



# CHERP Initiative Report



# Foreword

Welcome to the Recruitment Guide for the Community Health Equity Research and Promotion (CHERP) Initiative Report. This guide is a testament to the commitment and collaborative efforts of individuals dedicated to amplifying the voices of the sickle cell community. Link2Equity is honored to support Sick Cells navigate through the essential aspects of recruiting participants for the listening sessions that have shaped the CHERP Initiative Report.

At the heart of our mission for this project is the conviction that every voice within the sickle cell community deserves to be heard, understood, and acknowledged. We strive to ensure that the experiences, challenges, and triumphs of individuals living with sickle cell disease (SCD) are not only recognized but also become catalysts for positive change. This recruitment guide is a valuable tool that reflects our commitment to inclusivity, diversity, and equity in research.

The CHERP Initiative Report stems from the collaborative efforts of the Patient-Centered Outcomes Research Institute (PCORI)-funded Defining Value and Supporting Equity for SCD project. This initiative aims to transcend traditional research boundaries, encompassing the rich heterogeneity of lived experiences within the SCD population. Through a series of listening sessions, we explored critical themes such as lived experience, access to care, cultural barriers, patient-provider relationships, stigma, and mental health. Our journey involved engaging with diverse subpopulations within the sickle cell community, including the Aging, Hispanic/Latinx, Incarcerated/Formerly Incarcerated, and LGBTQIA+ communities. The insights shared by these individuals during the listening sessions were invaluable.

This guide provides a comprehensive overview of the strategies employed in outreach, emphasizing the importance of clear communication, establishing a single point of contact, and respecting the unique circumstances of potential participants. It delves into the significance of a large and representative sample size, addressing health literacy, and bridging the digital divide in the recruitment process.

Through this report, we invite you to explore the various dimensions of our recruitment approach and consider the unique challenges and opportunities presented by each subpopulation of the SCD Community interviewed. May this guide serve as a valuable resource for future research endeavors, promoting inclusivity, understanding, and positive change within the SCD Community.

Thank you for your dedication to advancing research, elevating voices, and fostering a future where every individual's experience with sickle cell disease is not only acknowledged but becomes a driving force for transformative action.

## **Ashley Valentine**

**Co-founder and President  
Sick Cells**

Sick Cells is a national sickle cell patient advocacy organization founded in 2017. Sick Cells' mission is to elevate the voice of the 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.

## **Deanna Darlington**

**Founder and President  
Link2Equity**

Link2Equity is a patient advocacy and health policy firm, founded with the power of unity as the driving force behind patient advocacy efforts. We employ innovative strategic methodologies that promote health equity and diversity among all groups and sectors within the healthcare ecosystem to build healthier communities.

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# Recruitment Guide

*Our mission is to elevate the voices of the sickle cell disease community and their stories of resilience-to ultimately influence decision-makers and propel positive change. Through this project, we hope to strengthen the diversity of patients participating in research and encompass the heterogeneity of lived experiences, goals, unmet needs, and priorities to inform future research efforts.*

*This body of work is a supplemental project from the PCORI-funded Defining Value and Supporting Equity for SCD. The aims of the CHERP project are to ensure research and advocacy produce strong and equitable results and drive policy solutions through listening sessions with key stakeholders. This effort will further advance the need for diverse participation in scientific studies to support equity and allow for findings to be applicable to the entire SCD population.*

*To accomplish this, we held a series of 4 listening sessions with subpopulations of the sickle cell disease community to discuss lived experiences, access to care, cultural barriers, patient-provider relationships, stigma, and mental health. Listening Sessions provide an opportunity to facilitate discussion among a group of individuals with the aim of gathering information about their experiences. We have developed this report to share guidance for the recruitment process.*

## METHODOLOGY

### Outreach Community Advisory Board

Sick Cells worked with a Community Advisory Board (CAB) member who served as a voice for the community and local study participants. CABs provide input into research and local study procedures and work to ensure that research strategies acknowledge and respect the values and cultural/ethnic differences among participants. Members of a CAB vary according to locale and situation. Membership may include community members who share characteristics of study participants (or study participants themselves), representatives of local patient advocacy organizations working with SCD-related services, programs, and persons diagnosed with SCD or their family members, community leaders, and professionals with relevant research and/or scientific expertise. This group played a significant role in supporting outreach efforts to potential listening session participants.

The Sick Cells CAB consists of 12 members essential in engaging local community members to participate in roundtable discussions and provide input on patient archetypes and education materials.

To properly inform our CAB members we shared an email detailing the goal of the project and requested assistance in recruiting listening session participants from the following communities:

- The Aging
- Hispanic/Latinx
- Incarcerated/Formerly Incarcerated (including family members)
- LGBTQIA+

It is worthy to note the beginning of recruitment and outreach occurred during Sickle Cell Awareness month, sickle cell conference season, and a season change into fall. During Sickle Cell Awareness month and the month after, many advocates were planning, traveling, and/or participating with scheduled events. There were several in-person conferences for SCD that occurred during this time too. Likewise, SCD is impacted by the weather. We had several participants with SCD go become ill thus missing their focus group, as a result of the season change.

Our goal in conducting this qualitative research was to host 4 listening sessions with 4-6 individuals each for 16-20 participants. However, the final participation count was 11, having only met the participation goal with one group (LGBTQIA+). The participation was as follows:

- The Aging Listening Session: 3 participants
- Hispanic/Latinx Listening Session: 2 participants.
- Incarcerated/Formerly Incarcerated Listening Session: 2 participants.
- LGBTQIA+ Listening Session: 4 participants.

We gathered all potential participant availability by sending emails with proposed meeting times set out in two-hour blocks. We then considered differing time zones and work/school schedules and sent calendar invitations to each participant with an email including the discussion guide questions for review before the call.

Participants are navigating their disease, work, school, families, social lives, and medical appointment schedules to participate in the research so regular communication and flexibility were key in our scheduling process. Email was used as the primary method of outreach. In addition, participants communicated via phone, handwritten letters, social media messaging, and in person at SCD-specific events.

Below is a chart detailing our methods of outreach for the varying subpopulations.

Method	Aging	Hispanic/latinx	LGBTQIA+	Incarcerated
1:1 Conversation at conference	X			X
Social media		X	X	
Email	X	X	X	X
Phone	X	X		X

Each session was offered as a virtual meeting using Zoom with the option to call into the session. In addition, as needed, we hosted 1:1 phone calls with participants based upon their availability. All participants were compensated for their time. Participants who became ill during their listening session time were given a small stipend for their efforts to communicate with Sick Cells.

## Honorarium

Participants received \$75 per hour as compensation for their time.

## RECRUITMENT METHODOLOGY

### A. Prior Relationship Building

Sick Cells has different programs and research projects. These programs aim to reach the broader community and highlight the subpopulations discussed in this report. From these previous encounters, the team built a rapport with-in the community and directory of individuals for the majority of the subpopulations.

- a. **Aging Population:** Sick Cells keystone program -Faces of SCD Storytelling Program - aims to educate about SCD through the voices of the community. This program empowers individuals and families within the SCD space to tell their stories through storytelling campaigns, social media, blogs, audio stories, and interviews. The storytelling campaigns can focus on regions of the US or specific themes. In April 2023, Sick Cells hosted a campaign, Thrive over 55, for individuals living with SCD who are over the age of 55. From this campaign, we were able to identify one listening session participant and a second listening session participant from a Chicago Storytelling Campaign captured in 2016.
- b. **Hispanic/Latinx Community:** Sick Cells conducted a research project in 2021, Hispanic Outreach Promoting Equity Project (HOPE) Project to understand the experiences of Hispanic individuals living with SCD. In addition, the team has published blogs of individuals sharing their experiences as a Hispanic/Latinx living with SCD. The team recruited two individuals from our previous work for the listening sessions.
- c. **LGBTQIA+:** Sick Cells published a blog series and a series of Faces of SCD Storytelling Campaign entitled Warriors with Pride from 2021-2023. This campaign in June gave a platform for individuals living with SCD who identify with the LGBTQIA+ community. We recruited all participants for the listening session from our Warriors with Pride Campaign, including one participant who has previously worked with Sick Cells on other storytelling efforts and our Project SCoviD (COVID-19 vaccination awareness project).
- d. **Incarcerated Population:** Sick Cells has done little work in this area. As a result, we relied on our community advisory board for a referral.

### B. Modes of Communication

The team used various modes of communication to reach participants. Overall, email communication was the least viable mode of communication for listening session recruitment. The team used the following modes of communication:

- a. **Emails:** From previous consent forms from Sick Cells projects and programs, participants included their personal email addresses. All participants received emails to invite them to participate in this project. Follow-up emails were sent to all participants and the community

advisory board. Due to the attendance at the national conference for SCD some emails were lost in delivery after communicating with participants through different channels. Subsequently, some emails were re-sent to confirm participation in the listening session. We received the least number of responses from direct email. In fact, we were able to coordinate with only two individuals via email alone. All other participants required an additional mode of communication.

- b. Direct Phone calls:** From previous consent forms from Sick Cells projects, programs, and relationships, participants included their personal phone numbers. After introductions at an in-person event and/or through communication from the community advisory board or Sick Cells' staff, personal phone numbers were used to invite individuals to participate in the listening sessions. In addition, phone numbers were used if there were technical difficulties logging in to the virtual listening session.
- c. Text messages:** In addition to direct phone calls, text messages were used as reminders for some participants and technical support during the listening session.
- d. Instagram Direct Messages (DMs):** Many of the participants involved in the previous programs and projects stayed connected via Instagram and other social media platforms. If emails were not responded to, Instagram Direct Messaging (DMs) was used as a source of communication to introduce the project, confirm receiving the email, and schedule and confirm listening session times.
- e. In-person invitation via conferences:** The Sickle Cell Disease Association of America (SCDAA) had its 51st in-person conference in October 2023. The conference occurred two weeks prior to the listening sessions. Sick Cells team was introduced to new individuals with SCD and caregivers in addition to previous acquaintances at the conference. A few invitations were verbally presented to eligible participants while collecting their contact information. In addition, previous acquaintances were notified about this project and to be fully aware of the project an email with additional information was sent to their personal email addresses.

Different modes of communication were more effective than others for the various groups. There was an observable difference based upon the participants' age groups, regularity of email usage in their daily lives, and use of social media in how participants were able to receive and respond to the invitation for the project.

- a. Aging Populations:** For this population, Sick Cells made follow-up phone calls and texts with the majority of the participants. A total of two participants in the aging group were introduced to the project at the SCDAA convention. One of which continued communicated throughout the project via handwritten letters. This group was not contacted via social media.
- b. Hispanic and LGBTQIA+ Populations:** Social media, direct phone calls, and texts were the most effective way to communicate with these groups.
- c. Incarcerated:** A direct phone call was how we contacted individuals from this population. An initial email was shared with this group and a participant acknowledged receipt but ultimately telephone was the most effective mode of communication as email responses did not occur.

## C. Communication Design

The initial mode of communication for all participants began with a detailed email including the background and purpose of the project, how to participate, and compensation. After 2 weeks of low response rate, the team modified the modes of communication specific to each subpopulation.

- a. Many individuals who have used email communication as their primary mode of communication have stayed in communication with the team via email throughout this project. Participants who (1) have jobs that require email usage or who have contacted Sick Cells through email demonstrated this preferred communication channel.
- b. Several participants are familiar with members of the Sick Cells team therefore, after brief conversations on the phone or text, this builds engendered willingness to participate.
- c. Sick Cells is active on social media, and many individuals are comfortable directly messaging Sick Cells. We used this mode of communication mostly with the LGBTQIA+ subpopulation. It is worth noting that the participants were mostly under the age of 30.
- d. The team met a few participants for the Hispanic subpopulation and Aging population at the national SCD conference. The team approached these individuals to invite them to participate in this project.

Overall, in person and social media communication were the primary drivers in recruitment and outreach for this project. Continuous communication aided in delivering information, confirmation of participation, technical support for attendance, and any follow-up questions or comments. Social media was highly effective in communication with ages 30 and below. Direct phone calls and text messages have been shown to build a high rapport with Sick Cells and the participants by engaging in conversation. In addition, direct phone calls can be accommodated for the time of day when participants are comfortable speaking on the phone or responding promptly to text messages.

We find that to achieve a more equitable research pool, it is important to tailor recruitment efforts to match how participants receive information.

## D. CHERP Initiative Timeline



*We would like to highlight that due to the different modes of communication and follow-up our original timeline was extended quite a bit. There was a need to be flexible with the timeline in order to include everyone because of work schedules, conferences, and illness. Because of this, we began drafting the report prior to completion of the listening sessions in order to meet our draft report deadlines.*

## RECOMMENDATIONS

### Sharing Project Detail

It is important to ensure that potential partners understand the project so they can determine whether they want to participate and if so, what they should expect as a participant.

To properly inform partners and potential participants, we recommend that recruitment outreach emails consist of information on:

- Project mission
- Expected level of participation
- Honorarium amount
- A general timeline

### One Point of Contact

We also recommend designating one established point of contact from a trusted messenger.

1. If the relationship holder is not the point of contact, we recommend that they make a formal introduction between the designated point of contact and the interviewees.
2. Trusted messengers are a key component to follow-up and were often used to support connecting and scheduling discussions with participants.

This is important for minimizing confusion in coordinating listening sessions across varying schedules and ensures that:

- All information shared is accurately and clearly communicated to participants
- There is an opportunity to build rapport with participants, and
- Participants have an open line of communication, and this provides a line of communication to direct their questions or concerns

### Large Sample

A large sample size ensures that the information shared is reflective of a broad and representative experience with the condition. While individualized experiences are important, recruiting the appropriate number of participants ensures that the conclusions are valid and reliable. Due to the nature of SCD and the propensity of a crisis and other lived experience that impact predictability of schedules we recommend oversampling the number of participants.

## Session Moderators

It's important to consider selecting diverse individuals as session moderators. Participants tend to be more responsive, trusting, and communicative when there are commonalities between them and the session interviewer such as age, race and ethnicity, sexual orientation and gender identity, and medical condition.

## Meeting Flexibility

It is important to consider alternative methods of engagement such as speaking with participants on the weekend or outside of traditional work hours, additional follow-up, flexibility in scheduling or rescheduling meetings, and one to one meetings if participants are unable to meet with the larger group of participants.

## Literacy

Literacy refers to the ability, confidence, and willingness to engage with language to acquire, construct, and communicate meaning in all aspects of daily living<sup>1</sup>. Literacy levels are largely socially and culturally constructed and influenced by a range of factors including but not limited to education, socio-economic status, environment, and health factors.

With this in mind, we recommend the use of simplified language throughout the drafting of discussion questions to ensure that all Listening Session Participants understand and are able to fully answer questions about their experience with SCD. Trusted messengers can aid in ensuring that written information is understood.

## Translation Services

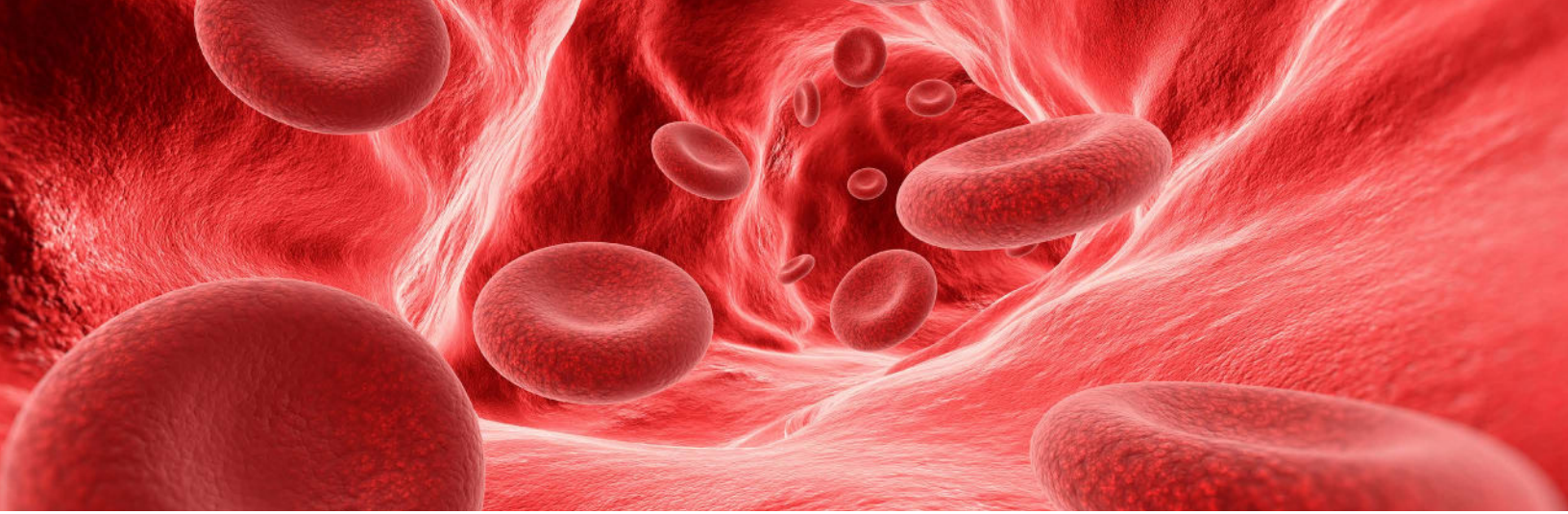
Additionally, when interviewing participants with different native languages it is important to provide translation services. Translators help facilitate by bridging language barriers and gaps in communication while maintaining the meaning of a message across cultures.

## Considering the Digital Divide

The digital divide refers to the gap between those that have access to modern communication technology (smart phones, telephone, television, personal computers, and internet connectivity) and those that do not<sup>2</sup>. Moreover, the digital divide refers to an individual's ability to utilize technology (log in to online account, join virtual meetings, check message notifications, etc.).

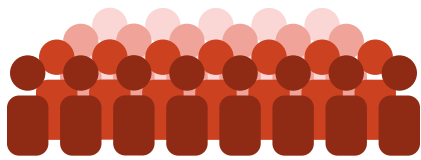
As advancements in technology evolve in the delivery of healthcare services, it is important to consider the ways in which these technologies exacerbate disparities in care for people who do not have access to these methods of communication or training for how to engage with the tools.

We recommend using broad points of contact for engagement such as trusted messengers, smart phones, and exploring the opportunities to convene for discussion with individuals living with SCD at in-person conferences or meetings throughout the year to narrow the digital divide.



# Key Findings

## Introduction



*Sickle cell disease (SCD) is a rare blood disorder that impacts about 100,000 Americans.<sup>3</sup>*

Sickle cell disease (SCD) is a group of inherited blood disorders caused by the presence of an abnormal form of hemoglobin known as Hemoglobin S. Individuals with SCD experience acute and chronic complications including vaso-occlusive crises, acute chest syndrome, various infections, strokes, and organ damage.

Disparities in care among marginalized populations lead to poor overall health outcomes for members of the SCD community<sup>4</sup>. To better understand these disparities, Sick Cells-a national non-profit organization dedicated to developing programs that educate, inspire and mobilize individuals to create community and policy-level change partnered with Links2Equity - a healthcare policy practice focusing on patient advocacy and health disparities, to host a series of listening sessions through the Community Health Equity Research and Promotion (CHERP) Project.

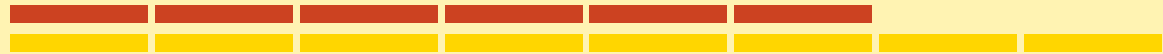
The listening sessions were comprised of following patient populations:

- Aging
- Hispanic/Latinx
- Incarcerated/ Formerly Incarcerated
- LGBTQIA+

## Aging

Generally speaking, the life expectancy of individuals with SCD is significantly lower than that of individuals without the disease.

*Despite advancements in treatment methods, a recent study found that the life expectancy for individuals with SCD in the US is still about 2 decades shorter than the average lifespan<sup>5</sup>.*



Because of the life expectancy gaps, there is a lack of robust data available on aging sickle cell patients. As treatment methods and therapies continue to improve, so will life expectancy.

To better understand and address the challenges associated with aging with SCD, we spoke to three individuals over 40 about their experiences. This group in particular spoke to a deep sense of life's fragility, having lived with SCD for many years and developed close relationships with others who have died from the disease.

## Hispanic/Latinx

*In the US, Hispanic/Latinx individuals are the second largest population impacted by sickle cell disease after African American/Black individuals<sup>6</sup>. According to the Centers for Disease Control (CDC), **sickle cell disease occurs in one of every 16,300 Hispanic American births<sup>7</sup>**. However, the true incidence is unknown, due to patterns and uncertainty around immigration and few US-based studies focusing on this population.*



*Above: Rivas Family, Sickle Cell Thalassaemia Patient Network Sickle Cell Walk, 2018*



We spoke with two individuals with a focus on cultural barriers that impact their experience with SCD. These participants shared that within their communities there is a severe lack of education about SCD. Because of this, they spend a lot of time educating people about what a SCD diagnosis means, how it differs from carrying the trait, and dispelling widely circulated myths about the condition.

*Left: Mariza, Sickle Cell Thalassaemia Patient Network Sickle Cell Walk 2018*

## Incarcerated/Formerly Incarcerated

Chronic health conditions are notoriously undertreated in the U.S. prison population. This is a significant problem for patients that suffer from conditions that are poorly understood.

Research on the access and quality of pharmacological care for common chronic conditions showed significant inequities in care among incarcerated people<sup>7</sup>. This is especially true for incarcerated persons with rare chronic conditions like SCD.

To better understand these experiences and identify gaps in care, we spoke with two individuals about their experience of living and caring for people diagnosed with SCD while being involved with the federal prison system. One participant spoke about the difficulties he faced because of assumptions medical providers have about incarcerated people in general which include being a drug addict, a criminal, or untrustworthy, and various other labels. On at least one occasion while incarcerated, his medication was taken from him and withheld by prison staff. He highlighted the importance of advocating for himself by leveraging the relationships with physicians he had outside of prison and building a rapport with new providers to ensure he received the best care.

## LGBTQIA+

Members of the LGBTQIA+ community experience challenges in access to care due to stigmas surrounding sexuality and gender identity and expression. Access to quality care for SCD is already challenging and stigma and implicit bias hinder healthcare professionals from providing adequate care.

We spoke with four individuals about the ways they have been impacted by SCD as members of the LGBTQIA+ Community. One participant shared that he has been repeatedly misgendered when seeking care and because of this found it difficult to trust that those providers had his best interest in mind when treating him.

*Below: Participants in Sick Cells' Pride Campaign, Cheresse R, Cory L, Tristan L, and Andre H.*





Above: Sickle Cell Advocates, Sickle Cell Foundation of Tennessee Walk, 2018

## Lived Experience

With chronic conditions like SCD the implications for individuals are lifelong. Typically, SCD is diagnosed at birth or in early childhood through a blood test as part of prenatal or newborn screening protocols<sup>8</sup>. Individuals with SCD face a range of challenges including chronic pain, fatigue, frequent medical interventions, emotional distress, social isolation, and financial strain.

### Common Symptoms

#### Chronic Pain

All participants spoke about the impact chronic pain has on their daily life.

There was significant variation in both the descriptions of their chronic pain and episodes of crisis and their methods of treatment. It is clear there is not a one-size-fits-all method for the management of SCD.

#### Increased Sensitivity to Cold

Many individuals also spoke about their increased sensitivity to cold temperatures and noted preventing pain crisis induced by cold temperatures as a significant aspect of managing the condition.



## Medication and Treatment Management

### Opioids

Medications used by participants for disease modification were Hydroxurea, Endari, and Adakveo. Common medications used for pain management were oxycodone and Morphine.

Other available medications include Oxbryta for disease modification and Dilaudid for pain management. Many participants noted that they do not like using pain medications and would prefer to avoid use if possible due to the side effects and stigma associated with using prescription opioids for pain management.

It should also be noted that in terms of difficulty accessing innovative medications one participant shared that despite being prescribed a brand name medication pre-authorization prevented him from receiving that and he was instead given an older generic prescription.

### Blood Transfusions

Another widely used therapy reported to have been helpful in managing complications of SCD is blood transfusion—a procedure in which red blood cells are separated from donated blood, tested, closely matched, and intravenously administered to another<sup>7</sup>.

### Medical Marijuana

Participants also shared that they have been prescribed marijuana for medicinal purposes.

Those who use marijuana medicinally report pain relief and a decrease in the symptoms of anxiety. There is limited research available on the benefits and detriments associated with the use of marijuana in treating the symptoms of SCD.

### Non-Clinical Approaches

From a non-clinical perspective, participants shared the importance of staying hydrated, eating at regular intervals, monitoring their protein intake, getting adequate rest and exercise. Holistic and creative outlets such as meditation, journaling, writing, and video production were also mentioned.

## Exercise/Activity

Participants shared that consistent and moderate exercise has been helpful and many attribute the pursuit of activities, interests, passions, and hobbies to staying well with SCD.

## Social Implications

Frequent pain, fatigue, and hospitalizations also create negative social implications for individuals living with SCD.

*Many listening session participants stated that even amongst their closest family and friends, there is a poor understanding of SCD and the limitations that the symptoms impose.*

There was wide variation in response from participants regarding whether their community growing up knew of their diagnosis. Participants primarily recalled that their close friends in school or that lived in their neighborhoods knew that they had SCD but did not fully grasp what that diagnosis meant. This theme was a continued discussion from the LGBTQIA+ community when discussing dating relationships and how partners do not fully understand the mental and physical implications SCD can cause. Many shared that it was helpful for their childhood friends in trying to understand why they could not always participate in extracurricular activities or were absent from school. Importantly, members from the aging listening session discussed that sharing insight about their condition with neighbors and friends in their community also served as a line of safety for many who noted they felt protected among people who knew some of the general symptoms of the condition.

*Below: Janice and her family, Marc Thomas Sickle Cell Foundation Walk, 2019.*



Others noted that they preferred not to share their diagnosis because of teasing, ridicule, and bullying by children who did not understand the disease and spoke about how isolating SCD has been. Many shared about experiences in which they were excluded from social gatherings and events because of how limited their ability to attend or participate has been in the past. Members of the aging listening session shared that they have found that young people do not want to share their diagnosis because of a fear that people know about the disease they won't be considered "cool" or accepted by their peers.

## Employment

Many also shared about the challenges to employment they experience because of SCD.

Participants discussed that because their employers are not educated about SCD, they do not understand the debilitating nature of the disease. Individuals that were frequently absent because of pain and hospitalization were prevented from advancing and even fired from their jobs.

Participants also noted that the perception of SCD among their colleagues negatively impacted their employment. Many feel that their credibility is often put into question as they are routinely quizzed about the need to utilize mobility aids and whether the symptoms are severe enough to warrant absence and/or workplace modifications. Many shared that because of the challenges experienced with employment it has been good to work for relatives or friends who are aware of their diagnosis.

Similarly, participants shared that professors and institutional administrators often question their ability to be present and fully engaged in academic programs because of fatigue and frequent hospital admissions.

*Below: Dennis, Sickle Cell Disease Association of Illinois Sickle Cell Walk, 2019.*





Above: Jo'veon, Sickle Cell Disease Association of America Michigan Chapter Sickle Cell Walk, 2019

## Access to Care

Site of care refers to the location where treatment for a particular condition is administered.

Due to the nature of SCD, a chronic condition that requires a range of medical providers and interventions, access to care can be difficult. To fully understand the complexities associated with access to care it is important to discuss the different sites of care utilized by individuals with SCD. Insurance has had a significant impact on the delivery of healthcare and often coverage is inadequate for rare conditions like SCD.



*A recent research study found that individuals living with SCD pay around four times as much in out-of-pocket costs in their lifetime for medical care as compared to individuals without the disease<sup>9</sup>.*

Access to care through insurance is essential to ensuring individuals with SCD can afford the necessary medical interventions, medications, and support services to effectively manage their condition and improve their overall health and well-being.

### Treatment Sites

Participants shared that in addition to the treatment to relieve symptoms at home, they also receive care in clinics, hospitals, emergency rooms, doctor offices, community health centers, and urgent care centers.

### Insurance/Reimbursement

Insurance has had a significant impact on the delivery of healthcare and at times coverage is inadequate for rare conditions like SCD. Participants identified Medicaid and commercial providers as their primary sources of insurance. For the most part, individuals found their insurance benefits are not only inadequate but difficult to understand.

## Wraparound Services

Many participants shared that they rely on wraparound services to fill the gaps in care created by inadequate insurance and the high costs they are expected to pay out of pocket for their care while others were not aware of the wraparound services available to them or how to access them.

One participant shared that living with SCD has caused a financial strain for much of her life. This coupled with her inability to maintain steady work has been an “overwhelming burden.”

## Insurance and Case Management Programs

Though many struggled to understand their insurance policies, there were a couple of outliers. Four participants felt that their coverage was not confusing. They found their programs to be robust and shared that they participate in insurance case management programs where they are regularly provided with referrals and connected with navigators who help with the coordination of transportation, co-pay assistance, and appointment support.

## Pediatric to Adult Care

There was also a clear consensus among all participants that there is a significant downward shift in the level of care and assistance in optimizing insurance benefits between pediatric and adult care for SCD. Specifically, individuals discussed feeling seen and heard, safe, and properly attended to during hospital visits as children. However, as adults, feel they are met with hostility, accusations, insinuations, and disrespect. It should also be noted that several participants overheard the pediatrician telling their parents that they were going to die at a certain age, which created traumatic experiences over the course of their childhood.

# Cultural Barriers

Cultural competence is the ability to effectively deliver health care services that meet the social cultural and linguistic needs of patients. Cultural competence improves health outcomes and quality of care. The lack of understanding among friends and family, community members, present challenges to living with SCD. Moreover, when seeking treatment, a lack of cultural sensitivity serves as a major roadblock to access quality care. These barriers can significantly impact various aspects of the condition, including diagnosis, treatment, and overall management. Understanding and addressing these cultural barriers is crucial for improving healthcare outcomes and quality of life for individuals affected by SCD.

A number of participants shared about encounter in which they were referred to as “sicklers” when noting the overall negative attitude of ER staff toward them when seeking care. These encounters left individuals feeling misunderstood, dismissed, and distrusting of their providers.

One participant noted his hesitancy to share his experience SCD with mental health professionals due to cultural norms that discourage sharing his “personal” or “family” affairs with

outsiders, this barrier is compounded by sharing personal information with members of the “white community” due to a lack of trust. This participant went on to say that he also struggled with sharing personal information with female therapist but has evolved over the years and now has a comfort level with therapy and sharing personal health issues with different races and genders.

## Providers

One participant from the Hispanic/Latinx listening session spoke to the role colorism can play by sharing that in the past, because she has lighter skin, healthcare providers didn’t think she had sickle cell disease and instead believed she was seeking drugs.

Another participant shared that she preemptively explains her ethnic/genetic history in an effort to help educate providers she encounters-something she feels she would not have to do in order to receive prompt and appropriate care if she was white.

One participant noted his hesitancy to share his experience with SCD with mental health professionals due to cultural norms that discourage sharing your personal health status, especially as a black man interacting with female healthcare providers.

In some instances, it was unclear whether providers were discriminating against individuals because of their diagnosis, their race or ethnicity, or a combination of the two.

A participant from the aging listening session noted that in his experience working as a support group leader and community health volunteer, he has found that many people within the general community believe that SCD is cured. He commits a lot of time and effort to educating not only the general community but health workers on cultural sensitivity through community health worker education programs.

Another participant from the aging listening session shared that within his community it was often assumed that he would never be capable of living a normal life. His pediatrician advised him that in regard to work he should find a job for which he uses his brain because his “body would not allow any other type of work.”

*Below: Co-Founder Marqus Valentine*



## Colleagues and Classmates

A member from the LGBTQIA+ session shared that because her disease is “invisible” many of her colleagues question whether she actually needs the accommodations she asks for at work (see employment section above). Many other participants shared that because the disease is not seen people don’t understand the challenges they face in day-to-day life.

A participant from the aging session shared that because of SCD she was a lot smaller than her peers and was bullied for that in school.

Another participant also shared that he found that young people do not want to share their diagnosis because of a fear that if it’s known that they have SCD they won’t be considered “cool”.

A participant shared that while in school and as an adult working, classmates questioned absences and his ability to continue to the next grade due to his absenteeism and as an adult colleagues questioned why he was able to have so many excused days off from work and this policy was not applied to them.

## Family Members

Participants across multiple listening session groups shared that within their families talking about any illness was taboo.

One also noted that he was considered to be weak by family members. This also contributed to negative beliefs about his parents and their ability to lead normal lives as caring for him made maintaining a job difficult.

*Below: Rivas Family and Donette, Sickle Cell Thalassaemia Patient Network Walk, 2018*



# Patient Provider Relationship

The patient provider relationship refers to a consensual relationship in which a patient knowingly seeks a physician's assistance and in which the physician knowingly accepts the person as a patient<sup>6</sup>. The hallmarks of a healthy patient provider relationships are trust, knowledge, regard, and loyalty<sup>7</sup>. Patients rely on their physicians for medical advice and treatment recommendations that are specific to their individualized conditions. As such, challenges to those key elements of patient provider relationship pose a significant threat to good health outcomes for individuals. It is important to understand the nuances in the experiences of individuals with SCD, given the amount of time they spend with healthcare providers.

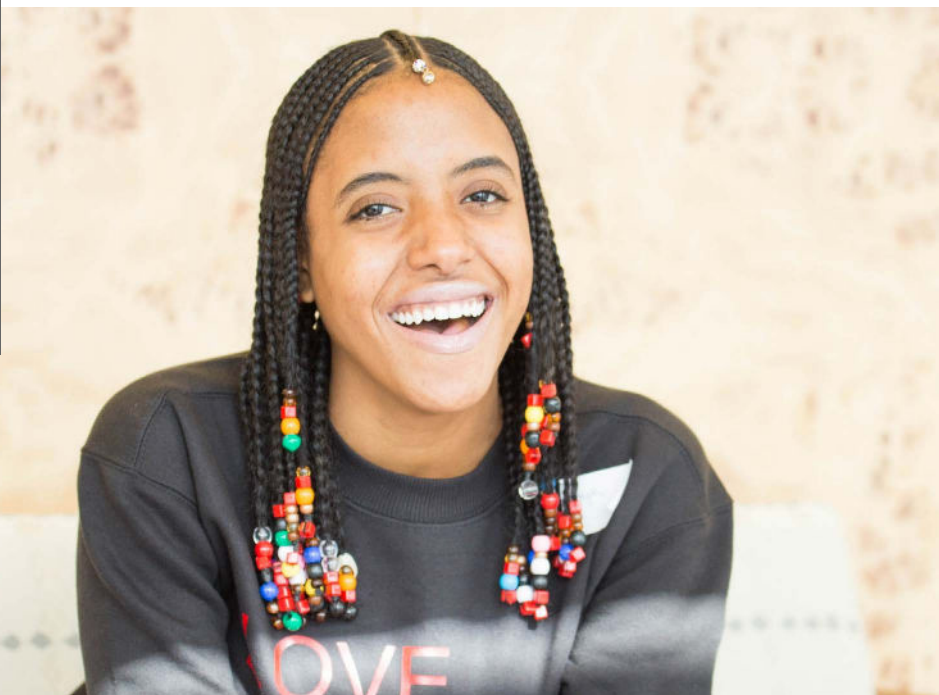
## General Practitioners

There was significant variation in participants' experiences with providers regarding information sharing.

*Overall, participants felt their general practitioners were often not informed enough about SCD as a whole to make recommendations and seemed unwilling to discuss different treatment options in depth.*

One participant shared that he saw his pediatrician until he was 35 years old.

*Below: Leslyn, Ohio Sickle Cell Event, 2019*





## **Emergency Room**

A majority of participants communicated that the poor treatment and lack of knowledge on SCD was a frequent occurrence in the emergency room. In fact, many shared that to the extent possible they avoid going to the ER because if they can find symptom relief in another avenue they would rather not be subjected to such negative environments.

One participant recounted telling hospitalists she would “rather be sick at home where she could at least be more comfortable” after being left under a cold air conditioner for hours waiting for pain medication. Many other participants noted that providers were dismissive because they didn’t “look to be in pain or sick.”

## **Working with Specialists**

However, many felt that their specialists - hematologists and internists - were thorough in working through the different treatment options available and making recommendations specific to each individual’s experience with SCD.

## **Comprehensive Care**

Participants also shared that finding comprehensive care has been so difficult they have relied on family and friends to facilitate the coordination of care in order to receive medication and appropriate treatment. One participant noted he has avoided relocating to remain in network with providers that they feel understand SCD, demonstrate empathy, communicate clearly, and create an environment where decision-making is shared.

## **Other Resources**

Outside of the advice from medical providers, individuals that we spoke with rely heavily on other members within the SCD community via support groups and foundations to learn more about others’ personal experiences with treatments that have been helpful.

# Stigma

Stigma is the negative social attitude connected to a characteristic of an individual that may be regarded as a mental physical, or social deficiency<sup>7</sup>. Stigma can be public, institutional, or even self-imposed<sup>12</sup>. As it relates to SCD, stigma perpetuates myths and misinformation adding to a lack of understanding about the condition. All of this contributes to isolation, discrimination, and barriers to adequate care.

Because SCD is a rare disease understudied and underfunded in the medical community, individuals with this condition face a number of challenges to receiving adequate health care. Those living with SCD are likely to experience stigma and an overall lack of access to specialists and meaningful treatment. It is also important to consider the interplay of social determinants of health with the intersectionality of race, ethnicity, sex, age, and sexual orientation. Notably, individuals with conditions characterized by pain, like SCD, bear a disproportionate burden of these challenges.

## Opioid Controversy

*Data shows there is a significant disparity in the treatment of pain across different population groups, with vulnerable populations being most inadequately treated for their pain<sup>8</sup>.*

Of key importance is the perception of opioids in America. These medications, when appropriately prescribed, are a critical and effective method of pain relief for many individuals living with SCD.

The use of opioid medications is controversial in the American health care system. Because of common misconceptions and negative rhetoric, the use of opioids for the treatment of chronic pain has been heavily criticized leading to bias in clinical decision-making and treatment provision. Moreover, because of systemic racism and implicit bias among health care providers, there are stark differences in the rates at which providers are willing to prescribe opioids as a pain management method to white patients as compared to non-white patients.

Participants shared that they have been referred to as “drug-seeking, lazy, unmotivated, and dramatic” in relation to their condition. More than half shared that they have been turned away when presenting at hospital emergency rooms in crisis, because of the misguided belief by providers that their pain was either fabricated or not significant enough to warrant medical intervention. For example, participants from the LGBTQIA+ and Hispanic/Latinx sessions reflected on their experience when providers did not believe them about their pain if they were consuming a meal or addressed with “you do not look sick or in pain” (see patient provider relationship above).

# Mental Health

Because SCD is a chronic illness characterized by pain, infection, stroke, and a range of other medical conditions, it can have a significant impact on mental health. Significant research shows a high incidence of depression in individuals with SCD<sup>13</sup>. Moreover, psychological conditions are a recognized contributor to morbidity in SCD<sup>14</sup>. Emerging research highlights the importance of exploring psychosocial variables as predictors of pain-related outcomes in SCD<sup>14</sup>.

Participants were very candid about the ways their mental health has been impacted by SCD. The most commonly reported experiences were depression, anxiety, and grief connected to the chronic nature of the condition, a lack of understanding, and seeing others close to them die. Numerous participants mentioned they experienced a “dark place” in their SCD journey where suicidal thoughts or behaviors impacted their life due to the pain and challenges presented by the disease. These participants pointed to therapy as being an integral component to manage living with the disease.

A participant from the aging listening session, who volunteers at the community level for SCD specific organizations noted that thoughts of suicide are “very regular” within the SCD community because of the toll the disease has had on their life. Many also spoke to traumatizing impact that being accused of being drug-seeking has played on their mental health.

*One shared that for much of his life, being diagnosed with SCD “felt like a death sentence.”*

His parents were warned that he would not live past a certain age several times throughout adolescence. He spoke specifically about how this was counterproductive and only increased fear around the disease. In early adulthood, he learned to shut off his emotions to avoid the debilitating stress that accompanied his diagnosis. He also noted that this helped with his pain because stress that is unmanaged would trigger crisis. Another participant who had been given a similar warning noted that he had been told all throughout his life that he would not live long and now finds himself as an aging adult with little put towards savings and retirement because of such a grim prognosis.

In all of the listening sessions at least one member shared that they find solace through various avenues including support group membership, therapy, and exercise when combatting the feelings of depression, stress, anxiety, and grief associated with SCD.

*Below: Sickle Cell Disease Association of Illinois Support Group, 2016*



# Conclusion

The aim of the listening sessions is to provide a platform for discussion among a diverse group of individuals with SCD. These discussions help us to better educate and equip community members, caregivers, researchers, and healthcare providers about the experiences of those living with SCD. Additionally, the listening sessions highlighted areas that should be explored further.

- Each session provided important details on the lived experiences of individuals with SCD and the challenges they face. However, there were a few limitations to the study including: A limited sample of participants from the various selected population groups.

Additional analysis will provide an opportunity to better understand the lived experiences of those with SCD by exploring in more depth:

- The differences in the levels of care from pediatric to adult care
- Accessibility of wraparound services
- Opportunities to develop insurance/reimbursement education tools and resources
- Wraparound service awareness efforts
- Physician Education and cultural competency training
- Resources on the importance of knowing your SCD status
- Clear professional guidelines on transition from pediatric to adult care
- Medical Guidelines for aging populations with SCD
- Proactive mental health professional guidelines for the SCD that encourage early treatment
- Additional opportunities to support SCD education and awareness at the community level such as toolkits for caregivers, family, and friends, and school aged children

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# Sponsors

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# Glossary

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## Acute Chest Syndrome

Acute chest syndrome (ACS) is a severe lung-related complication of sickle cell disease that occurs when red blood cells block blood vessels in the lungs. ACS is one of the leading causes of morbidity, hospitalizations and death in children and adults living with sickle cell disease.

## Blood Transfusion

A blood transfusion is a routine medical procedure in which donated blood is provided to you through a narrow tube placed within a vein in your arm.

## Hematologist

A hematologist is usually a board-certified internist, or pediatrician who has completed additional years of training in hematology. The hematologist generally focuses on direct patient care and diagnosing and managing hematologic disease, especially cancers.

## Pain Crisis

Pain crisis refers to recurrent episodes of pain that range in severity from mild to severe, usually occur very abruptly and are often localized around joints.

## Stroke

An ischemic stroke occurs when the blood supply to part of the brain is interrupted or reduced, preventing brain tissue from getting oxygen and nutrients.

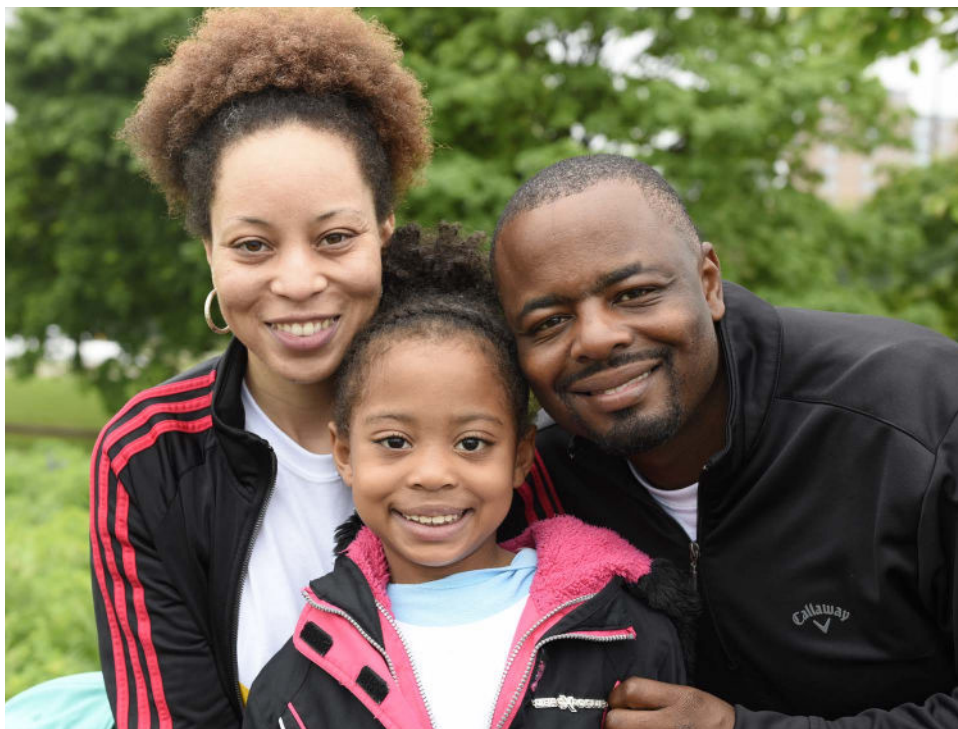
# Discussion Guide

# Discussion Guide

## Lived Experience

An individual's experience with SCD can change from day to day and throughout the course of life. It's important to consider the experience from a more long-term perspective.

1. How do you manage your sickle cell?
2. Thinking about your lived experience. What one component of the disease has had the greatest impact in your life and why? (i.e., economic burden, pain, stigma, new treatments, etc.)
3. Do you find that this has shifted? Would your response to part A be the same 5 or 10 years ago?
4. How do you stay well with sickle cell?
5. From your personal experience with SCD, can you provide an example of how you perceive persons diagnosed with SCD to be treated differently than other patients attempting to receive care and treatment in the healthcare system?



Above: Shorter Family, Sickle Cell Disease Association of Illinois Walk, 2017

## Access to Care

Insurance affects how people receive healthcare. This can make receiving care hard, especially for individuals who are treated in a clinic, doctor's office, or emergency room, hospital, community health center, urgent care centers, etc.

### SITE OF CARE

6. Where do you receive care for your SCD?
7. How has where you have received care impacted your experience? (i.e., smaller clinics, hospitals, emergency room, doctor office, community health center, urgent care centers)

### INSURANCE/REIMBURSEMENT

8. Do you feel you understand your insurance benefits?
9. Do you have resources (i.e., family members, doctor staff, nurse navigator, social worker, etc.) that help you understand your insurance benefits?
10. How would you like to better understand your insurance benefits?

### EMPLOYER

11. Is your employer aware of your SCD Diagnosis?
12. Do you feel comfortable having a conversation with your employer about lack of understanding of SCD?
13. Do you feel comfortable telling your employer about the lack of insurance coverage for SCD your current insurance plan offers?
14. Do you fear backlash around promotions, pay increases, and the security of your job if you have a discussion with your employer about the lack of coverage for SCD under your employer insurance plan?

## WRAPAROUND SERVICES

- 15.** Wraparound services offer additional support and include but are not limited to: manufactured, sponsored, patient assistance drug programs, manufacturer sponsored co-pay cards, Foundation co-Pay assistance programs, financial support, reimbursement/insurance case management programs, transportation, nurse navigators, foundations, support groups, referral sources, case management, counseling, crisis care and outreach, education, appointment support, coordination of care, health literacy, translation services, clinical trial navigation systems, resources to other patient advocacy organizations, and community health centers.
- What wraparound services are a part of your care?
  - Are there needs that are not met by the currently available wrap-around services?
  - Are there services offered to you by community health workers that have not been listed above?
  - How did you find out about these resources?

## CULTURAL BARRIERS

- 16.** What is the understanding of SCD in your community?
- Based on your experience, how could awareness and understanding of SCD be improved in your community?
- 17.** What are the major roadblocks to care you face as a patient in the SCD community who is (Aging, Hispanic/Latinx, LGBTQIA+, Incarcerated)

## PATIENT PROVIDER RELATIONSHIP

- 18.** Do you feel your healthcare providers have given you enough helpful information about treatment options?
- 19.** Would you say there is good communication between you and your healthcare providers? Are you given options that allow you to factor in your life circumstances?
- 20.** How have discussions with providers impacted your decision-making for pain management and treatment options?
- 21.** Have you experienced providers assuming you are seeking drugs when you go to the hospital in crisis?
- How has this situation impacted your access to treatment and care?
- 22.** What has been the most important tool for the treatment and management of your symptoms?
- In a clinical setting (doctor. office, clinic, emergency room)
  - Outside of a clinical setting

## Stigma

There are many stigmas (judgement by society or an individual that results in shame) associated with SCD because it is a rare blood disease characterized by severe pain. Too often, individuals are treated without compassion and healthcare providers fail to put themselves in the person diagnosed with SCD shoes in order to understand the condition and the journey.

- 23.** Do you believe stigma about SCD impacts your access to treatment and information on the disease?
  - a.* What are some examples of those stigmas?
- 24.** Can you share your personal experience with stigmas surrounding SCD?
  - a.* Among those close to you (family and friends)?
  - b.* Among Community members?
  - c.* Among medical providers (er staff, general practitioners, specialists)?
  - d.* Among employers?
- 25.** Are there tools or resources that you have found helpful in eliminating myths about SCD?
- 26.** Did you tell your employers that you have SCD?
  - a.* If so, how have they responded?

## Mental Health

Because SCD is a chronic illness characterized by pain, infection, stroke, and a range of other medical conditions, it can have a significant impact on mental health. Moreover, crisis forces hospital stays that disrupt day to day activities and relationships with friends and family members.

- 27.** What are the ways the diagnosis has impacted your mood and emotional and mental health?
- 28.** How has this changed throughout your life?
- 29.** What are some of the ways that you manage your mental health (depression, anxiety, grief, financial stress, etc.)?



*Above: Co-Founder Marqus Valentine, Sickle Cell Disease Association of Illinois Support Group, 2016*