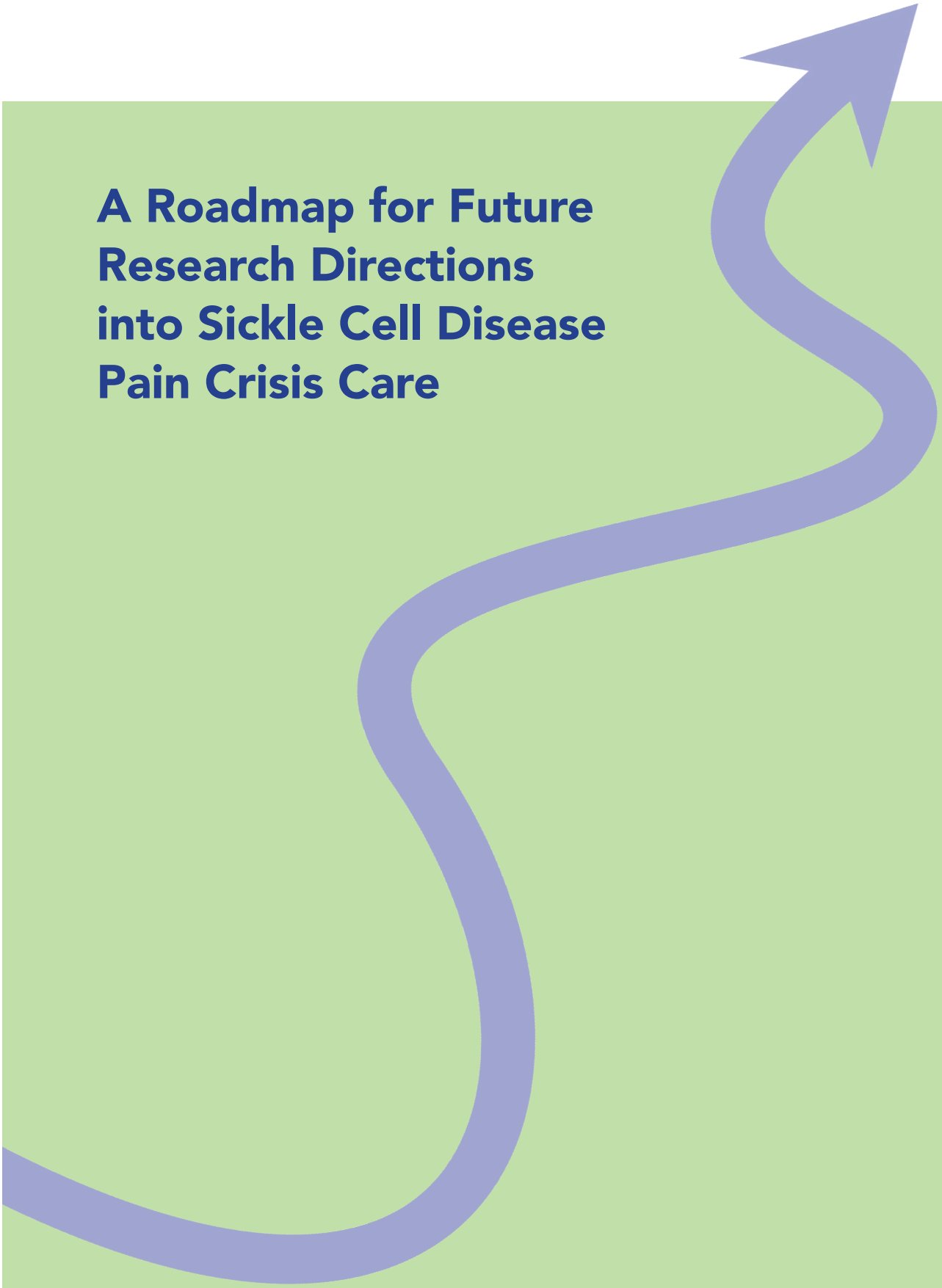
A Roadmap for Future Research Directions into Sickle Cell Disease Pain Crisis Care



mhqp
Massachusetts Health Quality Partners

MASSACHUSETTS SICKLE CELL ASSOCIATION

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EXECUTIVE SUMMARY

Massachusetts Health Quality Partners (MHQP) and the Massachusetts Sickle Cell Association (MSCA) collaborated to develop a Roadmap for research aimed at improving sickle cell disease (SCD) pain crisis care. The collaboration identified a critical need for structural changes in healthcare to improve SCD pain crisis care and its outcomes. To support the potential for such changes, the Roadmap presents challenges spanning various levels—from providers, departments, and medical centers to health systems and insurers—and offers research directions aimed at creating lasting improvements in SCD pain crises care.

Participants, including individuals with SCD, caregivers, providers, researchers, payor representatives, and administrators, attended two convenings to shape the development of the Roadmap. Discussions during the two multi-stakeholder convenings highlighted key research themes, including the need to increase provider and frontline staff knowledge about SCD, address biases, improve provider adherence to emergency department triage guidelines and individuals' care plans, improve access to providers who have specialized training related to SCD care, infuse greater empathy into patient experiences, allocate resources effectively, and ensure organizational accountability. Participants prioritized research themes focusing on enhancing provider training for SCD care and on improving patient experiences, and they discussed opportunities for organizational interventions to address these themes.

Five categories of interventions were proposed by the group:

1) Implementing disease-specific education, training, and certification programs for providers and frontline staff
2) Increasing access to providers in emergency department settings who have specialized training related to SCD
3) Fostering community engagement to increase provider empathy and support for individuals with SCD who are seeking care
4) Elevating patient voices
5) Improving data, transparency, measurement, and accountability

Researchers are urged to collaborate with the SCD community to develop and test PCOR/CER questions that align with stakeholder priorities. Acknowledging the persistent challenges and deeply entrenched inequities in SCD care, the Roadmap provides a foundation for future research and collaboration. The MHQP and MSCA teams are hopeful that this work will drive meaningful improvements in SCD pain crisis care.

ABOUT THIS ROADMAP

Massachusetts Health Quality Partners (MHQP) and the Massachusetts Sickle Cell Association (MSCA) collaborated to develop this Roadmap, which offers stakeholder-identified insights to guide research into improving sickle cell disease (SCD) pain crisis care. This document specifically highlights future directions for patient-centered outcomes and comparative effective research (PCOR/CER). Figure 1 below displays a summary of the process used to create this roadmap.

Figure 1: Creating the Roadmap for Future Research Directions into Sickle Cell Disease Pain Crisis Care

ACKNOWLEDGEMENTS

We extend our sincere gratitude to the MHQP team, including Autumn Bailey, Natalya Martins, and Karina Santamaria, and the MSCA team, led by Jacqueline Haley, Rajan Sonik, Philippa Sprinz, and Maureen Okam Achebe, for their invaluable collaboration on this project. Without their expertise and dedication, the development of the Roadmap for future directions into sickle cell disease pain crisis care would not have been possible.

Furthermore, we would like to express our deepest appreciation to all the participants who contributed to this project. Your insights, feedback, and commitment have been instrumental in shaping the direction of our work. In particular, we are grateful to the sickle cell warriors who courageously shared their personal experiences and perspectives, providing invaluable guidance throughout the Roadmap development process.

This project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASCS #30430).

Thank you to everyone involved for your unwavering support and dedication to improving sickle cell disease care.

> **"I've been kind of quiet in my living with sickle cell for my 30 years on earth so I want to be more intentional about sharing my story and add value in this space where so many people are working to inform others about this disease and get some wins."**
>
> **INDIVIDUAL WITH SICKLE CELL DISEASE**

1 IDENTIFIED A RESEARCH GAP

In 2022, Massachusetts Health Quality Partners (MHQP) and the Massachusetts Sickle Cell Association (MSCA) collaborated to set research directions on the topic of SCD pain self-management. Through this collaboration, discussions with stakeholders in the SCD community revealed that self-care tools serve as pivotal pain management strategies for individuals with SCD. However, it became evident that these strategies were often resorted to as a response to consistent experiences of discrimination and traumatizing, low quality care in emergency department settings. This work highlighted the need to research structural changes in healthcare, which target the underlying institutional factors that contribute to health disparities. By exploring these structural approaches, we can effectively identify the best ways to improve outcomes and promote equity in SCD pain crisis care.

The quotes below are from the project focused on SCD pain self-management research:

"I saw it with my child. Why do [patients] engage in self-management?... [Because the experience is] I'm just going to go to my ER or I'm going to go to my day hospital because I know I can get something, and I'll be home in a couple of hours. But that's not the case. It's if I go, it's going to be a nightmare. So let me try the Motrin, let me try the Tylenol, let me try the heating pad. None of it works. And you end up where you end up six hours into the pain crisis and it just is worse. [We need to look] at the question of why are we doing this self-management [in the first place]."

CAREGIVER

"If someone's frequently in the emergency department, they're like, oh, why are you always here, they must not be in pain they're drug seeking... And then also from a patient perspective, going to a place where you can normally get care, because if they see that you're like, oh, always going to [one hospital], but now you're going to another hospital, people are going to start saying like, oh, maybe... they are trying to work the system, get more pain meds... And then also emergency physicians as much as they're trying to work on it... they're not as diverse as our patient population... because of that, you also have issues with cultural competency... Labeling people before you even see them as a drug-seeker [further] delays their care."

PROVIDER

2 CONVENED STAKEHOLDERS

To address the lack of research into strategies to help providers and organizations improve SCD pain crisis care, MHQP and the MSCA held convenings in October and December of 2023 focused on setting future research directions on this topic. The effort was funded through the Patient-Centered Outcomes Research Institute's (PCORI) Engagement Awards program, a program that aims to bring more patients, caregivers, clinicians, and other healthcare stakeholders into the research process.

The meetings were facilitated by Dr. Lydia Pecker, Assistant Professor of Medicine and Director Young Adult Clinic, Sickle Cell Center for Adults at Johns Hopkins. Dr. Arvin Garg, Professor of Pediatrics, Vice Chair for Health Equity, and Founding Director of the Child Health Equity Center presented during the first meeting on the topic of healthcare system change through an equity lens. They were joined by 22 participants – individuals with sickle cell disease (SCD), caregivers, providers, researchers, payor representatives, and healthcare administrators.

Participants shared various motivations for participating in this project, including advocacy, their professional roles, and research interests, but they all shared a common commitment to improving how the healthcare system delivers SCD care.

"I wanted to join [the project] because… even though I've watched [sickle cell disease research] progress throughout the years, [it's] still at some sort of stalemate so, I've dedicated the time and experience and expertise I've had throughout the years to be able to advocate for others as well as myself."

INDIVIDUAL WITH SICKLE CELL DISEASE

"For years [I've] been so frustrated seeing the quality gap that relates to sickle cell care in terms of the care that's being received and the opportunities for improvement."

PAYOR REPRESENTATIVE

"[Part of my job is] understanding various ways in which our healthcare system and other systems in our society can be improved through the lens of various system failures… [I want to] be a part of conversations where we can be trying to make improvements."

RESEARCHER

DISCUSSED RESEARCH THEMES

During the first convening, Dr. Pecker engaged the group in a multi-stakeholder discussion to hear about SCD pain crisis care perspectives and priorities. Specifically, individuals with SCD and caregivers were asked to reflect on negative and positive experiences with SCD pain crisis care and what differentiated these experiences. Participants discussed various research themes aimed at improving SCD pain crisis care. They stressed the vital importance of amplifying the voices of individuals living with SCD and drew attention to the widespread lack of awareness and patient-centeredness in the context of SCD. They also illuminated the context of systemic injustices and structural shortcomings within healthcare that result in unequal access to quality care and the perpetuation of disparities in SCD pain management. Table 1 below shows descriptions of the research themes generated during the first convening, alongside quotes from the discussion.

Table 1: Research Themes Identified in Convening #1

RESEARCH THEME	DESCRIPTION	QUOTES
Increasing Provider and Frontline Staff Knowledge, Skills, and Confidence for SCD Care and Pain Management	The participants shed light on the lack of awareness and understanding of SCD among emergency department staff, who are often generalists. This includes limited understanding of the required pain medication doses and the urgency in administering them. They also emphasized that addressing these deficiencies goes beyond understanding the medical aspects of SCD; it's also about fostering empathy and ensuring equitable care delivery. This lack of awareness, deemed life-threatening, underscores the critical need to raise awareness about SCD among medical staff.	"You feel like doctors don't know anything about sickle cell and you know your life is in jeopardy." **INDIVIDUAL WITH SCD** "They're saying that this is not what we are taught in medical school but… there's the practical part but there's also the theoretical part of it and now we're in a setting where you're dealing with patients and individuals living with this disease and we're going through so much pain already." **INDIVIDUAL WITH SCD**

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Table 1: Research Themes Identified in Convening #1 *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
Provider and Support Staff Implicit/Explicit Bias Training	The discussion underscored the pervasive nature of health inequities. Individuals with SCD shared their experiences of racism and discrimination in the clinical setting where many clinicians' judgments are based on stereotypes, including preconceptions about race, socio-economic status, and pain care. These biases, both implicit and explicit, often result in delayed, subpar, or a complete lack of essential care. Participants felt that protocols that aim to address the effects of provider and staff bias in healthcare settings are needed.	"And to reverse [structural racism], that would require a provider stigmatization bias treatment protocol and those who are most impacted should be collaborating on how that protocol could or should be developed." **HEALTHCARE ADMINISTRATOR** "It's an educational aspect… breaking down those biases that we might acquire through training or throughout life but not only educating our practitioners and reviewing their processes in treating sickle cell patients but also ER and support staff and kind of educating them… not kind of looping us into a box or creating biases." **INDIVIDUAL WITH SCD**
Providers Accepting and Adhering to Patients' Individualized Care Plans	Participants stressed the significance of individualized care plans in SCD management, with specific reference to medications and pain crisis response. However, even when individuals with SCD create care plans with their hematolo-gists, there are instances when emergency department providers fail to accept and adhere to these essential care guidelines. In addition, challenges arise when care plans do not align across different healthcare facilities.	"When I was transitioning from pediatric to the adult care there was an instance where I had to crawl through the emergency room ...The doctor didn't want to look at my care plan… I had mentioned fentanyl nose spray and as soon as I said that, they looked at me as a drug seeker and the doctor told me that even if my labs came back and it showed that I was having a crisis that he didn't even feel comfortable giving me my regular pain meds." **INDIVIDUAL WITH SCD**
Lack of Adoption and Adherence to Established Pain Triage Guidelines	Individuals with SCD often present to the emergency department in severe pain, necessitating immediate and prioritized medical care. However, there is a lack of adoption and adherence to established pain triage guidelines in the management of SCD pain.	"When you know that you're triaging different patients as far as who is more acute or not and I think [the] whole psychology of triaging what is a more acute versus not meaning if a person has to say I have chest pain in order to get care and to be seen sooner versus I am having excruciating pain here, which may not be my chest but is just as valid. So, I think it's a matter of how we train ourselves as providers as far the significance of pain and the type of pain." **PROVIDER**

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Table 1: Research Themes Identified in Convening #1 *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
Lack of Emergency Department Providers Who Have Specialized Training Related to SCD Care	Participants discussed the need for emergency department providers who have specialized training related to SCD care, highlighted differences in access to high quality SCD care based on location, and identified access to adult care providers as a specific issue.	"The wait time is very difficult. One year I was experiencing a pain crisis – I've gone to two hospitals in the Boston area: one that's closer to me and another one that has a sickle cell center but even if I go to that hospital [with the sickle cell center], the wait time is still long. But if I go to the hospital close to me, the wait time is quick, but they don't know anything about sickle cell." **INDIVIDUAL WITH SCD** "Not every hospital has the good fortune of having a pain specialist on board." **PROVIDER**
Enhancing Patient Experience and Emotional Support in the Emergency Department	Participants underscored the need for more compassionate care during SCD pain crises. Individuals with SCD spoke about the dehumanizing aspects of treatment in the emergency department, emphasizing prolonged wait times and a lack of attention, empathy, and respect from staff.	"I have a port and so, often times, in those really, really bad experiences they'll take me into a room to access the port then put me back into the hallway and that's really demoralizing. And then sort of being forgotten about, when you're in a hallway you usually don't have a call bell and so you have to yell and so it feels very just sort of saddening and dehumanizing to have to scream for someone like 'help' or 'excuse me,' especially when you know your pain is getting really high and your window for your pain medication has passed." **INDIVIDUAL WITH SCD**
Allocation of Resources to Improve SCD Care	The allocation of resources in healthcare and the impact of Medicaid on access to innovative care was discussed. Participants recognized the resource constraints and time limitations that exist within healthcare settings and advocated for financial support to encourage necessary innovations in SCD care.	"You look at other disease models even beyond cystic fibrosis where innovation in clinical care lands in places where… it follows the money so to speak and it's an area where there's a tremendous potential and need for clinical innovation but we're not seeing it as much as we should. I think that combined with kind of the how you have resource investments to build up structural capabilities in health systems resonates with me." **PAYOR REPRESENTATIVE**

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Table 1: Research Themes Identified in Convening #1 *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
Organizational Accountability	Stories of inhumane treatment shed light on the lack of mechanisms for holding healthcare institutions accountable (e.g., methods to measure care quality). The lack of data on SCD care outcomes was also raised as a significant issue.	"There isn't really a mechanism [in place] for getting these stories that occur when people have been dehumanized in healthcare settings into [the hands of] those who have structural authority or power over situations. It is so hard to hear these stories, but we're weathered and not surprised to hear them happen… [There needs to be] a mechanism for getting that accountability." **PAYOR REPRESENTATIVE**

Following the first convening, the project team sent out a prioritization survey that asked participants to rate the research themes. The two highest rated research themes conducive to PCOR/CER were:

1. Increasing Provider and Frontline Staff Knowledge, Skills, and Confidence for SCD Care and Pain Management

2. Enhancing Patient Experience and Emotional Support in the ER

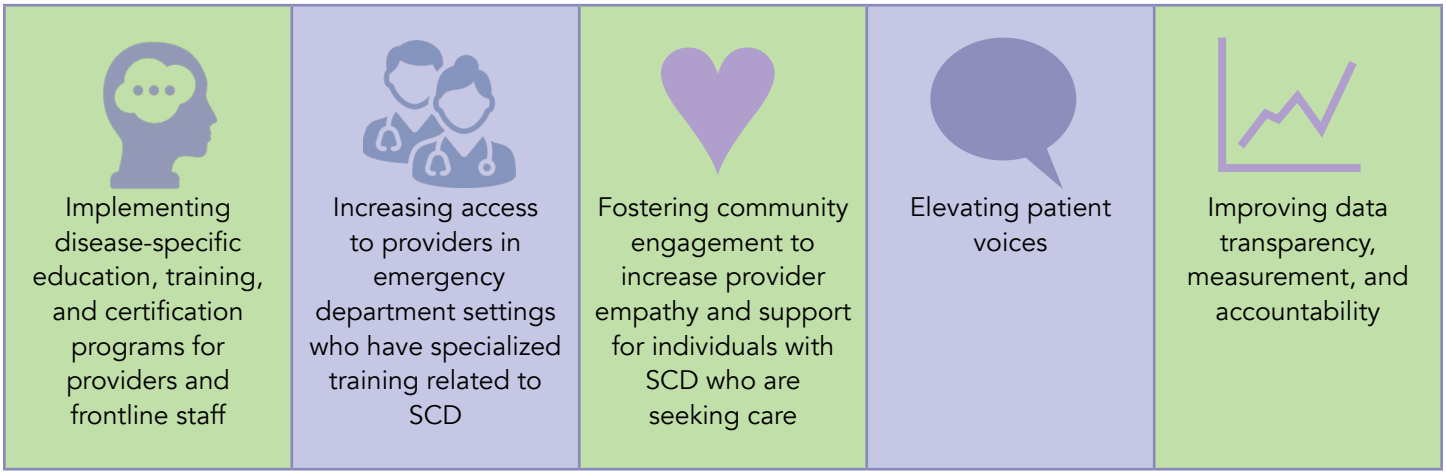
IDENTIFIED OPPORTUNITIES FOR INTERVENTION

During the second convening, Dr. Pecker led the group in a discussion to identify opportunities for interventions that address the research themes prioritized by participants. Specifically, participants were asked to generate ideas for potential structural interventions needed to address challenges that individuals with SCD face in the ER. See Table 2 below for more details on specific brainstorming topics and questions.

Table 2: Group Discussion Questions to Identify Opportunities for Structural Interventions Based on Prioritized Research Themes

RESEARCH THEME	ER CHALLENGE	GROUP DISCUSSION QUESTIONS
Increasing Provider and Frontline Staff Knowledge, Skills, and Confidence for SCD Care and Pain Management	Providers and frontline staff need targeted knowledge, skills, and confidence to effectively care for individuals with SCD.	• What aspects of provider and frontline staff medical school curriculum and educational programs should be addressed? • How might we require ongoing SCD provider and frontline staff training? • How might we implement educational programs to improve pain crisis care? • What other trainings/educational programs might support this? (e.g., implicit bias training, cultural humility training?)
Enhancing Patient Experience and Emotional Support in the Emergency Department	In the emergency department, patient experiences are low-quality, due in part to a lack of emotional support.	• What interventions should be put in place for providers to improve SCD pain crisis care experiences? • What can administrators, health plans, and organizations implement to help providers improve the experiences of individuals with SCD in the emergency department? (e.g., social support, organizational accountability, patient advocates/volunteers?)

Figure 2: Categories of Potential Interventions to Improve Sickle Cell Disease Pain Crisis Care Discussed by the Group



Implementing Disease-Specific Education, Training, and Certification Programs for Providers and Frontline Staff: Several participants emphasized the importance of education and trainings, calling for a broader understanding of SCD starting in and extending beyond medical school. SCD-specific education and ongoing trainings for providers and frontline staff could bridge gaps in clinical knowledge of SCD, while concurrently cultivating empathy and humanity in healthcare interactions. These interventions should encompass not only medical aspects but also include components related to social factors and the unlearning of harmful stereotypes and biases. The discussion involved exploring ways to implement such programs and making them mandatory for those working in the emergency department and other relevant areas.

> **"In order to keep your certification, you have to do certain things to keep yourself updated… to me [it] would be good for people because it wouldn't be like I've taken the training so that's the check off. No, you have to continually update yourself as to what's current in sickle cell treatment."**
>
> PROVIDER

> **"But I would suggest… that it would start with anyone working in the ER area be required to have a minimal educational training related to sickle cell and actually become certified. And that's not hard to do."**
>
> PROVIDER

> **"Emergency physicians need to be updated on the stigmatization of sickle cell disease, so they could prevent biases when they're treating patients."**
>
> INDIVIDUAL WITH SICKLE CELL DISEASE

> **"I think one piece of education that was lacking in my education that feels like it's lacking in a lot of other providers that I work with, with various other diseases, is the understanding of pain itself and this biopsychosocial contributors to pain."**
>
> RESEARCHER

Increasing Access to Providers in Emergency Department Settings Who Have Specialized Training Related to Sickle Cell Disease: Several participants voiced the need to create strategies to improve access to providers in emergency department settings who have specialized training related to SCD. Additionally, the group underscored the critical priority of promoting diversity in the workforce.

> **"There are other ERs that you go to that are more knowledgeable about sickle cell or they have a hematologist department that they can consult with, and they will charge you for that consultation to get the information."**
>
> INDIVIDUAL WITH SICKLE CELL DISEASE

> **"This would only work in an academic center or a bigger hospital, but as soon as they arrive there, you should call their hematologist, see what they recommend and then kind of go with their care plan."**
>
> PROVIDER

> **"If you're not having providers who actually look like the populations that they're serving, there is going to continue to be those biases."**
>
> PROVIDER

> **"[In the ideal situation,] if there was something that cannot be handled in the infusion center then you go to the emergency room. So, the infusion center will be the first stop not the emergency room. And probably that will take away some of the apprehension of us going to emergency room because we know we have an infusion center that we can go to."**
>
> INDIVIDUAL WITH SICKLE CELL DISEASE

Participants emphasized the significance of SCD-specific education and access to trained providers in emergency departments. However, they noted that despite knowledge in SCD care, a lack of empathy among healthcare providers can result in negative patient experiences. The quote on the next page shows that the reverse also holds true.

> **I had to go to the ER…**
> **The nurse came [and] my husband told him that I was in a sickle cell crisis. He said, 'I have no idea about sickle cell but I realize pain is pain,' so right then and there he connected. He understood that I was in pain even though he didn't understand sickle cell. The emotional connection in the ER [is] truly important because as soon as I heard that I relaxed because I knew he was going to deal with me in a particular way.**
>
> INDIVIDUAL WITH SICKLE CELL DISEASE

Fostering Community Engagement to Increase Provider Empathy and Support for Individuals with SCD Who Are Seeking Care: Participants identified several community engagement and support activities that could be implemented to improve SCD care. The purpose of many of these potential interventions is to enhance empathy, communication, and understanding between healthcare providers and patients during pain crises.

> **I think having community days where we bring patients from all of these different disease groups [together] with their providers and have sort of community building and community bonding time so that they understand what the people are like [and] separate [us] from our conditions. If they're able to see who the people are, then I think that will even inform our care better because then, they'll have a greater understanding of the person behind the disease.**
>
> INDIVIDUAL WITH SICKLE CELL DISEASE

> **It's about having physicians and support staff… try and create those spaces where they can hear from patients [and] families [so they] can understand and try to build connections, community, and empathy.**
>
> HEALTHCARE ADMINISTRATOR

> **Sickle cell is such a subjective experience… [Providers should] identify with their patients as humans and not just, you know, drug seekers or people trying to take advantage of them. I have seen doctors pull up their phone and Google things while I'm seeing them. And so even if they don't have the most robust knowledge, I think if they have a better view of their patients in those situations where even if they only see one sickle cell patient a year, they're more inclined to go and brush up on that knowledge rather than just make assumptions and unilateral decisions for that patient.**
>
> INDIVIDUAL WITH SICKLE CELL DISEASE

Elevating Patient Voices: The voices of individuals with SCD should be elevated through both quantitative and qualitative research methodologies in healthcare settings, research institutions, policy-making bodies, and community forums. Incorporating patient viewpoints is vital for improving healthcare delivery, shaping research priorities, influencing policy decisions, and fostering a more inclusive and patient-centered approach across various contexts in the medical and social spheres. Individuals with SCD are experts in their condition, yet this knowledge is consistently not acknowledged or respected by healthcare providers, especially in the context of pain management.

> **[The] patient experience [has] to be of quality.**
>
> PROVIDER

> **I've gone to an ER before and the clinicians told me [they've] never treated anybody with sickle cell [and they] need to get help…there was empathy there so, because they were not trained, [it] didn't leave me with a negative experience, it left me with okay, they are open, and they are willing to learn.**
>
> INDIVIDUAL WITH SICKLE CELL DISEASE

> **I feel like doctors prefer more quantitative data with numbers, but what about qualitative data with descriptive factors of, how we feel and how we maneuver the health care system during treatment? Even just applying more patient narratives, storytelling aspects.**
>
> INDIVIDUAL WITH SICKLE CELL DISEASE

Improving Data Transparency, Measurement, and Accountability: While the implementation of interventions to improve education and training, emotional support, access, and the incorporation of patient feedback are essential, participants emphasized the significance of holding entities accountable for providing high-quality SCD care. Without accountability mechanisms in place (e.g., measuring patient wait time for pain medication, perceived discrimination, and adherence to patient care plans), these other strategies will fall short. In particular, they highlighted the vital role of institutional support and prioritization of SCD care at the leadership level. This includes gathering data to assess quality of care metrics, ensuring adherence to established standards (e.g., clinical practice guidelines and care plans), incentivizing mandatory and ongoing trainings/certifications, and fostering a culture of transparency and continuous improvement in care delivery. Participants also stressed the exploration of various levels of accountability, incorporating measurement mechanisms at the provider, hospital, and state regulatory levels. Standards need to be set at the state, insurance, and system levels.

The discussion delved into the complexities of measuring the quality of care for SCD. Specifically, it was noted that it is difficult to measure care quality among small populations, such as individuals with SCD, due to limited data for robust analyses and difficulty in establishing standardized metrics that adequately capture the diverse aspects of SCD care. Despite these hurdles, there are actions that should be taken internally to improve care quality and ensure organizations are meeting specific benchmarks, even when the data are not perfect. Participants emphasized the essential practice of publicly disseminating data to foster transparency and facilitate ongoing improvement initiatives.

> **People will get training, they'll sit through a training, but they don't necessarily make it a priority unless your leadership makes it a priority.**
> PAYOR REPRESENTATIVE

> **There are systems in place as far customer relations, patient relations, and you can escalate these concerns. But we have to kind of jump through hoops to get results and these are like hoops of fire and so you have to jump through these things and you have to have a lot of tenacity to actually get any results.**
> INDIVIDUAL WITH SICKLE CELL DISEASE

> **Without data and transparency, we lose the opportunity to have accountability.**
> PAYOR REPRESENTATIVE

> **When patients have feedback, it needs to be publicly disseminated, meaning in a way where others can understand the feedback that's happening so it's not just localized for that institution but actually is seen by external [people] almost like auditors in a way.**
> PAYOR REPRESENTATIVE

5 IDENTIFIED OUTCOMES AND INTERVENTIONS FOR PCOR/CER QUESTIONS

Based on the discussions held during the two multi-stakeholder convenings, the project team identified patient-centered outcomes, as well as potential interventions that could be tested for effects on the outcomes that matter most to the SCD community. The overarching aim of this project is for researchers to leverage the findings from this Roadmap to drive PCOR/CER, with the ultimate goal of identifying optimal strategies for enhancing SCD pain crisis care. This involves developing PCOR/CER questions, which compare patient-centered outcomes of two or more approaches to healthcare.

What are outcomes that matter most to individuals with SCD and other SCD community members?

Based on the challenges and opportunities described by participants, several measurable patient-centered outcomes of interest were derived from the conversation (see Table 3 below).

Table 3: Patient-Centered Outcomes

OUTCOME TYPE	OUTCOMES
Patient-reported	• Medication-specific: time to wait for pain medicine, how quickly do patients have their pain re-checked after receiving medicine • Time to initial treatment (length of time it takes for a patient to receive their first treatment or intervention upon arriving at the ER) • Time to follow-up treatment (e.g., days to follow-up care with hematologist or primary care provider) • Health and well-being outcomes post-hospitalization • Delays in seeking emergency department care (i.e., time between symptom onset and seeking care) • Patient experience: satisfaction, communication with provider, provider empathy, feelings of safety/support with care, trust in provider/healthcare system, perceived discrimination, attitudes towards care
Clinical	• Pain triage guidelines: adoption rates of guidelines, adherence rates to guidelines • Care plan: existence/access to care plan, adherence to care plan • Admissions: healthcare utilization (e.g., rates of hospital/ER admissions/readmissions), length of time to admission (time in ER)
Provider Training/Education	• Completion rates for cultural humility/implicit bias and SCD-specific trainings/modules, completion of SCD-specific certification programs
Data Transparency and Accountability	• Collection and analysis of patient-reported outcome measures • Collection and analysis of patient experience data • Collection and analysis of quality measures at the organizational level (e.g., transitional care measures) • Measures aimed at assessing the use of these data to hold individuals/systems accountable • System leader attitudes regarding awareness and knowledge of SCD care • System leader SCD prioritization (methods such as surveys, outcome tracking, and resource allocation assessments to evaluate system leader prioritization of SCD within organizations)

What interventions could be tested for effects on patient-centered outcomes?
Examples of potential interventions that could be tested for effects on one or more of the outcomes listed in Table 3 from the discussion are outlined in Table 4 below.

Table 4: Interventions

RESEARCH THEME	INTERVENTIONS
Implementing Education, Training, and Certification Programs	• Examine the impact of provider trainings o Implement cultural humility training for providers and frontline staff o Implement implicit biases trainings for providers and frontline staff o Implement pain education trainings, specifically programs that examine pain through a biopsychosocial perspective o Implement trainings for providers and frontline staff on the nature of SCD, its complications, and its management • Examine the role of learning sessions o Have an SCD "champion" (someone who is knowledgeable about and dedicated to advocating for SCD) who comes to weekly staff meetings o Hold "lunch and learn" sessions featuring guest speakers who have expertise in SCD o Show short films or sessions during which healthcare providers and patients discuss the emotional and social aspects of SCD care o Implement programs that would require staff to stay with a patient throughout their time in the emergency department to understand the impact of their role (i.e., shadowing a patient) o Have patient and provider panels present details about SCD and its management, as well as the importance of psychosocial, behavioral, and other non-medical aspects of the disease at medical schools o Share additional lectures on SCD (e.g., 5 Pearls on Sickle Cell) with interns and residents • Examine the role of SCD-specific certifications for healthcare professionals in the emergency department (e.g., SAPPORT program through Johns Hopkins, which offers certification for advanced practice providers in SCD care) • Explore the role of clinical practice guidelines for providers to help them manage SCD-specific support and care • Investigate the impact of provider utilization of other specific resources (e.g., fact sheets, pain management plans, treatment cards, standardized protocols) o There are several guidelines and resources currently available. It is imperative to create an inventory of these resources, evaluate their effectiveness, and disseminate them appropriately.
Increasing Access to Providers in Emergency Department Settings Who Have Specialized Training Related to Sickle Cell Disease	• Examine the benefits of involving a hematologist consultant as soon as the patient arrives to the ER • Explore the benefits and costs of alternative emergency care setting approaches o Explore the benefits and costs of expanding infusion center hours o Explore the benefits and costs of aligning SCD programs with infusion centers

Table 4: Interventions *continued*

RESEARCH THEME	INTERVENTIONS
Fostering Community Engagement to Enhance Empathy and Support for Individuals with SCD	• Explore programs that enhance emotional support and practical assistance o Examine the impact of mentorship programs for individuals transitioning from pediatric to adult care - Note that the abrupt transition from pediatric to adult care and the problems associated with transition were highlighted throughout the two convenings. o Examine the benefits and costs of involving a social worker/patient navigator as part of the care team, particularly when patients are transitioning from pediatric to adult care o Investigate the role of volunteers/support personnel • Explore interventions to enhance empathy, communication, and understanding between healthcare providers and patients during pain crises o Investigate the role of narrative medicine workshops in improving communication and understanding between providers and individuals with SCD o Explore the role of community-based organizations in providing in-service educational sessions in hospitals o Explore the benefits of organizing community days that bring together individuals with SCD and providers for community-building activities • Assess the effectiveness of restorative justice approaches in repairing relationships after negative care experiences
Elevating Patient Voices (in healthcare settings, research institutions, policy-making bodies, and community forums)	• Investigate the impact of mechanisms to share patient experiences of care (e.g., quantitative surveys via mail, email, or text message), including complaints, cases of perceived discrimination, and measurements of empathy o Many individuals emphasized the importance of empathy in SCD care. It would be valuable to explore ways to measure perceived empathy from the patient's perspective. This involves assessing whether patients feel they received empathetic care, where they felt heard and understood. • Explore a patient-led approach of gathering qualitative data (e.g., individuals with SCD leading focus groups), underscoring the impact of narratives and patient stories • Investigate the impact of involving individuals with SCD in committees (e.g., organizing a Patient Action Committee)
Improving Data Transparency and Accountability	• Examine the role of incorporating patient-reported outcome measures and patient experience data into value-based programs with incentive payments • Examine the role of mandating electronic training modules focusing on SCD and SCD care as part of yearly performance evaluations for physicians and other providers • Examine how measuring the existence, access, and adherence to care plans/guidelines impacts patient care and outcomes • Measure the effectiveness of pain crisis care plan utilization and adherence in emergency departments o Note that several participants emphasized the importance of providers having access to adhering with individualized care plans. • Examine the role of Joint Commission certification for SCD care in ERs, focusing on measurable indicators such as patient satisfaction and times to administer pain medications

How might researchers utilize these findings to develop PCOR/CER questions?
Researchers should collaborate with individuals with SCD and others in the SCD community to develop PCOR/CER questions based on the findings from this project. By involving those directly affected by SCD, including individuals with SCD, caregivers, advocacy groups, and healthcare professionals specializing in SCD care, researchers can ensure that the questions formulated are relevant, meaningful, and address the most pressing concerns and priorities within the SCD community. This collaborative approach enhances the relevance and applicability of the research, ultimately leading to more impactful and patient-centered outcomes.

Based on this work, some examples of PCOR/CER questions could be:

- What is the impact of implementing a mentorship program for individuals transitioning from pediatric to adult care compared to standard care on enhancing emotional support for individuals with SCD receiving treatment for pain crises?
- How does the adoption of pain crisis care plans (ensuring provider access and adherence to these plans) compared to standard care influence pain management outcomes for individuals with SCD receiving treatment for pain crises?

CLOSING REMARKS

Through the results of this project, the MHQP and MSCA teams recognize that significant efforts are still needed to make meaningful strides in improving SCD care. We are optimistic that this Roadmap will be utilized by researchers in the SCD space to begin to facilitate the identification and implementation of the best ways to improve SCD pain crisis care. We are also hopeful that this project will catalyze ongoing collaboration among convening participants and the MHQP and MSCA teams.

If you have any questions about the research Roadmap, please contact Natalya Martins at nmartins@mhqp.org or Jackie Haley at jacqueline.haley@gbscda.org.