collection varied across the regions. In the Pacific, enrollment surveys were administered to patients eligible for HU (HbSS OR HbS-ß° Thalassemia), who then received additional follow-up care. In the Heartland, the focus was on developing a sustainable Access database that allows for easy data entry and the generation of flexible reports that can be customized and exported to REDCap or other statistical software.

The key components for the local registries developed during this project are those shared by most clinical registries:

- Well-specified common quality measures;
- Common data elements that allow measurement of the CQMs over time;
- A secure, on-line data-capture and storage system;
- Either an interface for automated data sharing or personnel to enter data;
- Analytic functionality to allow the measurement and sharing of quality measurement results over time;
- A legal framework to allow sharing of data between collaborating institutions

Depending on available resources, this framework allows a range of local registry solutions ranging from simple, and relatively labor intensive to much more complex but with a higher degree of automation. Levels of data sharing ranging from simple (aggregate, summary data only) to more complex (patient level data and common identifiers) are also available depending on governance and resource considerations.

TABLE 4:
Recommended Resources for Creation of Local SCD Health Registries

KEY COMPONENTS	RESOURCE
Well Specified Measures	SCDTDP Administrative Measures Data Dictionary (2014-2017) SCDTDP Minimum Data Set Data Dictionary (2014-2017) PSCRC Minimum Data Set Data Dictionary WISCH Measurement Bank
Common Data Elements	SCDTDP Administrative Measures Data Dictionary (2014-2017) SCDTDP Minimum Data Set Data Dictionary (2014-2017) PSCRC Minimum Data Set Data Dictionary PhenEx Toolkit PSCRC Enrollment & Annual Update PSCRC Minimum Dataset PSCRC Abbreviated Patient Form PSCRC Abbreviated Provider Form
Data Storage and Analytic Functions	REDCap
Legal Framework	Application for Study Review (PSCRC)

Website Resources for SCD

ORGANIZATION	URL
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 Sickle Cell Disease Network	http://sicklecell.wustl.edu/
Sickle Cell Improvement in the Northeast Region through Education (SINERGe)	http://wepsicklecell.org/sinerge/ http://www.hopkinsmedicine.org/Medicine/sickle/index.html
American Society of Hematology	http://www.hematology.org/Research/Recommendations/Sickle-Cell/
CDC	http://www.cdc.gov/ncbddd/sicklecell/index.html
NHLBI	https://www.nhlbi.nih.gov/health/educational/sickle-cell-awareness
NICHQ	http://nichq.org/project/sickle-cell-disease-treatment-demonstration-program
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/

Online Point of Care Resources for SCD

NAME & URL	DESCRIPTION
Dynamed Plus® http://www.dynamed.com/home/	Evidence-based, clinical information resource that is designed to provide the most useful information to healthcare professionals at the point of care. Subscription-based.
Medscape http://www.medscape.com/	Free clinical reference, part drug guide, part news aggregator, part CME app; good basic drug dosing and interaction checking; medical news and CME sections rival competitors; apps for iPhone, iPad, Android, and Kindle.
Essential Evidence Plus http://www.essentialevidenceplus.com/	Internet point of care information resource; subscription-based individual or institutional; $; 30-day free trial; mobile access; virtual demonstrations and podcasts; CME credit for using.
UpToDate® https://www.uptodate.com/	UpToDate® is an evidence-based clinical decision support resource that helps healthcare practitioners make decisions at the point of care. Subscription based, multi-platform.

This Model Protocol highlights select materials fostered and developed by the RCCs between 2014-2017. For a complete set of sickle cell disease resources, tools, and materials developed over multiple SCDTDP funding cycles, please view the SCDTDP 2017 Compendium of Tools and Materials at http://www.nichq.org/resource/compendium-resources-2017

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