

# ADVANCING CARE FOR SICKLE CELL DISEASE: A STRATEGIC ROADMAP

**A RESOURCE TO PROMOTE ACTIVITIES TO  
IMPROVE OUTCOMES OF SICKLE CELL DISEASE**

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# Foreword

Sickle Cell Disease (SCD) has consistently been deprioritized within the US healthcare system. Though it is a disease fraught with various complications that disrupt the lives of patients and their families, it has yet to receive the national attention required to advance care for the individuals living with the condition. As the US healthcare system strives to innovate and improve care delivery for all Americans, the climate is ripe for meaningful actions to be taken towards advancing care for individuals with SCD. To that end, Sick Cells and Avalere Health are proud to present the Advancing Care for SCD Strategic Roadmap.

In November 2020, we convened a multi-stakeholder dialogue and asked participants to share potential solutions to address the persisting gaps in SCD care. The culmination of these varying ideas resulted in the development of this Strategic Roadmap. The ideas presented here are not intended to be finite, but rather to inspire and encourage all healthcare stakeholders to immediately begin taking actionable next steps to improve the quality of care of those individuals with SCD. The Roadmap includes recommendations for actions that patients, advocacy organizations, providers, researchers, payers, and manufacturers can take today. We believe this Roadmap can serve as a valuable resource and encourage you to use it to increase awareness about SCD, build partnerships, and catalyze the implementation of these solutions presented here. We believe our cohesive efforts can greatly improve the lives and outcomes of individuals with SCD and their families.

## **Ashley Valentine**

Co-Founder and President  
Sick Cells

[Sick Cells](#) is a nonprofit sickle cell patient advocacy organization founded in 2017. Sick Cells' mission is to elevate the voice of sickle cell disease (SCD) community and stories of resilience. By highlighting the grave disparities in the sickle cell community, Sick Cells aims to influence decision-makers and propel change.

## **Kristi Mitchell**

Senior Vice President  
Avalere Health

[Avalere Health](#) is a vibrant community of innovative thinkers dedicated to solving the challenges of the healthcare system. Avalere delivers a comprehensive perspective, compelling substance, and creative solutions to help you make better business decisions. As an Inovalon company, Avalere prizes insights and strategies driven by robust data to achieve meaningful results.

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# Overview of the State of Sickle Cell Disease

## Background

Sickle cell disease (SCD) is a group of inherited blood disorders caused by the presence of an abnormal form of hemoglobin (Hemoglobin S- Hgb S). These hemoglobin S tend to aggregate after unloading oxygen forming long, rod-like structures that make the red cells to assume a sickle shape. The sickle shape causes red blood cells to get stuck in small blood vessels leading to the clogging of blood vessels.<sup>1</sup>

According to the Centers for Disease Control and Prevention (CDC), it is estimated that approximately 100,000 Americans suffer from SCD and it occurs in about 1 out of every 365 Black or African American births and about 1 in every 16,300 Hispanic-American births.<sup>2</sup> With the prevalence of SCD among a minority population in America, understanding the social determinants of health (SDoH) of these patients is essential to understanding the gaps in SCD care and identifying befitting solutions to improve the health outcomes. Survival for people with SCD in the United States has dramatically improved with nearly 95 percent of individuals born with SCD reaching 18 years of age compared to the 1970s, where life expectancy was generally below 20 years old.<sup>3</sup> This improvement has been attributed to several childhood interventions, including newborn screening programs, penicillin prophylaxis, and pneumococcal vaccination.<sup>3</sup>

Individuals with SCD suffer from both acute and chronic complications which include recurring episodes of vaso-occlusive crisis (VOC), acute chest syndrome (ACS), infections, stroke, and organ damage affecting every organ in the body. These chronic complications require care coordination from a multidisciplinary team which include primary care physicians (PCPs) and hematologists among other specialists.

## Economic Burden of Sickle Cell Disease

The increased risk of complications associated with SCD leads to increased frequency in emergency department (ED) visits. Vaso-occlusive crises are the most common cause of ED visits and hospital admissions among SCD patients.<sup>4</sup> According to the 2019 Healthcare Cost and Utilization Project (HCUP) report, the total cost of inpatient admissions for SCD in 2016 was \$811.4 million.<sup>5</sup> Moreover, individuals with SCD have 3 times the charges for hospitalization associated with an ED visit per 100 people compared to those with congestive heart failure and also higher than those with HIV and asthma.<sup>6</sup>

The chronic nature of SCD and its associated complications contribute to patients' high health care utilization and costs, with an estimated lifetime cost of \$8,747,908 for a patient with a 50-year life expectancy.<sup>7</sup> End organ damage (EOD) worsens the economic burden of SCD, with healthcare costs 2-5 times higher among SCD patients with EOD compared with those without EOD.<sup>7</sup>

## Gaps in Sickle Cell Disease Treatment and Management

The SCD care continuum is complicated and requires consistent multi-provider coordination and adequate collaboration between patients/caregivers and providers (see Figure 1). While SCD life expectancy has improved over time, there are various barriers preventing individuals with SCD from accessing high-quality care and treatments. Select gaps include:

**Table 1: Gaps in Sickle Cell Disease Care**

**Systemic Racism and Access to Care**

Systemic racism within the US healthcare system greatly impacts the type of care SCD patients receive, the level of support provided to their caregivers, the breadth of funding available for research, and the drug coverage decisions for new life-saving therapies. Across the country, Black and Brown people face disparities accessing care, the quality of care received, and health outcomes. The attitudes and behaviors of health care providers have been shown to be one of various factors that contribute to health disparities.<sup>8</sup> Furthermore, negative attitudes displayed by ED providers have been found to be associated with a lack of adherence to recommended guidelines for treating pain in the ED and research has also shown that negative attitudes are a major barrier to the delivery of high-quality pain management in SCD.<sup>9</sup> Individuals with SCD and their caregivers often experience low-quality care as a result of implicit bias and racist encounters within the healthcare system.<sup>10</sup>

**Inadequate or Delayed Pain Management**

Underlying concern about opioid addiction is the most common reason for inadequate or delayed treatment of pain in SCD patients who present in the ED. Stigma from this bias leads to delays in treatment delivery, under prescribing of opioids, and poor SCD management.<sup>11</sup> Only 0.5% to 8% of SCD patients are truly addicted to opioids, which is not far from the rate of opioid addiction in the general population at 4.8% (excluding heroin addiction) and no worse than the average opioid addiction rate among people who suffer from chronic pain in the United States.<sup>12 13</sup>

**Suboptimal Transition from Pediatric to Adult Care**

Children with SCD have better access to care through academic medical centers, which tend to have a multidisciplinary team and SCD specific expertise. Adults are more likely to receive care in community hospitals where providers are less knowledgeable about the disease and SCD-specific care are less common.<sup>14</sup> The transition from the more comprehensive care received in childhood to adulthood is challenging and precludes adults from receiving consistent, broad-ranging care.

**Inadequate Primary Care SCD Knowledge**

Due to the complicated nature of SCD management, primary care providers often lack the knowledge and experience to adequately manage this patient population. In a survey conducted by Improving Health Outcomes and Medical Education for Sickle Cell Disease (iHOMES) network, approximately 40% of 129 Johns Hopkins community physicians surveyed reported being uncomfortable with their ability to provide ambulatory care or manage comorbidities for sickle cell patients. More than half were also uncomfortable managing sickle cell crises, medications and pain.<sup>15</sup>

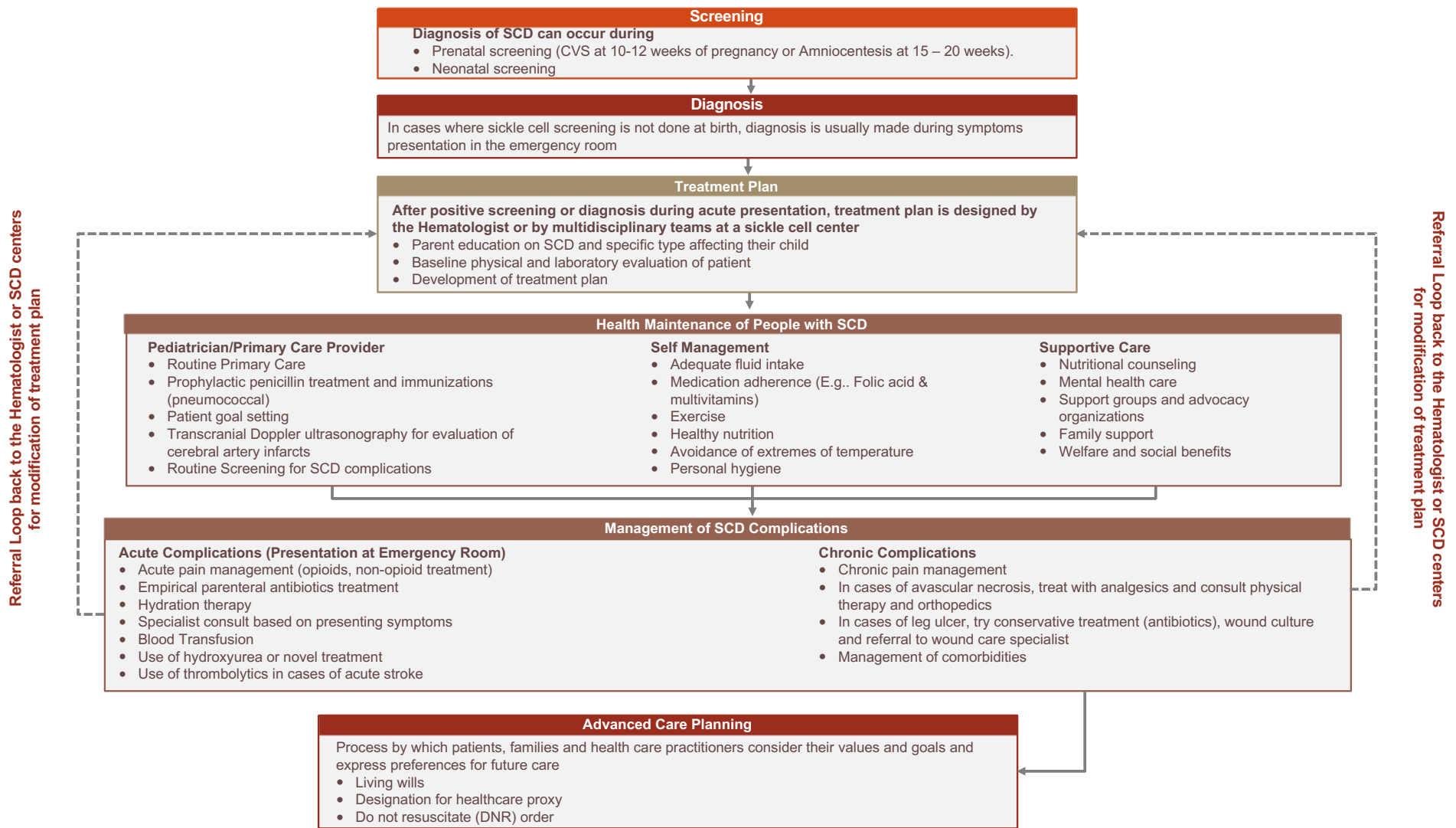
**Inconsistent and Inadequate Insurance Coverage**

The Centers for Medicare & Medicaid Services and state Medicaid programs are the leading payers for SCD care. Even though they pay for most SCD services, there is limited coverage for therapies to treat comorbidities of SCD and novel therapies. Likewise, high deductibles might also preclude use of services.<sup>16</sup>

**Poor Coordination Amongst and Between Providers and Supportive Care**

Inadequate coordination of services between PCPs and hematologists or other specialists often lead to higher rate of acute care utilization and readmission. SCD is complex and requires a functional multi-specialty care team with resources for care coordination even when patient has been discharged.

**Figure 1—Sickle Cell Disease Care Continuum**



CVS: Chorionic Villus Sampling; SCD: Sickle Cell Disease

# Introduction to the Strategic Roadmap

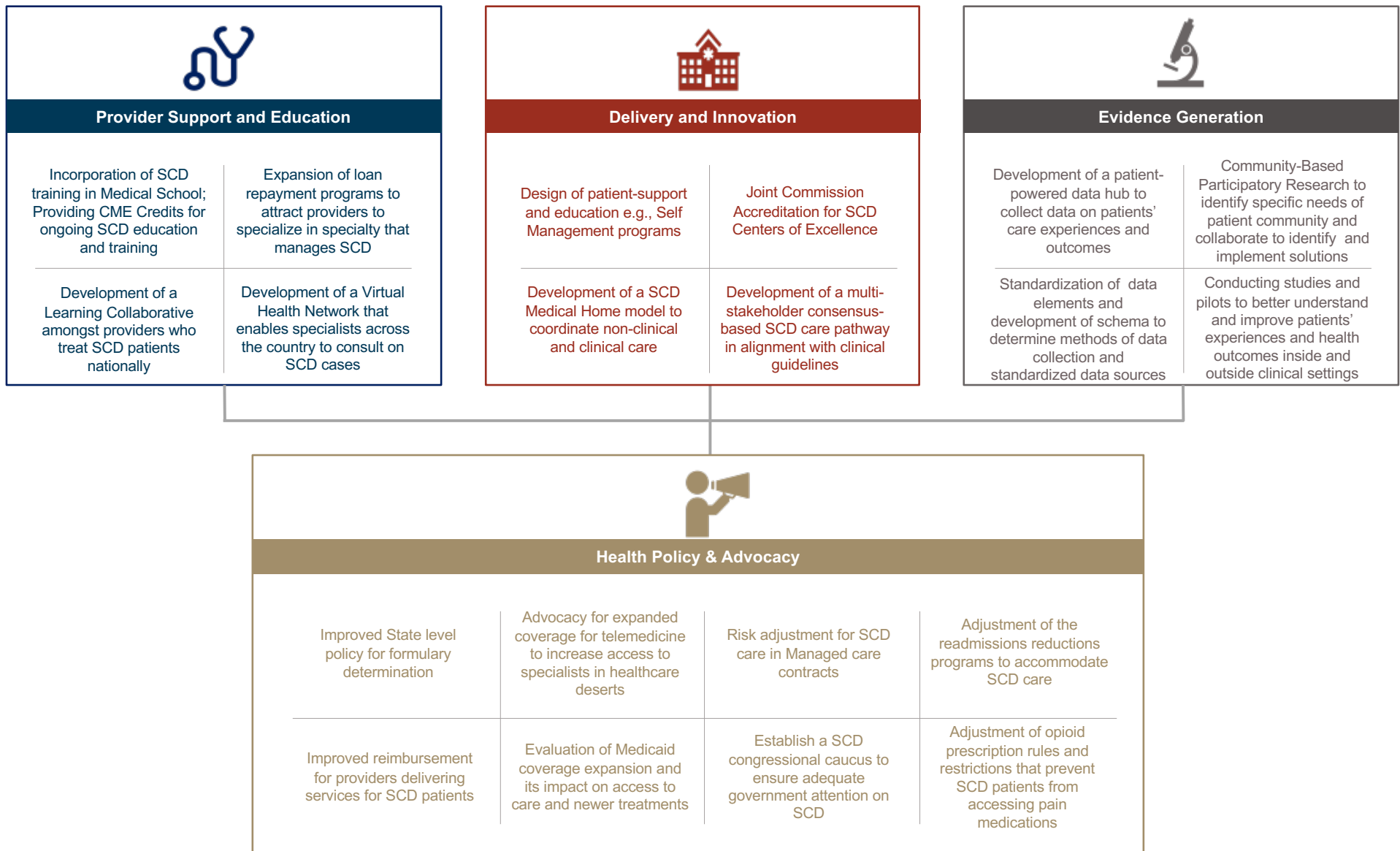
SCD is characterized by life-altering complications that require cohesive treatment and management to improve the quality of life for patients and their caregivers. There are vast opportunities for the US to design a health system that can adequately provide high-quality care for these patients and properly equip providers with the knowledge to deliver that care. To that end, Sick Cells and Avalere Health convened a multi-stakeholder group of patients and caregivers, patient advocates, government officials, payers, manufacturers, researchers, and medical professionals through a Dialogue, “Taking Action on Improving Quality of Life for Individuals with Sickle Cell Disease”, focused on identifying innovative approaches to improving SCD care in the US. The goal of this meeting was to collaborate and develop consensus-based solutions that will advance treatment and management of SCD in the near term. The solutions proposed in the Dialogue informed the development of the ideas presented in this Roadmap.

## The Strategic Roadmap

This Roadmap is intended to serve as a practical resource to assist healthcare stakeholders in identifying solutions they can implement to improve outcomes for SCD patients. As a patient-centric guidance to SCD stakeholders, the Roadmap includes 4 inter-related domains, as outlined in Figure 2, that comprise an extensive framework for advancing SCD care:

- **Improve Provider Support and Education:** Given the intricacies of SCD care, there are not enough providers with comprehensive training and expertise to care for individuals with SCD. Structured medical education and ongoing training of all providers who are likely to treat SCD patients can lead to better outcomes to patients when they present to the clinical setting.
- **Advance SCD Care Delivery and Innovation:** Similar to other chronic conditions, SCD requires evidence-based innovative care delivery. There are opportunities to develop integrated delivery models focused on complication prevention, management, and treatments in collaboration with multi-providers, patients, and their caregivers.
- **Support Evidence Generation for SCD:** Advancement of SCD management and treatment requires evidence-based interventions and solutions. There are vast opportunities for stakeholders to conduct research to understand factors that lead to improved patient outcomes and optimal management of the condition.
- **Advance Health Policy and Advocacy to Improve SCD Quality of Care:** Advocacy is an important tool to increase national, state, and local focus on SCD. SCD must receive legislative support in order to achieve the goal of improving patient outcomes. Health policies that affect treatment reimbursement, adequate insurance coverage, and funding for research and community-based organizations (CBOs) support must be evaluated to improve outcomes for individuals with SCD.

**Figure 2—Roadmap to Advance Sickle Cell Disease Care**





# Improve Provider Support and Education

Adequate SCD treatment and management requires specific knowledge about the pathology of the condition and techniques for reducing complications. The unpredictability and persistence of complications related to SCD can be challenging for providers who might not be familiar with the condition.<sup>17</sup> Outlined below are tactics for improving provider education and support.

### **Incorporation of SCD training in Medical School and provision of CME Credits for ongoing SCD education and training:**


Expanding the training curriculum for medical students and nurses, as well as, augmenting the provision of CME credit for practicing providers would improve their structural competency and knowledge of best practices

and novel therapies for SCD management. The SCD Training and Mentoring Program (STAMP), under the U.S. Department of Health and Human Services Office of Minority Health, uses Project ECHO's (Extension for Community Health Outcomes) tele-mentoring platform for training PCPs to equip them with appropriate knowledge and skills and co-management support for SCD care.<sup>18</sup> Expansion of the training and mentoring program to community providers across the country, particularly in rural areas, will help them better manage SCD patients and ensure proper care coordination.

**Expansion of loan repayment programs to attract providers to specialize in a specialty that manages SCD:** Various states offer medical school loan forgiveness programs to encourage primary care providers and providers with select specialties to practice in their state on the completion of their residency program. The Kansas Bridging Program aimed to attract psychiatric residents to practice in Kansas is an example that could be modeled. States can implement similar programs for SCD-related specialists, which would improve access to hematologists or providers equipped to properly manage SCD patients.

**Development of a Learning Collaborative amongst providers who treat SCD patients nationally:** A Learning Collaborative is a systematic approach to process improvement where organizations share their experiences to accelerate learning and broader implementation of best practices.<sup>19</sup> Providers can benefit from the development of a de novo collaborative or the expansion of existing SCD learning collaboratives like the Hemoglobinopathy Learning Collaborative (HLC) and the SCD Treatment Demonstration Regional Collaborative to ensure that there is adequate opportunity for additional providers in varying regions to learn from shared experiences.

**Development of a Virtual Health Network:** A Virtual Health Network (VHN) is group of affiliated providers across the country leveraging the use of telehealth to provide specialist care and support for other providers especially PCPs. Examples of Virtual Health networks are the University of Texas' VHN and Project ECHO where providers in large academic medical centers



Provider Support and Education	
Incorporation of SCD training in Medical School; Providing CME Credits for ongoing SCD education and training	Expansion of loan repayment programs to attract providers to specialize in specialty that manages SCD
Development of a Learning Collaborative amongst providers who treat SCD patients nationally	Development of a Virtual Health Network that enables specialists across the country to consult on SCD cases

consult or co-manage patients in various parts of the country.<sup>20,21</sup> Building on the existing networks, there are opportunities to mitigate the issue of provider shortage and lack of care coordination for patients with SCD.

## Advance SCD Care Delivery and Innovation

Chronic conditions are often fraught with complications and co-morbidities which require coordination of care amongst various specialists. The intricate nature of such conditions has been the impetus for the development of specific care delivery models that entail the implementation of evidence-based interventions focused on improving outcomes for patients. To that end, there are vast opportunities to develop new, innovative care models specific to SCD.

**Design of patient-support and education e.g., self-management programs:** A self-management program equips individuals to actively identify issues and solve problems associated with their illness.<sup>22</sup> While there are resources available to educate patients, a formal self-management program would include evidence-based techniques for managing SCD. For example, the Lung Association’s asthma self-management program has been proven to assist patients in better managing their conditions.<sup>23</sup> Community-based organizations (CBOs), patient advocacy groups, professional societies such as American Society of Hematology, and patients can collaborate to develop a self-management program to improve patients’ understanding of their condition and techniques that can deploy to better manage SCD.

**Development of a SCD Medical Home model:** The medical home is a model where care is patient-centered, comprehensive, team-based, highly comprehensive, and centered on quality and health outcomes.<sup>24</sup> Sickle cell disease requires coordination of care across a wide array of providers such as hematologists, pulmonologists, neurologists, emergency care physicians, nurses, social workers and other types of providers. The development of a medical home specific to SCD can standardize care coordination methods, implement the use of valid and reliable quality metrics to track and monitor progress, and target health outcomes for SCD patients.

**Development of a multi-stakeholder consensus-based SCD care pathway in alignment with clinical guidelines:** Care pathways are multidisciplinary tools for care process management in which tasks or interventions by providers involved in patient care are defined, optimized, and sequenced with the goal of improving patient safety, quality, and efficiency of care.<sup>25</sup> To design a care pathway for SCD, it is important to align with relevant SCD clinical guidelines like the American Society of Hematology (ASH) 2020 guidelines for sickle cell disease and the National Heart Lung and Blood Institute (NHLBI), 2014 clinical practice guideline.



**Joint Commission Certification for SCD Centers of Excellence:** The Joint Commission’s accreditation and certification programs are recognized and leveraged by many states in their quality oversight activities. The designation of center for excellence awarded by Joint Commission enterprise for stroke care, perinatal care, and cardiac care can reduce unwanted variations in care and improve patient experience and manage costs.<sup>26</sup> Similar certification can be developed for SCD care to help align the application of clinical guidelines and best practices.


## Support Evidence Generation for SCD

Developing interventions to improve care and outcomes for individuals with SCD requires supporting evidence. There are opportunities to collect data to better understand patients’ experiences in and out of the clinical setting. This type of data can support the development of new delivery models, payment arrangements, and coverage determinations for novel therapies amongst other opportunities.

**Development of a patient-powered data hub to collect data on patients’ care experiences and outcomes:** Patient registries are an organized system that use observational study methods to collect clinical or non-clinical data to evaluate

specific outcomes by a disease or condition in order to improve health outcomes and the satisfaction of patients and providers with medical care.<sup>27</sup> In 2018, the Sickle Cell Disease Association of America (SCDAA) launched the first patient-driven registry for SCD called “Get Connected” and ASH also launched a data hub in 2020 for submission of data for patients with coronavirus disease 2019 (COVID-19) and hematological conditions.<sup>28,29</sup> Such data hubs provide platforms for patients to store and privately share their information, including getting access clinical trials information. There are opportunities to develop patient-driven data hubs that can collect unique patient information such as social needs impacting access to care, experiences at different points of care, and management of crises.

**Promote Community-Based Participatory Research (CBPR):** CBPR entails collaboration between researchers and community members, which may include a needs assessment, planning, research intervention design, implementation, evaluation, and dissemination of community-level interventions. An example is the National Institute on Minority Health Disparities (NIMHD)’s CBPR program where community members and researchers are exploring projects addressing cancer, diabetes, heart disease and HIV/AIDS.<sup>30</sup> SCD will benefit from the CBPR model by enabling researchers to connect better with the SCD community, especially Black and Brown communities who are most affected. It also provides an avenue to bridge the trust gap with the minority community and involve them in every step of the research.

 <b>Evidence Generation</b>	
Development of a patient-powered data hub to collect data on patients’ care experiences and outcomes	Community Based Participatory Research to identify specific needs of patient community and collaborate to identify and implement solutions
Standardization of data elements and development of schema to determine methods of data collection and standardized data sources	Conducting studies and pilots to better understand and improve patients’ experiences and health outcomes inside and outside clinical settings

**Standardization of clinical data elements:** Multi-stakeholder consensus on the standardization of clinical data elements and development of schema to determine methods of data collection and standardized data sources is needed. This will provide an efficient process for future data collection and analyses for outcome research. Additionally, there are opportunities to develop new data elements that capture the breadth of complications that SCD patients experience in and out of clinical settings.

**Conducting outcome-based studies and pilots:** Outcomes-based studies would improve provider and payers’ understanding of SCD care and improve patients’ experiences and health outcomes inside and outside clinical settings. Examples of such studies include:


- Evaluating the near- and long-term impact of COVID-19 on SCD patients
- Evaluating impact of optimal discharge planning on 30-day readmission
- Impact of SCD therapies on SCD-associated complications and the impact of SCD therapies on ED utilization
- Role of telehealth in medication adherence and reduction of ED visits

## Advance Health Policy and Advocacy

Policy development or modification requires collaborative advocacy efforts among various stakeholders to ensure issues and gaps in SCD care are at the forefront of the national discourse. Outlined below are some policy issues and recommended advocacy efforts that could be implemented to address the identified SCD-related problem.

**Improved reimbursement for providers delivering services for SCD patients:** Sickle cell disease care is complex and expensive due to the associated complications. Providers often face reduced reimbursements for treating and managing SCD patients. There are opportunities for payers to improve reimbursement rates and reward providers for the care they provide. These new arrangements can be designed under a value-based arrangement.

**Advocacy for Medicaid Expansion:** Majority of SCD care is covered by Medicaid, but there are existing gaps in SCD coverage for patients not covered by Medicaid like high deductibles which causes selective use of services.<sup>31,15</sup> Efforts should be made by CBOs and patient advocacy groups to identify advocates within the states that have not expanded and explore opportunities for regional or partial Medicaid expansion to ensure coverage of SCD patients in the underserved population.



Health Policy & Advocacy	
Improved State level policy for formulary determination	Advocacy for expanded coverage for telemedicine to increase access to specialists in healthcare deserts
Improved reimbursement for providers delivering services for SCD patients	Evaluation of Medicaid coverage expansion and its impact on access to care and newer treatments
Risk adjustment for SCD care in Managed care contracts	Adjustment of the readmissions reductions programs to accommodate SCD care
Establish a SCD congressional caucus to ensure adequate government attention on SCD	Adjustment of opioid prescription rules and restrictions that prevent SCD patients from accessing pain medications

**Advocacy for expanded coverage for telehealth:** Due to the COVID-19 pandemic, CMS has expanded telehealth coverage to cover office visits, hospital and other visits provided via telehealth across the country including patients' places of residence for the period of the pandemic.<sup>32</sup> An expansion of telehealth for SCD care coordination beyond the pandemic period ensures adequate access specialists for SCD patients especially in remote areas.

**Improved state-level policy for formulary determination:** State-level policy for formulary determination plays a vital role in SCD care since Medicaid provides coverage for majority of SCD patients. The establishment of an evidence-based single formulary determination process for state programs will help ensure that Medicaid managed care providers cover therapies that offer best value for their members.

**Adjustment of the readmissions reductions programs to accommodate SCD care:** SCD is associated with an increased rate of inpatient admission and higher likelihood of readmission. An inclusion of SCD as a disease condition in the Hospital Readmission Reduction Program by CMS creates an extra incentive for hospitals to develop comprehensive discharge protocols and manage care coordination for SCD patients without the pressure of being financially penalized.<sup>33</sup>

**Risk adjustment for SCD care in managed care contracts:** Due to the complex nature of SCD care and the associated risk in managing SCD patients, managed care organizations are faced with the uphill task of ensuring access to proper care, managing care coordination, and mitigating risk of member readmission following an inpatient admission. State Medicaid programs need to factor these challenges and provide risk adjustment in managed care contracts to ensure SCD members get optimal care.

**Continued Advocacy for the SCD congressional caucus:** Congressional Caucuses are pivotal for ensuring that their priorities receive legislative and financial support.<sup>34</sup> Given the high costs associated with managing and treating SCD, a formal SCD-specific Caucus can be formed to create legislature that ensures adequate funding and support for advancing SCD care in the US. The formation of such a Caucus would ensure support for SCD research funding through federal agencies, collaboration between public and private organizations, and advancement in public policies to address access to care.

**Adjustment of opioid prescription rules and restrictions that prevent SCD patients from accessing pain medications:** In April 2019, the CDC issued a clarification to its 2016 guidelines following concerted efforts by ASH, American College of Emergency Physicians, and SCDA, stating that recommendations were not intended to deny opioid to patients with cancer or SCD related pain.<sup>35</sup> Continued advocacy is needed by these organizations to ensure hospitals modify their policies or protocols to avoid undertreatment of SCD related pain.

## Key Recommendations for Stakeholders

Sickle cell disease care requires a multi-stakeholder approach. In order to ensure optimal care and improved outcomes for patient with SCD, each stakeholder type will need to embrace a unique set of roles and responsibilities. While various recommendations have been outlined in previous sections. Table 2 presents key opportunities for stakeholders to pursue.

**Table 2: Recommendations for Various Stakeholders to Improve Quality of SCD Care**

Stakeholder	Recommendations
<b>Health Systems and Providers</b>	<ul style="list-style-type: none"> <li>• Incorporate trainings on implicit bias and structural competency in training protocols for clinical staff.</li> <li>• Work with other SCD centers in the region to set up SCD learning collaboratives for shared learning and adoption of best practices.</li> <li>• Develop and provide educational resources for ED providers on managing SCD patients when they present to ED.</li> <li>• Lead the development of care pathway development and facilitate prospective studies to validate developed care pathway.</li> <li>• Participate in quality improvement initiatives that involve the development of patient self-management resources.</li> </ul>
<b>Community-Based Organizations and Patient Advocacy Organizations</b>	<ul style="list-style-type: none"> <li>• Advocate for better incorporation of SCD training, bias training, and structural competency into medical school curriculum and continuous medical training modules.</li> <li>• Drive the development of patient self-management programs, collaborating with providers and professional societies.</li> <li>• Collaborate with researchers and local community members and engage in community-based participatory research.</li> <li>• Lead the development of patient powered data hubs to collect clinical and non-clinical data, track health outcomes, and translate that information into actional strategies.</li> <li>• Lead advocacy efforts for expansion of Medicaid coverage, increased coverage for telemedicine, and improved state level policy for formulary determination.</li> <li>• Support the formation of a bipartisan SCD Congressional Caucus to maintain SCD in the national discourse and ensure support for SCD research funding.</li> </ul>
<b>Public and Private Payers</b>	<ul style="list-style-type: none"> <li>• Collaborate with health systems to set up SCD Virtual Health Networks which ensures access to specialists and increased care coordination for their members with SCD.</li> <li>• Develop, test, and implement a SCD medical home model to facilitate better coordination of SCD care coordination.</li> <li>• State Medicaid programs can develop risk adjustment models that factor in the complexity of SCD care for managed care contracts.</li> </ul>

Stakeholder	Recommendations
	<ul style="list-style-type: none"> <li>Implement pilot programs to identify and test interventions (e.g., SCD referral pathways) that improve care delivery, patient engagement, and health outcomes.</li> </ul>
<b>Federal/state Government Agencies</b>	<ul style="list-style-type: none"> <li>Government agencies the U.S. Department of Health and Human Services Office of Minority Health can help provide funding and coordinate the setting up of regional virtual health networks.</li> <li>Given that Medicaid is the primary payer for individuals with SCD, states can implement a SCD patient-centered medical home demonstration for hospitals to help manage the high level of readmissions.</li> <li>The National Institute on Minority Health Disparities (NIMHD) can expand its existing CBPR program to cover SCD research.</li> </ul>
<b>Research Organizations</b>	<ul style="list-style-type: none"> <li>Collaborate with patient advocacy organizations to develop patient-powered data hubs and design research agendas focused on interpreting the data and designing interventions.</li> <li>Conduct research focused on non-clinical outcomes in collaboration with community members under community-based participatory research. Research might include studies and pilots focused on understanding and improving patients' experiences and health outcomes inside and outside clinical settings.</li> </ul>
<b>Professional Societies</b>	<ul style="list-style-type: none"> <li>Lead the development of a multi-stakeholder care pathway for SCD in alignment with updated clinical guidelines.</li> <li>Organizations such as the American College of Physicians (ACP), the American Academy of Family Physicians (AAFP), and the American Academy of Emergency Medicine (AAEM) might consider the weight of CME credits assigned to ongoing SCD education and training.</li> <li>Societies that develop pain management guidelines have the opportunity to create specific recommendations for SCD management given the frequent occurrence of pain as a complication.</li> <li>ACP and AAFP can increase SCD educational programming in their annual meetings to highlight the level of importance SCD should take.</li> <li>Organizations such as ASH can collaborate with patient advocacy groups to develop patient self-management programs and resources.</li> <li>Professional societies like ASH and AAEM can lead the way in developing and testing performance measures.</li> <li>Organizations like ASH can work with the Joint Commission to work on SCD Certification to establish centers of excellence in this space.</li> </ul>
<b>Manufacturers</b>	<ul style="list-style-type: none"> <li>To support clinical trial results, engage in CBPR to understand impact of therapies on patients' outcomes and communities' barriers to accessing therapies.</li> </ul>

Stakeholder	Recommendations
	<ul style="list-style-type: none"> <li>• Support evidence generation for novel innovative therapies. Data generated can be leveraged for SCD care pathway development and the update of SCD clinical guidelines.</li> <li>• Consider the inclusion of outcomes such as the impact of therapies on readmissions in SCD patients and comorbidities associated with SCD in clinical trials.</li> <li>• Develop SCD-focused comprehensive patient support services to mitigate access and affordability barriers to treatment.</li> </ul>

## Conclusion

While the challenge to advance care for patients with SCD seems daunting, it is indeed achievable, especially with engaged active partners leading the way. Poor provider knowledge about SCD, poor transition between pediatric to adult care, inadequate pain management, systemic racism, and poor care coordination are some of the main barriers affecting the quality of care for patients with SCD that can be overcome. A multi-stakeholder approach is needed to mitigate these barriers and ensure improvement in the quality of care for these individuals. This Roadmap provides a blueprint for action by highlighting 4 key domains and strategic recommendations to improve SCD care and where each stakeholder can identify and implement specific strategic recommendations. The goal of this Roadmap is to provide a patient-centric starting point, but success in improving the quality of care for patients with SCD care requires contribution from the entire healthcare, medical, and patient community and consistent advocacy efforts to maintain the issue in national consciousness and realize progress along the way.



## Appendix: Dialogue Attendees

- **Ahmar Zaidi, MD**, Children's Hospital of Michigan
- **Beverley Francis-Gibson**, Sickle Cell Disease Association of America
- **Bryan Loy, MD**, Humana
- **Caroline Freiermuth, MD**, American College of Emergency Physicians
- **Chris Traylor**, Former the Acting Deputy Administrator and Director, CMS & CHIP
- **Cory Lewis**, Patient Advocacy
- **Deneen Vojta, MD**, United HealthGroup
- **Elizabeth S. Klings, MD**, Boston University Center of Excellence in Sickle Cell Disease
- **Matt Powers**, Former administrator of the Illinois Medicaid program
- **Francesca Valentine, MSN, BSN**, Patient Advocacy
- **Julie Panepinto, MD**, Medical College of Wisconsin in Milwaukee
- **Lauren Neves**, PhRMA
- **Loren Rives**, American College of Emergency Physicians
- **Maia Laing**, Department of Health and Human Services
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- **Sara Davis**, CRISPR Therapeutics
- **Scott McGoohan**, Vertex Pharmaceuticals
- **Terrance Hill**, Patient Advocacy
- **Vikki Walton**, Novartis

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