

# Roundtable on Leveraging Data to Address Sickle Cell Disease

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**Key Takeaways Report**  
August 2020



# Introduction

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Sickle cell disease (SCD) is the most common inherited blood disorder in the United States. There is a nationwide demand for population-level SCD surveillance data to address the needs of the sickle cell community, and for other data to support better treatments and healthcare options for people with SCD.

This report presents high-level takeaways from the virtual *Roundtable on Leveraging Data to Address Sickle Cell Disease* held on June 25, 2020. The nonprofit Center for Open Data Enterprise (CODE) and the U.S. Department of Health and Human Services (HHS) Office of the Chief Technology Officer (CTO) co-hosted the Roundtable, in partnership with the HHS Office of the Assistant Secretary of Health (OASH). The event brought together medical experts, patients, and patient advocates to discuss the data needed to improve SCD diagnosis, treatment, and patient care. This report summarizes their input and insights to provide an overview of challenges, potential interventions, key datasets, and possible policy solutions to improve care for Sickle Cell Disease patients.

The Roundtable was part of a project using the Health+ methodology, now being utilized by HHS, which applies human-centered design, discovery, and prototyping to focus on specific, high-impact health needs. The Roundtable and an associated Webinar built on insights gained during an initial human-centered design process carried out by &Partners (now Coforma). In the final phase of the Health+ methodology, a Healthathon that applied insights from the Roundtable and key datasets identified by its participants was held to prototype potentially high value approaches to the management and treatment of SCD. This report served as a resource for the Healthathon, which was hosted by the HHS Office of the CTO and &Partners (now Coforma) between September 7 and September 25, 2020. You can learn more about the Healthathon at <https://data4scd.crowdicity.com/>.

For more information on SCD, its impacts, current treatments, the state of data collection, and an in-depth exploration of SCD patients' experiences, please refer to the [Briefing Paper](#) developed by CODE in preparation for the Roundtable and Webinar and the [Human-Centered Design Report](#) developed by &Partners (now Coforma).

## ABOUT THIS REPORT

The Center for Open Data Enterprise (CODE) is an independent nonprofit organization based in Washington, D.C. CODE's mission is to maximize the value of open and shared data for the public good, by working with government agencies, businesses, nonprofits, and researchers who are both data providers and data users. Since it was founded in January 2015, CODE has held more than two dozen Roundtables and Workshops with the White House and federal agencies focusing on topics including medical research and health care, energy and the environment, and the federal data strategy. CODE has also developed informational materials and recommendations to promote the use of government data and public-private collaboration around data sharing and application. In addition to working with government agencies in the U.S. and internationally, CODE partners with private sector companies, foundations, and other nonprofit organizations to achieve its mission. For more information, please visit [www.odenterprise.org](http://www.odenterprise.org).

This report was written by Matt Rumsey, CODE's Research and Communications Manager, with support from Roundtables Program Manager Paul Kuhne and Research Associate Temilola Afolabi. The report was produced by the Center for Open Data Enterprise and represents CODE's independent synthesis of input from the Roundtable on Leveraging Data to Address Sickle Cell Disease held on June 25, 2020. It is not a U.S. government report. Information and opinions in this report do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, or any other component of the federal government. Federal Advisory Committee Act rules were not applicable to the Roundtable, which was an invitation-only event designed to elicit individual views and suggestions from experts in the field. This report is not meant to represent a consensus of Roundtable participants, but reflects CODE's analysis of individual participants' input and other research done before and after the Roundtable.

## **OVERVIEW OF THEMES**

The Briefing Paper, Webinar, and Roundtable focused on three major themes in SCD data collection: Improving continuity of care for SCD patients, with a focus on the transition between pediatric and adult care; improving SCD care in the emergency department; and assessing treatment options and improving sustainable treatment. Discussion at the Roundtable on each theme covered four areas: challenges, possible interventions, key data sets, and policy solutions. This report provides an overview of each theme and the key challenges and possible interventions related to that theme. The report concludes with sections on data needs and policy solutions that cut across all three themes.

# Improving Continuity of Care for SCD Patients: The Transition from Pediatric to Adult Care

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Pediatric SCD patients are often treated with more swiftness and concern, particularly in the emergency department (ED), than adult patients. As patients get older, they face numerous challenges related to their insurance status, quality of care, and regular complications associated with aging that may be amplified due to their SCD diagnosis.

## CHALLENGES

**Life Transitions** - Young SCD patients expect to celebrate the same milestones as other children as they transition to young adulthood, such as graduating from high school, going off to college, and getting their first jobs. However, these changes may come with additional challenges for SCD patients. For example, when moving for school or to pursue job opportunities, SCD patients may need to find new support systems and medical providers, possibly without the help of family or other support systems that they previously relied upon. They may simultaneously be facing the loss of their insurance.

**Insurance** - Children with SCD can often access insurance through their parents or Medicaid, giving them comparatively greater access to coverage than their adult counterparts. This starts to change as SCD patients age. When they hit 19 many patients lose access to Medicaid. Similarly, those with insurance through their parents lose access under the Affordable Care Act when they reach age 26.

**Quality of Care** - Regardless of where they live or their insurance status, SCD patients will have to transition from pediatric providers to adult providers as they age. Unfortunately, there are a number of issues that can negatively impact the quality of care that SCD patients receive as they get older.

- There are fewer primary care physicians, hospitals, and specialists that excel at treating adult SCD patients.
- It may be more difficult for adult SCD patients to access social support services as they age out of pediatric environments and take more control over their own care.
- There are challenges related to electronic health record (EHR) data access and the consistency of care plans for adult patients.

**Informational Challenges** - Similarly to other pediatric patients who transition to adult care, SCD patients often struggle with a lack of education and access to information about their conditions and care as they transition from childhood to adulthood. In addition, SCD patients at the Roundtable described how they had been left out of discussions of their condition when they were children, or even as old as high school age, leaving them ill prepared to manage their illness as young adults.

## INTERVENTIONS TO IMPROVE THE TRANSITION FROM CHILDHOOD TO ADULTHOOD AND CONTINUITY OF CARE FOR SCD PATIENTS

**Continuity of Care** - The Roundtable surfaced a number of potential interventions that could improve the transition from childhood to adulthood and the overall continuity of care for SCD patients.

- Overall, there is a need for a more structured process for moving patients from pediatric to adult providers. This could include the development of dynamic and shareable care plans that patients can share when they are seeing a new provider or have to go to the emergency department.
- At the same time, new incentives should be identified to encourage doctors to specialize and focus on working with adult SCD patients. These could include special training opportunities or other career incentives, changes in reimbursement for SCD treatment, and more.
- Additional interventions can include more community support and efforts to work with college and university health offices to better understand and work with enrollees who suffer from SCD.

**Information and Education** - Roundtable participants identified education and information as vital to ensure a smooth transition between childhood and adulthood for SCD patients.

- Broadly, targeted education should be provided to SCD patients throughout their lives, particularly during childhood, to help ease their transition journeys and ensure that their care is consistent.
- This education could include toolkits and resources to help SCD patients through particularly challenging situations, for instance when moving, needing to find new providers, or while researching and choosing health insurance.
- Finally, the Roundtable identified the possibility of sharing more SCD patient stories as a powerful educational tool.

### Use Case: Personal Paramedics

A potential solution to improving quality of living for SCD patients is providing recurrent paramedic services to afflicted patients. One patient shared how she was enrolled in a program where a paramedic would come to her home regularly to check on her wellbeing and measure her vital signs. Additionally, when the patient is admitted to the ED, the same paramedic is responsible for visiting the patient and ensuring their needs are met while admitted. This provision of these paramedic services gives those with SCD an extra point of care as well as a stronger support system.

# Improving SCD Care in the Emergency Department

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The ED should ideally be a patient's last resort when seeking pain management, but some patients must use the ED because they lack access to primary care, specialized hematologists, and individualized treatment. SCD patients often face a number of obstacles when admitted to the ED. Emergency department doctors and personnel may lack knowledge or experience working with SCD patients, may be biased against them, and may not have access to useful data that would help them deliver appropriate care.

## CHALLENGES

**Bias and Trust** - Bias and lack of trust were identified as major challenges throughout the Roundtable. Issues with bias and trust can flow both ways, with ED doctors being biased against patients and patients lacking trust in ED providers.

- In the ED, bias can often emerge in the form of providers assuming that SCD patients are “drug seeking” or “frequent fliers” who may not actually be in acute need of opioid or other pain medication.
- Providers may not trust or accept data or information volunteered by patients, despite the intimate knowledge that most patients have about their own conditions, and suitable care plans given by a provider that have been proven to work for them.
- Bias can come from a number of places, but it may often result from the overall lack of specialists or specific protocols and procedures for SCD patients in the ED.
- Patients may also lack trust in Emergency Department doctors, assuming that they will not administer care appropriately or refer to the treatment plans that patients and their providers present.

**Lack of specialists/procedures/protocols** - The lack of providers who understand SCD, protocols, or standard procedures in the ED can lead to a number of issues.

- Out of date or missing protocols mean that doctors and nurses do not have the proper training, which can interfere with care in the ED and cause confusion when transitioning patients from the ED to inpatient environments. These issues may include inappropriate or unnecessary blood transfusions, long wait times for pain medication, and a lack of understanding of potential complications or underlying issues.
- Broadly, there is significant variation in care levels between hospitals and EDs. For example, some hospitals have SCD specialists on staff while others may rarely see SCD patients. Urban hospitals and EDs in areas with large SCD patient populations may be better prepared than rural hospitals in areas with small or geographically dispersed SCD patient populations.

**Data Access** - Data access was raised as an additional issue that limits the quality of care for SCD patients in the ED.

- The data available to healthcare providers in the ED may contain too much information, not enough information, or may simply lack the structure and organization necessary to make it useful.

ED providers also often lack access to a patient's EHRs, which often include information about their specific medical condition, making it more difficult to provide timely and adequate care.

- Better access to social determinants of health (SDOH) data in the ED could also help improve care by giving providers more accurate information about the social factors that may impact the severity of a patients' condition or comorbidities.

**COVID-19** - The COVID-19 pandemic has introduced additional complications for SCD patients seeking care in the ED.

- The adoption of telehealth has accelerated rapidly during the pandemic, but individuals without consistent internet access cannot take full advantage of this emerging approach.
- SCD patients may still be able to seek care in the ED, but doing so could put them at increased risk of contracting COVID-19. This presents a difficult choice for SCD patients - and others with certain underlying conditions - who may be more likely to experience severe symptoms and other complications from COVID-19 if they contract it.<sup>1</sup>
- Due to social distancing and other safety requirements, patient advocates may not be able to join SCD patients in the ED.

## INTERVENTIONS TO IMPROVE CARE IN THE EMERGENCY DEPARTMENT

### Best Practice: Emergency Department Sickle Cell Care Coalition (EDSC<sup>3</sup>)

Significant challenges with ED care identified during the Roundtable included the lack of specialized knowledge and targeted protocols for SCD treatment, as well as issues with bias and trust that hinder communication and ultimately limit the quality of care available to SCD patients in the ED.

These challenges exist, in part, due to a lack of resources or infrastructure for ED providers to learn more about SCD and modernize their protocols. The EDSC<sup>3</sup> was developed to improve the care offered to SCD patients in the ED through evidence-based emergency care and improved provider-patient-family communications. The EDSC<sup>3</sup> pursues its goal through research, education, advocacy, community outreach, and health care performance metrics.

**Patient Empowerment** - The Roundtable identified several broad interventions that can further empower SCD patients in the ED.

- New approaches including patient-specific care plans, electronic treatment bracelets, portable health records, and other methods can give patients more control over their health data and case histories while increasing provider confidence in the information.

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<sup>1</sup> <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

- Advocates and community health workers can help deepen relationships with EDs,
- Better methods of alerting primary care providers to their patients' ED visits can provide additional support to SCD patients.

**New/Adjusted Protocols** - The Roundtable made it clear that many EDs need to update their protocols and procedures - which may not have been tweaked in 25 years - for caring for SCD patients.

- These changes can include a greater emphasis on listening to patients, who are often experts in their own conditions.
- Overall, protocols should be more consistent. Specific ideas for improving protocols included developing tools to help ED providers evaluate and understand the needs of SCD patients and improving connections between EDs and local specialty clinics.

**Information/Data Sharing** - Finally, better information sharing was identified as a key to improving SCD care in the ED.

- Health Information Exchange programs can be strengthened.
- Measurements of pain levels can be standardized and made interoperable.
- High-level dashboards of metrics can be made available.
- Efforts to integrate rural hospitals with larger health systems will help with information sharing and improve care. For example, practitioners at rural hospitals and EDs may be less likely to know about SCD patients or see them irregularly. Integrating with larger health systems can provide additional information, education, and resources.



# Assessing Treatment Options and Improving Sustainable Treatment

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Identifying pathways to sustainable treatment is perhaps the biggest challenge facing SCD patients and those who provide their care. The Roundtable identified a range of challenges standing in the way of sustainable treatment including the need for education, issues with access to treatment, bias, and data quality and availability.

## CHALLENGES

**Education and Access to Information** - Education and access to information is a challenge to SCD patients, their healthcare providers, and others who may interact with them.

- Patients often lack information and opportunities for education - particularly once they reach adulthood - on their treatment options, how those treatments are applied, and the results of research.
- There are not enough doctors who specialize in treating SCD, and even specialists often lack understanding of existing and emerging treatment options.
- Others who may interact closely with SCD patients, including nurses, daycare providers, employers, schools, and others, need additional education, information, and support.

**Issues with Existing Treatment Options and Treatment Access** - Roundtable participants identified a range of issues related to SCD treatment.

- There is no clear model for treatment, leaving every provider and patient to approach their care differently.
- There are a number of treatments available, but hydroxyurea - the most common - is cumbersome and many patients and doctors are hesitant to use it. Other treatments lack adequate effectiveness research.
- While treatments are available, they are often difficult to access. Many SCD patients struggle to maintain insurance coverage, and treatments can be prohibitively expensive without it. Pharmacies don't often carry SCD treatments because the population of patients is small and they lack financial incentives to do so.
- Outside of a hospital or ED setting, SCD patients may lack the support they need to understand their treatment options and navigate complicated procedures to access them.

**Bias** - From the emergency department to treatment, bias impacts the treatment of SCD.

- Trust is often lacking between providers and patients, particularly for treatment in the ED, for the reasons described above.
- Bias also emerges in research, which may limit the development and long term impact of SCD treatments in a number of ways. It can show up in the interpretation of data and impact who is recruited for research. While some researchers may believe that Black Americans are reluctant to participate in medical research, this assumption is not supported by evidence. However, many researchers may fail to recruit Black Americans for research studies for reasons of bias.

**Data Quality and Availability** - There are numerous issues with data quality and availability that impact SCD patients, especially in their treatment.

- More support is needed for research and data collection. Specifically, there is little research on how SCD interacts with other conditions like diabetes; there are few existing patient registries and most are underfunded; and there is a dearth of longitudinal data, with more funding needed for clinical, multistate, and surveillance data collection.
- Outdated datasets need to be updated and interoperability issues need to be fixed. For example, EHRs often lack key data around pain medication dosage and are not interoperable. There is also a lack of consistent data elements and definitions across states. Finally, SCD patients are often miscoded, limiting the usefulness of existing data without further cleaning.
- There are also regulatory hurdles that limit the usefulness of existing data. For example, private companies may have large amounts of claims and EHR data, but they cannot share their data for research purposes because of varying state Medicaid regulations. Hospitals may also use existing HIPAA regulations to avoid sharing valuable information.

## INTERVENTIONS TO IMPROVE SUSTAINABLE TREATMENT

**Education and Engagement** - Education and engagement are two major pathways to improved, sustainable SCD treatment.

- For patients, education should be a lifelong pursuit with targeted, actionable information presented at different periods of time. For example, education should be approached differently for 5 year olds than for 15 year olds. The SCD community can learn from best practices for education and engagement for other diseases. For example, diabetes and other chronic diseases have robust models for patient and family engagement and training that could be replicated.
- More providers need to be trained to help SCD patients, and those that are well trained need to be equipped to help explain complex issues to their patients.
- Researchers need to be prepared to engage SCD patients in clinical trials, proactively share the results of their research with the patient community, and potentially market new treatments directly to patients. Overall, the research community should prioritize patient-centered outcomes research (PCOR) and leverage new technology to fill research gaps.

**Data and the Social Determinants of Health** - Data on the social determinants of health (SDOH) can be helpful in improving sustainable treatments. However, data collection standards need to be implemented, population health and clinical data need to be integrated, and a holistic approach to integrating data into treatment needs to be embraced. Data hubs and care plans can potentially help patients manage their pain medication and treatment outside of medical facilities.

**Provider Level Improvements** - In addition to training more providers, other steps can be taken to improve SCD patient care, for example:

- Hematologists should be engaged early and often. This can happen at specialized SCD centers where resources exist to connect patients with needed social services. More robust connections can be made between providers and treatment centers that specialize in SCD and other doctors and healthcare facilities.
- Providers should also become more knowledgeable about existing treatment methods and best practices for SCD.

### **Best Practice: Incentive payments for providers**

Many roundtable participants raised the new idea of providing incentive payment to physicians for treatment of patients with SCD. The HHS Office of Minority Health will be offering a funding opportunity in the near future targeted for State Medicaid Offices and their partners to develop incentive payment systems. The development of such a system is meant to encourage providers to prescribe hydroxyurea and other treatments to children with sickle cell disease. Currently, physicians simply do not have the incentive to invest in treatment options when a very small percentage of their patient populations have SCD.

# Datasets

The Roundtable surfaced a large number of datasets that can potentially be helpful for SCD treatment and improved care. Some of these are already publicly available; others exist, but may take additional efforts to share more widely; and some do not exist yet, but can be targeted for development. Some apply to one of the three broad themes of the Roundtable, while many cut across multiple themes.

## IMPROVING CONTINUITY OF CARE FOR SCD PATIENTS, WITH A FOCUS ON THE TRANSITION FROM PEDIATRIC TO ADULT CARE

SDOH Datasets	Clinical Datasets	Other Datasets
<ul style="list-style-type: none"> <li>• Food and nutrition: access to healthy options, food deserts</li> <li>• Safety</li> <li>• Education</li> <li>• Economic</li> <li>• Transportation</li> <li>• Weather, temperature and environment</li> <li>• SDOH data to show impact on adults</li> <li>• Homelessness</li> </ul>	<ul style="list-style-type: none"> <li>• Patient history</li> <li>• Clinical morbidity data</li> <li>• Transfusion and blood data</li> <li>• Genetic and newborn screening data</li> <li>• Hospital admission               <ul style="list-style-type: none"> <li>• Readmission rates</li> <li>• Complaints about physicians and care</li> <li>• Discharges patient didn't agree to</li> <li>• Removal from ED rooms</li> </ul> </li> <li>• Other disorders</li> </ul>	<ul style="list-style-type: none"> <li>• Social support data</li> <li>• Patient driven data collection</li> <li>• Specific patterns of complications</li> <li>• Access to PCP/care/insurance</li> <li>• Patient/clinic resources</li> <li>• Social support data</li> <li>• Overall utilization data</li> <li>• Datahub for transition research</li> <li>• Patient geographic and demographic data</li> <li>• Geospatial mapping</li> <li>• Longitudinal patient data</li> </ul>

## IMPROVING SCD CARE IN THE EMERGENCY DEPARTMENT

SDOH Datasets	Clinical Datasets	Other Datasets
<ul style="list-style-type: none"> <li>• Nutrition and food deserts</li> <li>• Transportation</li> <li>• Housing</li> <li>• Internet access</li> <li>• Psychosocial highlights</li> </ul>	<ul style="list-style-type: none"> <li>• Time to first pain medication administration</li> <li>• Patient medication dose history</li> <li>• Readmission rates</li> <li>• Discharge data</li> <li>• Individualized pain data</li> <li>• Patient history data</li> </ul>	<ul style="list-style-type: none"> <li>• Dehydration</li> <li>• Bloodbank data</li> </ul>

## ASSESSING TREATMENT OPTIONS AND IMPROVING SUSTAINABLE TREATMENT

SDOH Datasets	Clinical Datasets	Other Datasets
<ul style="list-style-type: none"> <li>• Internet access</li> <li>• Housing</li> <li>• Transportation</li> <li>• Nutrition</li> <li>• Educational environment</li> <li>• Safety</li> </ul>	<ul style="list-style-type: none"> <li>• Longitudinal data</li> <li>• Pain medication dose data in ER</li> <li>• Prescription and prescription adherence</li> <li>• Private data (labs, healthcare admin, etc)</li> <li>• Treatment and outcomes data</li> <li>• Newborn screening, and morbidity</li> <li>• Patient history</li> <li>• ED/Hospital utilization</li> </ul>	<ul style="list-style-type: none"> <li>• Patient feedback</li> <li>• Appointment show/miss rates</li> <li>• Private data (healthcare admin, claims labs, etc)</li> <li>• Medicare/Medicaid data</li> <li>• SCD patient registry</li> </ul>

### DATASETS THAT CUT ACROSS THEMES

SDOH Datasets	Clinical Datasets	Other Datasets
<ul style="list-style-type: none"> <li>• Nutrition</li> <li>• Safety</li> <li>• Education</li> <li>• Transportation</li> <li>• Housing</li> <li>• Internet access</li> </ul>	<ul style="list-style-type: none"> <li>• Patient history</li> <li>• Patient medication dose history</li> <li>• Newborn screening and genetic data</li> <li>• Discharge data</li> <li>• Readmission data</li> </ul>	<ul style="list-style-type: none"> <li>• Expanded longitudinal data collection</li> </ul>

# Policy Solutions

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In addition to short-term actionable steps, many of which were explored during the September Healthathon, the Roundtable surfaced a wide range of potential policy solutions to improve SCD treatment. Many of them crossed the three broad themes explored by the Roundtable, making it clear that even targeted policy changes can have wide ranging impacts for SCD patients. Moving forward it will be key for policy to be made through multidisciplinary discussions and efforts that include patients, at-risk communities, and other key groups.

## PROTOCOLS/PROCEDURES/BEST PRACTICES

A major issue raised throughout the Roundtable, specifically in reference to the transition between childhood and adulthood and the patient experience at the ED, was the lack of adequate protocols, procedures, and best practices. Two policy suggestions emerged:

- There should be specific protocols and procedures in place to help SCD patients transition from childhood to adulthood. There is also potential to create a specific “transition” period for SCD patients that would provide them with continuing support as they deal with changes to their insurance status, finding new adult providers, and other challenges.
- Credentialing for hospitals and providers can be tied to compliance with protocols and other guidelines. This could include novel approaches like consumer or “Yelp” style scoring.

## MEDICAID & OTHER INSURANCE

Insurance issues are a significant hurdle for SCD patients. The Roundtable surfaced a number of specific recommendations.

- Medicaid access should be guaranteed into adulthood for any SCD patient who wants it.
- Certain Medicaid rules that impact SCD patients can be reformed. Specifically, rules that limit SCD patients to certain providers based on geography may now make it difficult for patients to seek care multiple times in short periods.
- Explore value based care and ensure that providers are properly reimbursed for treating SCD patients. Find additional, payer-side approaches to incentives for doctors to specialize in SCD treatments.
- Leverage Medicaid funds to develop policies to help with the transition from adolescence to adulthood.

## DATA

Data issues are standing in the way of treatment and care for SCD patients in a number of ways. The Roundtable identified numerous steps that could lead to increased collection, interoperability, and use of SCD data by patients, providers, researchers, and more.

- EHR data needs to be interoperable and patients should have something similar to the “Blue Button” that will ensure they have access to their own data. Fully implementing the 21st Century Cures Act (Cures Act) may accomplish these goals.
- Patient data should be shared at the point of care. It should be standardized, clearly shared, and made combinable.

- The SCD data collection program, which is currently active in California and Georgia with plans to expand to 7 additional states, should be expanded even more widely.
- Encourage states to allow use of limited datasets for research under Medicare and Medicaid rules. This would ultimately allow for data collected by private industry, including the pharmaceutical industry, to be put to better use.
- New technologies (including Interactive Voice Response calls, SMS, email, and social media) should be leveraged for patient engagement, outreach, and data collection.

## RESEARCH

Research into SCD treatments and care needs to be expanded, improved, and better communicated. This can be done in a number of ways.

- SCD research infrastructure should be funded through Congressional appropriations for research and data collection. Through this mechanism, various efforts including state level clinical databases, industry research on treatment and effectiveness, and the work of interested stakeholders can be brought together. More data on where SCD patients live and how they access care can be collected and aggregated.
- A library of outcomes research for SCD treatments should be developed.

## SCD SPECIFIC CARE

The Roundtable identified a number of policy changes that could be particularly impactful with respect to SCD patients' care. They include:

- Speciality SCD Centers/Clinics/infusion centers should be developed and funded. Some already exist, but the number is small. More of these comprehensive, multidisciplinary centers can provide the SCD community more consistent access to care while also supporting further professional development among providers. These centers should explore ways to better connect with Medicaid patients (potentially including through telehealth) who are currently underserved by existing centers.
- Support/develop Community Based Organizations (CBOs). CBOs work at the local level to meet community needs and have close ties to patients and advocates.
- Ensure that SCD patients aren't categorized as opioid seeking. This could be achieved by implementing a registry of SCD patients, providing them with proof of their SCD status that could be safely shared with EDs and other providers, fully interoperable EHRs, or other approaches that may emerge via the fight against the opioid epidemic.
- HHS should support SDOH interventions around transportation, homelessness, and more that may improve the lives of SCD patients.
- The Health Resources and Services Administration (HRSA) - which works to improve health outcomes and address disparities - could expand their grant program to cover SCD training for providers.

# Conclusion

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The virtual *Roundtable on Leveraging Data to Address Sickle Cell Disease* brought together medical experts, patients, and patient advocates to discuss the data needed to improve SCD diagnosis, treatment, and patient care. Their input and insights provide an overview of challenges, potential interventions, key datasets, and possible policy solutions to improve care for Sickle Cell Disease patients.

Many of the issues raised during the Roundtable cut across the key thematic areas being discussed, raising the possibility that even small improvements could have significant positive impacts for Sickle Cell Disease patients across the country. This document serves as a step towards those impacts by informing both the SCD Healthathon that was held in September 2020 and the larger Health+ SCD project for which it was developed.