



Focus Group Report

Michigan Department of Health and Human Services

2026-2030 Sickle Cell Disease Strategic Plan



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Learn more about the MDHHS Michigan Hemoglobinopathy Quality Improvement Program

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I. Overview of Sickle Cell Disease

Sickle cell disease (SCD) is the most commonly inherited blood disorder affecting approximately 100,000 Americans. SCD affects one out of 500 Black or African American births and one out of 16,300 Hispanic American births.ⁱ According to the Michigan Sickle Cell Data Collection (MiSCDC) Program, a U.S. Centers for Disease Control and Prevention (CDC) funded disease surveillance project, approximately 4,000 individuals with SCD live in Michigan.ⁱⁱ

SCD is caused by a genetic mutation in hemoglobin, which predisposes red blood cells to become rigid and misshapen, or “sickle”-shaped. SCD is a lifelong condition complicated by acute and chronic medical problems, which can be life-threatening and disabling. Common complications include episodic severe pain, chronic hemolytic anemia, increased vulnerability to infection and multi-organ damage.ⁱⁱⁱ SCD adversely impacts the physical, emotional, social and vocational lives of both the individuals affected and their families across the lifespan.

The three main types of SCD are:

Hemoglobin SS disease (also called sickle cell anemia): This is the most common type of SCD and happens when a person inherits two genes for hemoglobin S (one from each parent). In hemoglobin SS disease, the body destroys the sickled cells. When this occurs, the number of red blood cells is lowered, resulting in anemia.

Hemoglobin SC disease (also called sickle cell hemoglobin C disease): People with this condition have fewer cells that change from a round shape to a sickle shape. In people with hemoglobin SC disease, one parent has sickle cell trait, and the other parent has hemoglobin C trait. Hemoglobin C is another type of abnormal hemoglobin.

Sickle beta thalassemia (also called sickle cell thalassemia disease): This form occurs when a person inherits one sickle cell gene and one beta thalassemia gene. Red blood cells still change into a sickle shape. There are two types of beta thalassemia: “zero” ($S\beta^0$) and “plus” ($S\beta^+$). Those with $S\beta^0$ usually have a severe form of SCD. People with $S\beta^+$ tend to have a milder form of SCD.

II. Background

The Michigan Department of Health and Human Services (MDHHS) has partnered with the [Sickle Cell Disease Association of America-Michigan Chapter \(SCDAA-MI\)](#) since 1987. The SCDAA-MI facilitates follow-up care of infants identified through Michigan’s Newborn Screening Program (NBS) who are diagnosed with sickling conditions. It also engages people of all ages who have SCD and their families, providing awareness and education, system navigation, patient advocacy, and employment and career counseling services.

Beginning September 2024, the MDHHS Division of Lifecourse Epidemiology and Genomics (LEGD), in conjunction with staff from [Michigan State University’s Institute for Health Policy \(MSU-IHP\)](#), collaborated with the SCDAA-MI to conduct five focus groups comprised of individuals living with SCD or sickle cell trait (SCT), as well as parents/caregivers of those who have SCD/SCT. This study was determined to be non-human subjects research by the MSU-IHP Institutional Review Board (IRB) and was accepted by the MDHHS IRB.

MSU IHP developed a discussion guide which identified agreed upon topics and a series of probes or follow-up questions to direct the groups' conversations (Table 1). The discussion guide, along with other participant recruitment materials, was shared with SCDA-MI for their review and feedback. Subsequently, participant recruitment activities were initiated and focus groups scheduled. Recruitment activities targeted SCDA-MI clients and patients receiving care in various sickle cell clinics across Michigan. The SCDA-MI facilitated participant sign up and provided transportation assistance, when needed.

Five focus groups were held between November 4 and December 2, 2024, in Detroit, Saginaw, Lansing, Benton Harbor and Grand Rapids at pre-arranged locations. Additionally, one virtual focus group of patient advocates (PAs) was held in January 2025. Sessions took approximately an hour and a half to two hours to complete and no identifiable information was collected from participants by MDHHS. Discussions were led by a neutral facilitator from MSU-IHP who asked pre-determined questions. Focus group responses were recorded, coded by themes and subthemes, organized into major categories, condensed and synthesized into key findings.

These findings serve as the basis for this report and will be used to inform Michigan's 2026 SCD Strategic Plan, a comprehensive public health blueprint for how to best address the needs of individuals (children and adults) with hemoglobinopathies. This focus group report seeks to capture the views and experiences of populations affected by sickle cell and to identify strategies to improve SCD/SCT programming across the lifespan. Through these efforts, program staff have learned more about the concerns people with SCD/SCT have, as well as those of their caregivers, including participants' experiences and perceptions in accessing and/or receiving health care, using health insurance and their ability to obtain health information and medications. Additionally, the focus groups helped to highlight the impact that social determinants of health (SDoH) have on those living with sickle cell conditions, as they care for themselves and their families.

III. Focus Group Questions

The following table is a list of shared topics covered in each focus group, along with the "probes" used to stimulate and guide discussions. The first column identifies specific topics. The second column includes conversation starters and probes used with patients/parents/caregivers (PPC) during in-person focus groups. The third column contains conversation starters and probes used with the PA focus group that met virtually.

Table 1. Focus Group Topics, Conversation Starters and Probes

Topics	Conversation Starters & Probes For PPC Focus Groups	Conversation Starters & Probes For PA Focus Group
1. SCD Information Availability & Use	1. When you were first diagnosed with SCD, how did you get information about your condition? a. Who provided the information?	1. What resources do you use to update your own knowledge about SCD? 2. What resources do you recommend to your clients

Topics	Conversation Starters & Probes For PPC Focus Groups	Conversation Starters & Probes For PA Focus Group
	<ul style="list-style-type: none"> b. Where did you find the information? c. What information did you find most helpful? 2. When you found information on your own, did you consider it reliable? Why or why not? 3. How challenging was it to find the information you were looking for? 4. What kind of information was difficult to find? <ul style="list-style-type: none"> a. Where would be the best place to provide this information? 5. What is the best way to present SCD information? (brochure, website, booklet, etc.) 6. What other learning tools or resources do you think would have been helpful? 	<ul style="list-style-type: none"> with SCD or their caregivers? 3. Are there any brochures, websites, videos, etc. you think are most effective? 4. In your opinion, <ul style="list-style-type: none"> a. What types of SCD information do clients have the most difficulty accessing/finding? b. What types of information do they find most difficult to understand? <ul style="list-style-type: none"> i. Do you have any ideas about how to improve how this information is presented? c. What kind of SCD information is not readily available, or not available at all? 5. Do you have any specific recommendations about SCD tools or resources you would like developed?
2. Barriers Related to Health Care Access	<ul style="list-style-type: none"> 1. Who typically provides treatment for your SCD? <ul style="list-style-type: none"> a. Have you been referred to a hematologist? <ul style="list-style-type: none"> i. What was your experience like? ii. Did it differ from care you received elsewhere? How? 2. What are the biggest challenges that you/family/caregiver face in accessing care from your primary care doctor or medical specialists? 3. If you are unable to manage your pain at home, what experiences have you had when seeking pain management elsewhere? <ul style="list-style-type: none"> a. Where did you go? b. What about day treatment programs, transfusion centers, urgent care, contacting hematologist? 	<ul style="list-style-type: none"> 1. In your experience advocating for those with SCD and their caregivers, can you describe some of the most common barriers your clients encounter when trying to access health-related care? <i>For example, obtaining referrals to specialists, pain management, access to SCD specific treatment centers, infusion centers, or obtaining prescription medications?</i> <ul style="list-style-type: none"> a. What types of challenges/barriers to accessing health care are you most often asked to assist them in overcoming? 2. If you could change one thing about the health care

Topics	Conversation Starters & Probes For PPC Focus Groups	Conversation Starters & Probes For PA Focus Group
	<ul style="list-style-type: none"> c. What was the outcome? d. What challenges did you encounter? <ol style="list-style-type: none"> 4. What is your experience with obtaining and/or managing the medications you need to take every day? <ul style="list-style-type: none"> a. What barriers or challenges have you experienced? b. Does your pharmacy stock the medications that are prescribed for you? c. If not, how long have you had to wait to get them? What was the reason you had to wait? 5. Have you shared your SCD diagnosis with decision makers (i.e., teachers, administrators, supervisors) at your school/workplace? 6. In what ways does your school/workplace support your needs? <ul style="list-style-type: none"> a. Are there any kinds of support you need but aren't currently receiving at school/work? 	<p>delivery system related to SCD care, what would it be?</p> <ol style="list-style-type: none"> 3. How do you support those with SCD or their caregivers in matters related to their school or workplace? 4. If you could change one thing about how schools or workplaces accommodate those with SCD, what would it be?
3. Transition to Adulthood and Adult Care Providers	<ol style="list-style-type: none"> 1. Thinking about your transition from child to adult care providers, what barriers did you experience? <u>OR</u> As you/your child approach(es) adulthood, do you think transitioning to adult care providers will be challenging? How so? / Why not? 2. At what age do you think it would be best to begin talking to children about transitioning to adulthood and their role as an adult living with SCD? <ul style="list-style-type: none"> a. What information do you think is most important to provide? (first, second, third) 	<ol style="list-style-type: none"> 1. In your role, what challenges have you observed as your clients transitioned from pediatric to adult care providers? <ul style="list-style-type: none"> a. Do you have suggestions as to how this transition could be made easier? 2. In your opinion, what would be the best way to prepare youth for this transition? <ul style="list-style-type: none"> a. At what age do you think this preparation should begin? b. What do you think are the three most important areas to address?
4. Barriers Related to SDoH	<ol style="list-style-type: none"> 1. What are the greatest challenges you encounter related to SCD management? 	<ol style="list-style-type: none"> 1. What challenges most significantly impact the

Topics	Conversation Starters & Probes For PPC Focus Groups	Conversation Starters & Probes For PA Focus Group
Directly Impacting Care of SCD	<ol style="list-style-type: none"> 2. Are there any obstacles that prevent you from: <ol style="list-style-type: none"> a. Scheduling or attending routine appointments for sickle cell care? b. Taking your medications as prescribed? c. Managing or treating pain? d. Contacting or communicating with health care providers? e. Receiving care in a timely manner? 3. What would be the best way to let you know about the resources available to you for things like transportation, support groups, groceries, education/employment, financial, health care benefits, childcare? 	<p>ability of a person with SCD to manage their condition? (i.e., transportation, financial support, childcare, education/employment.)</p> <ol style="list-style-type: none"> a. What strategies or resources have you found effective in addressing these barriers? 2. Thinking about your efforts to collaborate with health care providers and agencies, <ol style="list-style-type: none"> a. What works well: <ol style="list-style-type: none"> i. With physicians or physician office staff? ii. With local health departments? iii. With Community Mental Health agencies? iv. Others? b. What needs improvement? 3. How do health care providers or systems collaborate with you to provide better access to support services? <ol style="list-style-type: none"> a. Overall, do you think health care providers are aware of the services you provide? <ol style="list-style-type: none"> i. What do you think could be done to increase awareness? b. From whom do you typically receive referrals? <ol style="list-style-type: none"> i. What do you think could increase the number of referrals you receive from other sources?
5. Access to Insurance Coverage	<ol style="list-style-type: none"> 1. How has your health insurance coverage affected your ability to get the care you need? 	<ol style="list-style-type: none"> 1. In your experience, how frequently do health insurance-related

Topics	Conversation Starters & Probes For PPC Focus Groups	Conversation Starters & Probes For PA Focus Group
	<ol style="list-style-type: none"> 2. Have health insurance co-pays or deductibles prevented you from seeking the care you need? 3. Did a lack of health insurance ever impact your ability to seek the care you needed? 4. What do you know about current Children's Special Health Care Services' (CSHCS) benefits for those living with SCD over age 26? 	<p>challenges/barriers impact your clients' access to SCD care?</p> <ol style="list-style-type: none"> a. For example: coverage, copays, deductibles or lack of insurance. 2. What are your strategies for helping people with SCD and their families address these challenges? 3. Are you aware that the CSHCS age-related benefits for SCD have been extended to those over the age of 26 years? <ol style="list-style-type: none"> a. Do you have any questions you would like to ask about this important change? b. Have you had the opportunity to talk about this with your clients and their caregivers? What questions, if any, have they asked about it? c. Do you have the resources you need to answer their questions or to share with them?
5. Interactions with Health Care Professionals	<ol style="list-style-type: none"> 1. Thinking about your interactions and conversations with health care professionals (doctors, nurses, social workers, dieticians, others), how well do you think they understood your concerns? <ol style="list-style-type: none"> a. How comfortable are you expressing your questions or concerns to your provider? b. Did they give you time to ask questions? c. Did they take time to answer your questions? d. Did they explain the meaning of words that were new to you? e. Were you satisfied with their response(s) to your concerns? 	<ol style="list-style-type: none"> 1. From your perspective, how well do health care professionals understand the needs and concerns of persons with SCD and their families? <ol style="list-style-type: none"> a. What have your clients or caregivers shared with you about their interactions with health care professionals? 2. What advice would you give to health care professionals to improve their communication and care for persons with SCD and their families? 3. How do you support persons with SCD in

Topics	Conversation Starters & Probes For PPC Focus Groups	Conversation Starters & Probes For PA Focus Group
	<ul style="list-style-type: none"> f. Did they check to be sure you understood their advice, recommendations or instructions? g. Did they treat you with dignity and respect? <ol style="list-style-type: none"> 2. What advice do you have for health professionals about the way they communicate with patients about SC disease or trait? 3. Do your health care provider(s) include you in decisions that are made about your care? How? 4. When you experience sickle cell crisis, are you confident you will receive the care you need? Why or why not? 	<p>advocating for themselves during medical appointments or emergency care?</p> <ul style="list-style-type: none"> a. Are there any tools or other resources you use or would recommend that would assist clients/caregivers in communicating with health care providers? <ul style="list-style-type: none"> i. Are there any tools or resources you think need to be developed? <ol style="list-style-type: none"> 4. What steps could providers take to ensure persons with SCD, and their families are included in decisions that are made about their care?
6. Conversation Summary	<p>Summary Remark: In our conversation today, we talked about where you go for information about SCD, the challenges you face in managing it, those who provide your health care, and your school and workplace.</p> <ol style="list-style-type: none"> 1. Is there any one thing you think we overlooked? 2. What is the most important thing you think MDHHS should keep in mind as we go forward with the state's SCD strategic planning process? 3. If you could talk with your state senator or representative today about SCD, what would you want to tell/ask them? 4. What would you like health professionals to understand about what it's like to live with SCD? 	<ol style="list-style-type: none"> 1. Is there anything we haven't covered that you think is important to discuss? 2. What do you think is most important for us to keep in mind as we continue the MDHHS SCD strategic planning process? 3. In your role, are there any additional resources or support you need to assist persons with SCD and their families?

IV. Focus Group Participants

Focus group participants included individuals with SCD/SCT, parents of minor children with SCD/SCT, other family representatives who care for those with SCD and patient advocates.

PPC Focus Group Participants: Participants were primarily African American and age 18 and older. Attempts were made to recruit other racial and ethnic minorities whenever possible. Children under 18 years of age were excluded from the study. Parents/guardians were responsible for providing opinions about their minor's experiences. Among PPC focus group participants, there were 41 individuals who participated in the sessions. Additionally, participants were polled to identify if they had SCD or SCT trait, and/or if they were a patient or a parent/caregiver. The results are provided below. **Please note:** Some individuals identified themselves as having SCD or SCT and as being a parent/caregiver of someone with SCD/SCT. When this occurred, they were included in counts for each category they identified.

Table 2. Participants – PPC Focus Groups

Total Number of Participants:	41	Participants (#) 41 Total	Female (#) 33 Total	Male (#) 8 Total
Diagnosed or Parent/Caregiver		Location		
Have SCD	19	• Detroit - 11	• Detroit - 8	• Detroit - 3
Parent or caregiver of someone with SCD	22	• Benton Harbor - 9	• Benton Harbor - 7	• Benton Harbor - 2
		• Grand Rapids - 8	• Grand Rapids - 7	• Grand Rapids - 1
Has SCD trait	9	• Lansing - 6	• Lansing - 6	• Lansing - 0
Parent of someone with SCD trait	8	• Saginaw - 7	• Saginaw - 5	• Saginaw - 2

While the PPC Focus Group participants were primarily of one racial group, differences in age, country of origin, socioeconomic backgrounds and educational attainment arose organically through conversations as personal stories were shared. Some participants indicated they learned of their SCD diagnoses before Michigan added the condition to its [NBS panel](#). Others had been diagnosed while living in different states or other countries (i.e., Georgia, California, Kenya, the Caribbean). Some were originally misdiagnosed and told they had bone cancer, malaria or a different chronic condition. Several overheard doctors telling their parents they would most likely die at a young age. Others were told they would not be able to have children. Some talked about how their diagnosis had led them to careers in the health field and a few were nurses. Each of the groups contained a good cross-section of individuals representing all socioeconomic and educational backgrounds. Most groups contained both males and females. While specific data was not collected on all these variables, it was reflected in the meeting recorder notes.

In addition to the PPC participants, each focus group was attended by three MSU-IHP and two MDHHS staff members. One MSU staff member served as discussion facilitator, while the remaining MSU-IHP and MDHHS staff took detailed notes of the conversations that occurred.

PA Focus Group Participants: This group consisted of individuals either employed by SCDA-MI or who served as affiliate employees. Administrative staff involved in outreach, education and community awareness were invited to participate in the virtual session, as were the patient advocates assigned to the Detroit headquarters and out-state Michigan offices. Additionally, the Children's Hospital of Michigan (CHM) staff, who provide advocacy services through their SCD clinic, were also invited. In total, 11 PAs attended the two-hour virtual session.

The session was led by the same MSU-IHP facilitator who led the PPC focus groups. One other MSU-IHP and two MDHHS staff people were in attendance for these meetings to listen and take notes. The virtual meeting was also recorded, and a transcript of the meeting was generated.

Table 3. Participants - PA Focus Group

PA Focus Group Participants		
Participants	11	100%
SCDA-MI	9	82%
Administration	4	36%
Patient Advocates (Detroit, Benton Harbor, Lansing, Grand Rapids/Muskegon, Saginaw/Flint)	5	45%
Children's Hospital of Michigan, Detroit	2	18%
SCD Clinic Transition Specialist/Social Worker	2	18%

V. Participant Compensation

Each PPC focus group participant received a \$50 gift card from MSU-IHP as an incentive for their participation. For those who identified during the registration process that they needed transportation assistance, the SCDA-MI provided a \$25 gas card. PA focus group participants did not receive any incentive for their participation. The PA virtual focus group was scheduled during regular work hours, and their participation was included as part of their work assignment for the day.

VI. Focus Group Findings

From the many topics discussed, three key areas of concern emerged: education/awareness, access to quality health care and health insurance benefits. Health inequities permeated the

focus group discussions, making them foundational to addressing all other concerns. As such, they have been added as a fourth key area.

This report is organized by key focus areas. Each section/subsection begins with a quote from a focus group participant and includes information they provided. Comments from PA participants that reflect unique perspectives are included under the heading of “Patient Advocates.” Each section concludes with a list of improvements gathered from focus group participants to address expressed issues and identified concerns.

A. EDUCATION AND AWARENESS

“Living to Learn.”

General Education/Awareness: In general, many focus group participants identified the need for more education/information about SCT and SCD:

- Some participants indicated that their parents learned how to care for SCD through verbal instructions received from health care professionals. Other participants thought their parents may have received a pamphlet/booklet from their doctor’s office after diagnosis. Many groups felt they had big gaps in knowledge about their condition, available treatment options, self-care practices and SCD progression over time.
- Specific education for those with SCT was lacking. Participants with SCT indicated their parents had received little information beyond a notification at the time of their original diagnosis, which was most likely at birth. Some became aware they had SCT after birthing their own children. While those with SCT are often asymptomatic, some PPC focus group participants with SCT reported they experienced pain regularly and a few reported being hospitalized for pain crises. While their symptoms did not occur as frequently as someone who had a SCD diagnosis, to them the pain was very real.
- Participants who were internet savvy used Google, Web MD, Mayo Clinic and/or other health information sites to learn about their condition. Others used the internet to research alternative treatments and/or natural remedies. However, given the large number of medical and disease specific sites currently available, some participants wondered which sites were the most trustworthy.
- Parents/caregivers from all focus groups talked about the need for age-appropriate materials that could be shared with children to help them understand their SCD condition and to instill healthy habits.
- Nutrition education was identified as a need in at least three focus group meetings. Some participants expressed interest in understanding how nutrition affects their health conditions, particularly how healthy eating can help reduce inflammation and support lymphatic function.
- Information about exercise was also identified as lacking. This concern was raised by participants who were parents of youth who wanted to play sports. These participants described the tension they experienced in wanting to both protect their child from getting hurt and empower them to live full and active lives. Specifically, they wanted to know which sports were the safest for their child with SCD, which ones posed unnecessary risks and how they could ensure good hydration for their child while playing sports.

- Participants also expressed both a need and desire for more information about treatment options, risks associated with those options and how to make informed decisions about which options to pursue. Participants wanted to know more about SCD research but were unsure how to access and interpret research.
- Across all the PPC focus groups, the SCDA-MI was repeatedly singled out as a trusted and valued source for all things sickle cell related. Because of the SCDA-MI's unique role as the state's newborn screening coordinating center, many knew of the organization from an early age and were familiar with the SCDA-MI website. Some had participated in trainings or received one-on-one counseling sessions from the organization's medical director, who had also worked as a pediatrician at the sickle cell clinic located at CHM. Participants described innovative games, videos and other training materials that the SCDA-MI had created and shared with them to assist in learning about their condition; and many appreciated how the organization promoted SCD awareness through sponsored events (i.e., Sickle Cell Walk, Sickle Cell Day).
 - Among those not born in Michigan, a few did not know about SCDA-MI, but upon hearing about the organization from other focus group participants, they wanted to learn more.
- All focus group participants believed that more should be done to make all people aware of SCD and how it impacts those who have it. Participants of each group spoke about how little was known about SCD by the general public, and specifically by white people. They felt this lack of knowledge contributed to issues that those with SCD faced in both schools and workplaces.

Patient Advocates:

- PA participants agreed that the internet contains many reliable SCD informational/educational resources and, given how many people have smart phones, these resources are readily available.
- Additionally, PAs offer SCD programming both online and in-person, as well as in group and individual settings to meet the various learning styles of their clients. Their efforts go beyond their respective organizational walls and into the community through their participation in various events (i.e., health fairs, conferences, church events).
- In addition to educational resources, PA participants have compiled service information from many community-based organizations related to employment, housing, behavioral health, utilities, etc. Not only do PAs provide information about these services, but they also assist clients and their families in accessing those services, as needed.

Teacher: "Where does the agitation come from?"

Parent: "Sickle Cell"

Education – Schools: Parents of school-aged children expressed frustration with the lack of knowledge that teachers, school nurses, administrators and other school personnel possessed about SCD and its impact on children with the diagnosis.

- Parents expressed frustration at having to start each school year either educating or re-educating their child's teachers and school administrators about SCD. Many complained that they lacked adequate training materials to share with school personnel.
- Parents stated that school policies and practices vary by individual school building, and that there are no standardized approaches for supporting students with SCD across districts.
- Despite parent participants' best efforts to describe their child's health condition, including pain management needs, frequent hospitalizations and/or requests for special accommodations, educators did not seem to understand the impact that acute pain can have on a child's behavior during the school day (i.e., shortened attention span, chronic fatigue, agitation or acting out).
- Parent participants described how school policies and actions did not align. Examples included:
 - Children were not offered Individualized Education Program (IEP) Plans or 504 Plans even after schools were informed about their child's SCD diagnosis.
 - Children were provided ice packs to soothe injuries when heat applications were more appropriate.
 - Parents received truancy letters during times when their child was hospitalized.
- Parents also described situations where their child was unnecessarily removed from gym classes or not allowed to participate in recess. Stories about children having to sit out, sit alone and/or be isolated from their peers were mentioned by many focus group participants.
- In one case, a parent was surprised that their request for educational accommodations due to their child's SCD condition resulted in the family being placed on the school's charity list for financially vulnerable students.

Patient Advocates:

- PA participants shared how they help families with school issues, specifically in obtaining 504 Plans, IEPs and learning resources. They reported that requesting a 504 Plan/IEP was not difficult. It typically involves submitting a letter of request. However, PAs confirmed hearing from multiple families that while the school may establish a plan, certain schools do not always respect the plan. When that occurs, additional conversations are needed between families and school personnel, with which PAs can assist.

“Working harder to make up lost points in attendance.”

Education – Colleges: Young adults going off to college face new challenges because of their SCD diagnosis, making the transition to college even more difficult.

- Patient and parent participants alike described the distance between the campus and the hematology office and the amount of effort it took to transport a student back and forth, especially if that student needed transfusion, infusion or other services. They questioned why those services could not be provided at a hospital or clinic closer to campus.

- Patient and parent participants also stated that colleges and/or specific professors did not always make accommodations for missed assignments or exams due to medical-related absences or hospitalizations. One participant recalled a college student being told to, “come back after their SCD was gone.”
- For students living on campus, this may be the first time they were managing their condition without parental support. For these students, going to college was an even greater adjustment.
- Parent participants also expressed concerns when their student chose not to inform their roommates of their condition. These participants worried about how roommates would respond during an emergency.

Patient Advocates:

- PA participants described how they assist those attending college by sending letters to administrators to inform them of a student’s SCD diagnosis and their need for special accommodations. This helps to ensure that the college student with SCD receives the same opportunities for success that other students have.

“Child was in the hospital for six weeks; I lost my job.”

Education – Employers/Workplaces: A lack of special accommodations for those with SCD can impact employee and employer relations. Employees who are frequently absent due to their SCD condition may be mislabeled as unreliable and/or lazy and may suffer job termination. While federal laws have been put in place that mandate specific accommodations for employees with chronic conditions, securing those accommodations can be difficult.

- According to PPC participants, many employers know little about SCD. This lack of knowledge translates into a lack of understanding when pain crises or other SCD complications occur. Employers do not understand that pain can be frequent and unpredictable in someone with SCD. Educational resources for employers are not readily available.
- Some PPC participants indicated they had been fired from their job due to absences associated with their or their child’s SCD condition.
- Others described difficulties encountered when applying for the Family Medical Leave Act (FMLA), which they either didn’t receive or received only after multiple request submissions.
- Some indicated they were intentionally not seeking employment because they doubted their ability to maintain a job, citing frequent illnesses and/or hospitalizations – either their own or their child’s - as a barrier.
- Some chose health care careers with the hope that health care employers would be more understanding of their condition.
- Overall, participants recognized that problems associated with employment impacted their ability to maintain a livable income, as well as created health insurance, life insurance and retirement issues for them and/or their families.

Patient Advocates:

- PAs described assisting workers by sending accommodation letters to employers, when requested.
- PAs talked about how they could assist with career planning, job referrals and schedule appointments with Michigan Rehabilitation Services (MRS), and other training programs.

“Keep the information flowing...”

Suggested Improvements: Education and Awareness

The following ideas were discussed among participants as ways to address the need for more education and awareness programs/services.

- Promote the history and prevalence of SCD in Michigan.
- Promote people living and thriving with SCD/SCT as role models.
- Develop sickle cell public awareness campaigns that use traditional and non-traditional methods to get the word out:
 - Develop and publish news releases and public service announcements and air commercials.
 - Make sure pamphlets, brochures, booklets, FAQ handouts (hard copies and/or electronic formats) are accessible by placing them in locations frequented by those with SCD (i.e., doctors’ offices, EDs, clinics, hospital lobbies).
 - Post SCD-specific social media content on social media platforms commonly accessed by young people (i.e., YouTube, Facebook, X, TikTok, Instagram, Snapchat).
 - Use digital lobby signage (i.e., videos for waiting rooms) as an additional educational resource.
- Create comprehensive websites and/or apps that people with SCD/SCT and their families/caregivers can use to learn more about their disease, available treatment options, disease progression, pain management techniques, self-care practices and healthy behaviors. Also include tools for self-advocacy to ensure those with SCD/SCT are well-equipped to navigate their systems of care and are properly informed of their rights.
- Publicize current evidence-based research on SCD treatment advancements and alternative treatment options. Make information easily accessible on public sites frequented by people interested in sickle cell.
- Identify and make available age-appropriate and culturally sensitive resources for children so they can learn about their condition from an early age.
- Provide peer support and/or other alternatives to children who are limited in their access to recreational or other activities so that they can form positive relationships with people their own age. This could be accomplished through friendship groups, buddy systems, peer modeling, peer tutoring or peer support groups.
- Assist schools/colleges in developing more standardized policies and approaches for students with SCD, which may include remote learning or other accommodations to help students be successful.

- Provide people with SCD/SCT opportunities to share their experiences and learn from and connect with others that have the same condition. This could be accomplished through peer support groups, virtual meetings, conference attendance and/or closed Facebook pages.
- Provide more information to those with SCD/SCT about nutrition, physical activity and other healthy behaviors so they can improve and/or maintain their health.
- For those with SCT, provide additional follow-up services to ensure they are aware of their trait diagnosis as they enter their reproductive years.
- Compile tailored resources for school/college personnel and employers to explain SCD/SCT, how it impacts people with the condition and the special accommodations available to them.
- Develop videos that feature students and employees describing their lived experience with SCD that can be used to educate school personnel and employers about the condition and the special accommodations they may need.
- Assist adults with understanding and obtaining life insurance, and retirement planning tools so they can plan for their own and their families' futures.
- Provide additional funding as needed to support these ideas as suggested.

B. ACCESS TO QUALITY HEALTH CARE

“Care should be around the corner.”

Accessible and Available Health Care: Repeatedly, participants talked about inaccessible care and a lack of providers who were knowledgeable about sickle cell. This was true for both primary care practitioners (PCPs) and hematologists.

- Adults of all focus groups reported issues with finding hematologists and PCPs who were knowledgeable and willing to treat patients with sickle cell.
- While those who lived in the Detroit area had better access to hematologists, the quality of available care varied and was not perceived as equal. Unfortunately, transportation limitations restricted some individuals' ability to choose their preferred providers.
- Many of the adults with SCD who lived outside of the Detroit metro area indicated they had problems finding a hematologist that would treat them. Many of the hematologists in out-state Michigan were more focused on treating oncology patients. Participants residing closer to a tertiary care center were more likely to find a hematologist or a SCD clinic, but those that did not, either had to travel some distance or accept a hematologist/oncologist who they considered less knowledgeable and/or interested in their condition.
 - To prove their point, a few shared stories about being referred to a hematologist office and not being able to reach anyone. No one would pick up the phone or return their call, even after leaving messages.
- There was much agreement that PCPs lack information and knowledge about sickle cell. The lack of communication between hematologists and PCPs was also reported as an issue.
- This lack of knowledge and communication posed unique problems for participants of Grand Rapids and Benton Harbor focus groups, where the PCP, not the hematologist, was the prescriber of pain medications.

- Nursing was another health care profession that was seen as lacking knowledge and in need of more education. Focus group participants who were nurses themselves indicated that nursing curriculums did not include much information about the disease.

Patient Advocates:

- Medical staff need to listen to their patients. Often, they are the expert in the room about SCD and have so much to share. “Please listen!”

“Why is the adult model so different?”

“Our pediatrician is our quarterback.”

Pediatric vs. Adult Care: Regardless of location, stark differences were identified between pediatric and adult specialty services.

- Across multiple locations, focus group participants who were parents/caregivers of children with SCD reported that the care they received through pediatric hematology was informed, interdisciplinary, integrated and person-centered. Some likened the pediatric hematologist to a “quarterback” – who was actively involved in their child’s treatment and care coordination plans.
- In contrast, adult hematology services were characterized as being non-comprehensive, fragmented, uncoordinated, uninterested and non-empathetic. Often, adult patients in need of care had to visit the ED because there were no other options.
- As parents/caregiver participants listened to adults describe the ineffectual care they had received, they expressed confusion and concerns about their child’s future care needs.
- Young adults who had grown up receiving care through the pediatric model indicated they also did not understand why these changes had occurred and found it difficult to adapt.
- Everyone agreed that SCD conditions worsen with age. As such, it requires more disease management and care, not less.

Patient Advocates:

- PAs agreed that clients often report positive experiences with pediatric care teams; but once they transition to adulthood, many clients expressed frustration with their providers, citing a lack of empathy in how their care is managed.

“Is there anything you need is such a loaded question.”

“What are you asking me? Is my rent paid?”

Care Coordination: Care coordination is a patient-centered approach which assesses a patient’s needs and organizes services designed to meet those needs^{iv}. Through care coordination, patients then receive assistance in navigating systems to make sure the services needed are obtained. Several focus group participants described their struggles in trying to identify and/or access the services they needed.

- Many parents/caregivers identified a need for additional supports, feared the loss of income due to extended bouts of illnesses, and worried about providing food and shelter during periods of employment transition. Furthermore, they struggled to balance caring for their sick

child and meeting the needs of their other children. Importantly, they described how struggles were magnified in single parent households when dealing with illnesses and major setbacks. Participants recognized the need for therapy for all family members to address stress-induced effects caused by chronic conditions.

- Several adults described how many of the handholding supports and resources they received as a child were no longer available to them as an adult. Many understood the importance of self-advocacy skills but were unable to utilize those skills effectively in the midst of a pain crisis. They need additional support, too.
- Several participants indicated they would benefit from a case coordinator, case manager or social worker to help them navigate the health care system, as well as to help address other issues associated with their social and mental health needs.
- Many participants did not seem to be knowledgeable about community resources for housing, utility assistance, transportation providers, etc., that could be tapped to assist with basic needs and address the SDoH (i.e., those non-medical factors that impact health outcomes). They indicated that information should be more accessible and available at places that people frequently visit (i.e., ED rooms, physician offices, urgent care clinics, hospitals, SCD websites). Several thought that screening for the SDoH should occur as part of medical appointments.
- At every focus group, people identified the need for behavioral health services. Sometimes those needs came in the form of requests for professional therapy rather than direct peer support. People were interested in where they could access counseling for themselves or for their children. For others, they wanted peer support groups – a place where they could meet with others who had SCD and share their lived experiences, learn from each other and walk the journey together.

Patient Advocates:

- PAs described the stigma surrounding mental health treatment. While they felt many of their clients would benefit from those services, they feared they would not admit to needing help.
- Costs associated with obtaining mental health services were identified as a barrier to care. PAs indicated that some insurances do not pay for mental health services and not all family members have the same insurance coverage. So, while a person with SCD may have coverage for mental health services, those who live with them may not.
- Grief counseling was identified as another gap. Many parents/caregivers experience guilt when a person with SCD dies. Sharing grief with others can lessen their burdens and help with emotional healing.
- After time, burnout of burdens born by PAs in caring for high need clients is too great and they need to step away from the work to do something else. Unfortunately, their departure takes a toll, leaving gaps in the organization's institutional knowledge about community resources.

***“One day I won’t be in the room, and he will have to navigate all of this himself.
He is the one who has to identify his pain.”***

Health Care Transition: According to Got Transition, Health Care Transition (HCT) is the process of moving individuals from a child/family-centered model of health care to an adult/patient-centered model.^v Focus group participants described their health care transition preferences and their experiences.

- Some participants described a model of health care transition, which featured a period in which both pediatric and adult providers engage together with the patient in the young adult’s care. During this period, a gradual shift in care responsibilities occurs between pediatric and adult providers. Using this approach helps ensure that trusting relationships between patients and doctors are formed. As a result, adult physicians have the opportunity to learn about their patients, their treatment needs and preferences.
 - According to one parent participant, this model for transition is being utilized by hematologists in Chicago and Los Angeles, places where they had previously lived. However, it was not available in West Michigan.
- For many, health care transition should also offer opportunities to young adults to gain independence by learning how to make their own appointments, manage their medications and communicate with their physicians – skills they will need throughout their lives.
 - Some participants talked about how unprepared they were to manage their own care when they became adults because they were used to their parents interceding on their behalf (i.e., talking to doctors, getting prescriptions, etc.). While they may have been present at the appointments, the conversations were about them not *with* them.
 - Some indicated they had been instilled with good self-care skills and routines early on but lacked self-advocacy skills, never feeling like their voices were heard.
- Much discussion occurred around what age health care transition should begin. For many, it made sense to start in the teen years, acknowledging that individual maturity was an important factor to consider.
- Some parents/caregivers involved young children in treatment and care planning activities.
 - One parent asked doctors to speak directly to the child because she was the patient.
 - Another described how she would make the child answer the doctor’s questions. When a doctor asked the parent a question, she would restate it to the child so that he was the one who answered it.
 - Others worked to establish healthy routines with their child early on. These routines resulted in a child who was more engaged and self-sufficient in managing their medications, vitamins and hydration.
- Regardless of age, most participants felt it was important to involve children in the decision-making processes.

Patient Advocates:

- One challenge clients face when transitioning from pediatric to adult care is the lack of continuity in care. Many of those with SCD experience a disconnect with new adult providers, who are unfamiliar with their history or specific care needs. This can leave clients

feeling overwhelmed. Once they transition to the adult provider, these clients may have problems staying connected to the new providers (i.e., cancelling or not showing up for appointments, skipping lab work).

- PA participants stated that clients need to develop essential skills, (i.e., self-management, communication and health care system navigation capabilities). They need tools and resources that will empower them to make informed decisions. PA participants agreed with the gradual transition of care approach, stating that it provides more emotional support which is needed to cope with the changes and challenges inherent with transition.

“Other patients can show up to the ED and get treatment in their pajamas. I am feeling my worst, yet I am expected to show up and look presentable, be an advocate for myself, converse normally with my provider.”

Pain Management: The topic of pain was at the forefront for much of the focus group discussions. Chronic pain and/or the management of pain were a focal point for many. Participants shared their ED experiences, including their inability to obtain pain medications, and their lack of access to therapies (i.e., transfusion or infusion) known to ameliorate the associated pain and suffering. A few participants identified a need for day-treatment services as a way to side-step lengthy ED wait times and improve access to needed pain management services.

- Parents of children with SCD had fewer complaints about the ED. Some parents shared their hematologists called ahead to the ED to notify them that the child was enroute. ED staff were waiting for their arrival and the child received prompt and informed care.
- In contrast, adults described sitting in ED waiting rooms for hours before being transitioned back to the exam area.
 - Adult participants described wait times ranging anywhere from five to 12 hours - unbearable for those in the midst of a pain crisis.
 - One person stated if she needs to go to the ED, she goes by ambulance. Arriving by ambulance helps ensure she will receive prompt treatment.
 - Another person confessed she exaggerates her pain to be seen quicker.
- Participants indicated once they were in the exam area, physicians and nursing staff did not seem to know how to treat their SCD condition and participants described the care they received as inadequate.
 - ED physicians questioned patients about their current treatment plan instead of consulting with their hematologist and/or accessing treatment information via the health system's electronic medical record (EMR).
 - Some ED physicians did not respond to patient questions.
 - Several participants were prescribed Tylenol when a stronger pain medication was indicated.
 - ED physicians and nurses didn't seem to understand what biomarkers to review, what the results meant and if they related to the patient's pain or symptoms.
 - Some ED nurses lacked necessary competencies when performing venipunctures and/or phlebotomy procedures. Some participants complained of multiple needle sticks,

- bruising and rolled or blown out veins due to failed attempts by nurses to draw blood and/or start intravenous therapy (IV).
- Some questioned why the nurse opted not to use the port that was already in place for IV medications.
 - Several adult patients felt they were discharged in a rush, without their pain resolved or their questions answered. Of these, some needed to return to the ED soon afterwards.
 - When asked if they received care from urgent care centers, participants responded that urgent care centers were not equipped to handle SCD patients. They could not prescribe pain medications and lacked the medical equipment and training needed to assess their conditions. If a patient with SCD presented at an urgent care center, they would be referred immediately to the ED.
 - Some talked about their need for transfusion services for treatment of vaso-occlusions and/or iron overload. Others were looking for pain clinics, infusion centers or day treatment clinics – places where they could go for treatment instead of the ED. For many, these services were not available in their community.
 - In the case of infusion centers, some indicated that while services may be available, they were only available to oncology patients.
 - Others indicated that in some places where infusion services were available to them, they could only be accessed through the ED.
 - One patient noted they received all their pain medications through palliative care.
 - A few mentioned their doctor suggested medical marijuana.
 - Within the Lansing focus group, MSU's SCD Lifespan Clinic and Sparrow Hospital's ED were both singled out as having made significant improvements to their SCD pain management services to better meet the needs of patients with SCD.
 - Some of the participants, once they received a prescription for opioids/narcotics or other pain medications, reported problems with getting the prescriptions filled.
 - Some participants had to wait for pharmacists to order medications, which caused significant delays – in some cases up to a week or more. One participant wondered why the pharmacist couldn't pre-order her medications, since she always picked them up at the same time each month.
 - One participant talked about waiting for all six of her medications to come in before picking them up because she couldn't afford multiple trips to the pharmacy.
 - One participant indicated that their physician first had them call around to various pharmacies to find one that had the medication in stock before he would send in the prescription.
 - Obtaining compounded medications was difficult for several participants due to the limited number of compounding pharmacies in the state.
 - Those who were able to pick up their medications through the hospital pharmacy had less problems with getting their pain medication in a timely manner.

Patient Advocates:

- PA participants stated, “We know pain gets worse the longer you have pain.”
- PA participants would like to see the drug abuse stigma addressed. They would also like to see the establishment and adoption of a nationwide, standardized set of care protocols for EDs to ensure timely and appropriate treatment during pain crises.
- Finally, they believe that physician education is key to seeing improvements in SCD treatment and pain management.

***“It is expected that I continue to learn about my disease.
I expect providers to learn along the way, too.”***

Suggested Improvements: Access to Quality Health Care

- Participants identified a shortage of physicians and other health care professionals who were trained and knowledgeable about how to care for people with SCD. To remedy this problem, participants recommended:
 - Improvements be made to health professional curriculums so that those entering the fields of medicine, nursing and other ancillary service careers would be more knowledgeable about SCD, including its treatment and care. Educational changes should be structured to include didactic, experiential and on the job learning opportunities for students, interns and/or residents.
 - Additional training should be made available to practicing health care professionals so they can learn more about SCD, how to treat it and its complications, and advancements in care. (i.e., clinical trials, transplantation, cell and gene therapies). Additional training is especially needed for organ failure.
 - Larger health care systems should ensure comprehensive hematology clinics and other related services (i.e., transfusion, infusion, day treatment programs) are available and accessible to people with SCD where they live.
 - EDs should adopt and implement protocols and quality improvement processes designed to reduce time-to-first dose of pain medication; improve ED pain care beyond the first dose of medication; and improve ED patient safety.
 - Additionally, ED staff should receive annual sensitivity training to assist them with improving their communication skills. Some participants also suggested ED staff receive simulation-based training in pain management.
 - Lastly, some participants recommended ED and hospital staff alike utilize ultrasound technology or vein finders to assist with blood draws and/or IV placements.
- Participants called for more supportive services for patients and their families in the forms of community health workers, care coordinators, case managers and other individuals who can assist patients with accessing needed health care, educational, social and community-based services.
- Participants agreed that the health care transition was critical to ensure healthy outcomes in young adults. A smooth transition from pediatric to adult providers can help safeguard young adults from many of the serious challenges they may face (i.e., disease exacerbation and increased health care utilization, personal stressors, less parental protection, insurance

changes and lack of system navigation experience). Participants agreed that a gradual shift in treatment responsibilities was ideal, because it allowed time for the doctor/patient relationship to form. Once a connection is made, participants suggested that adult providers adopt patient-friendly communication methods (i.e., text notifications, appointment reminders, medication check-ins) to maintain relationships with the patients and build their confidence.

- Participants also agreed that health care transition was a process along a continuum by which the adolescents with SCD and their families gained self-management skills and learned to self-advocate. Young adults could benefit from tools and resources designed to help them develop these competencies. One participant suggested developing and distributing a SCD well-being checklist.
- Participants asserted the importance of incorporating patient-centered decision-making and self-determination approaches into clinical practices.
- To further their ability to make treatment decisions, participants recommended that evidence-based research be made available and decision tools be developed that assist patients and families with understanding the pros and cons associated with specific treatment options.
- Participants recommended those with SCT be notified of their condition as they approach adolescence/young adulthood. Also, people with SCD and SCT and their partner should be offered reproductive health counseling so they can make informed decisions about whether they should have children.
- Participants stated their need for more behavioral health services. Those with SCD experience higher rates of depression, anxiety, chronic pain and opioid use, which can put them at higher risk for psychiatric disorders or exacerbate existing psychiatric conditions. Families would also benefit from additional behavioral health supports to assist them.

C. HEALTH INSURANCE BENEFITS

***“It’s a huge deal that if you [can] sign up for CSHCS -
your sickle cell disease will be managed.”***

Insurance Issues: Costs associated with higher rates of ED visits, hospitalizations and ongoing treatments pose economic hardships for those with SCD and their families, reinforcing the need for adequate health insurance coverage. The focus group participants recognized its importance and identified the following issues related to health insurance benefits:

- Participants recognized the importance of health insurance to their family’s overall financial security. A few described accumulating medical debts during times when they lacked health insurance.
- Many participants understood that employment was key to obtaining adequate health insurance coverage. For some of those not employed, finding health insurance coverage was challenging.
- Young adult participants, who were currently covered by their parent’s insurance plan, were unsure on how to obtain their own coverage and where to go for guidance.

- Lansing participants who worked for MSU talked about being able to add a rider to their health insurance policy that provided additional coverage for their sickle cell condition.
- A few participants had applied for Medicaid but were denied because they made slightly more than the income threshold allowed. They currently had no health insurance and had stopped seeing their doctor.
- While many participants had been enrolled in CSHCS as children, not everyone knew about its eligibility expansion for adults ages 26 and older with SCD.
 - Many of those who had heard about the program's expansion had enrolled.
 - Some participants who had never heard about the program were encouraged to enroll by those who had been on the program and understood its benefits.
 - A few misinformed participants thought eligibility was income-based.
- Several participants mentioned problems they encountered when switching health plans.
 - Some participants cited problems getting prior approvals renewed.
 - Others talked about delays they experienced filling or refilling needed medications because of pharmacy benefit confirmation processes; or unanticipated changes in formulary drug lists.
- Participants who were covered by more than one health insurance plan (i.e., had primary, and secondary coverage) experienced coordination of benefit issues.
 - Participants who had employer-based coverage as primary and Medicaid as secondary talked about jumping through additional hoops. If their primary insurance denied coverage for a service, they needed to appeal that decision before Medicaid (i.e., secondary coverage) would pay.
 - One participant, who was dually enrolled in Medicare and Medicaid, experienced a \$240 increase in her monthly medication costs because of Medicare co-pays. When she was only covered by Medicaid, she didn't have co-pays.
- Even for those with insurance, the cost of medication was identified as a barrier to medication adherence because of medication co-pays.
 - Some participants complained that their local pharmacies did not accept their health insurance or passed on high co-pays to the patient.
 - Medication co-payments varied by pharmacy for the same individual and the difference between co-pay amounts was substantial. In one example, the participant stated that the first pharmacy she approached told her that her insurance didn't cover the medication prescribed. They asked for \$160 upfront at pick-up. The second pharmacy she approached had no issues processing the insurance claim and the medication was 100% covered.
 - Some participants described problems in receiving medications in a timely manner through their insurance's mail order pharmacy vendor.
- Non-Emergency Medical Transportation (NEMT) assistance offered through health insurance plans received mixed reviews.
 - Some reported never experiencing transportation issues.
 - Others complained that the insurance's contracted transportation vendors were rude, nasty and late.
 - Lansing participants singled out the Davies' Project as a solid resource for NEMT services.

Patient Advocates:

- PAs stated many PCPs and hematologists do not accept Medicaid. This reduces the number of doctors available to treat those with SCD.
- PAs indicated that loss of coverage was a recurring problem. Sometimes, patients arrived at appointments only to find out they had lost their coverage because they failed to submit updated paperwork during the renewal period; or they didn't understand how to renew their coverage. Because some of these families are transient, they were more likely to forget to update their addresses or phone numbers in the insurance system, meaning they missed renewal correspondence. PAs work to assist these patients in getting their insurance reinstated.

Suggested Improvements: Health Insurance Issues

- Some focus group participants supported universal coverage for all health care.
- Others felt strongly that those enrolled in state insurance programs should never receive a denial for needed services.
- It was suggested by several groups that CSHCS eligibility expansion for adults should be better promoted.
- Some participants agreed that there was a need for more health insurance advocates and/or system navigators. Health insurance advocates can assist by:
 - Reviewing, explaining and correcting medical billing statements.
 - Clarifying insurance benefits and exclusions.
 - Assisting with out-of-network charges.
 - Helping to obtain prior authorizations.
 - Appealing denied claims.
 - Aiding those who have more than one health plan with benefit coordination.
- Some felt that NEMT benefits should offer more accessible and customer-friendly services.

D. HEALTH INEQUITIES

“It’s about equity, equitable care and access to high level of care.”

Health Inequities – Health inequities refer to the differences observed in health status or distribution of health resources between different population groups. Focus group participants cited differences between the care that was available to them compared to the care available to those with other chronic conditions. They also reported experiencing implicit biases when seeking medical care.

- Many participants believe that because SCD is viewed as a Black person’s disease, it has not received the same attention or resources as other chronic conditions, (i.e., cystic fibrosis, cancer). Participants noted the following:
 - Hematologists are not interested in treating those with SCD.
 - SCD participants reported having insufficient access to transfusion, infusion and day treatment services - services they reported as being more available to cancer patients.

- Patients with SCD lacked access to nutrition education programs, something diabetics can readily access.
- Progress in developing disease modifying therapies for SCD has been historically slow.
- Participants stated that funding levels (both federal and foundational) were higher for cystic fibrosis research compared to sickle cell research, even though there are considerably more people diagnosed with SCD.
- When asked if they were treated with dignity and respect by medical professionals, many stated it depended on the situation, the patient and the medical staff involved.
 - Hematology offices were more likely to treat patients with dignity and respect, especially if the patient was a child. Many parents felt listened to and engaged. Some adults reported feeling respected by the hematologist and their clinic staff.
 - Adults seeking pain medications, on the other hand, often felt stigmatized as drug abusers who could not be trusted to truthfully identify their pain levels.
 - Some participants recognized that opioid-dependency can be real for those who suffer from frequent vaso-occlusions.
 - Others disagreed and claimed the number of people with SCD who were addicted to opioids was overstated.
- Focus group participants described ED staff as having become desensitized to their condition.
 - Many participants felt like ED doctors did not listen to them about the severity of their pain. They also felt ignored when they tried to share what medications had worked in the past. Doctors who did not listen were labeled as arrogant and/or non-empathetic.
 - Many participants talked about uncaring nurses, who were demanding and accused them of faking or exaggerating symptoms.
 - Several participants thought that long waits in the ED were associated with staff members' implicit bias which fed into assumptions about drug seeking behavior. This was most true for adult Black males, who reported sitting in EDs up to 14 hours before being seen.
 - One participant indicated she was expected to sign a pain medication agreement, a contract drawn up between the patient and physician to ensure opioid medications were used as prescribed. This participant found the contracting process degrading and reported that the amount of pain medication provided was insufficient.
 - A few participants shared racially motivated comments that had been directed at them:
 - One doctor asked parents, "What were you thinking by having a child with SCD?"
 - Another told a Black woman with SCD she was "smart" for having married a white man.
- As a result of these attitudes, many participants described overcompensating behaviors when presenting at the ED:
 - Mothers at the ED with a child in a pain crisis made sure they were well-dressed and that they communicated in a professional manner. One mother talked about making sure she wore her wedding ring so that the ED staff did not assume she was a single, unemployed Black mother.

- Children were instructed to respond politely to ensure they received appropriate care, regardless of the severity of their pain.
- Many adults felt they were subject to judgements based on looks, income and/or educational attainment. Those who were health professionals themselves made sure ED staff knew they worked in the field.
- For many participants, negative attitudes and interactions from ED staff became a barrier to seeking care. As a result, some delayed treatment until their symptoms became severe and unavoidable, while others chose not to seek care at all—leading to serious health consequences.
- Most participants expressed confusion as to why they received less compassionate care as adults than they had as children - given that pain tends to increase with age. This discrepancy left them feeling baffled.

Patient Advocates:

- PA participants want others to know that people who suffer from SCD often feel devalued, disrespected, misunderstood, overlooked and underfunded.
- To ensure equity, PA participants suggest health care providers operate using a collaborative care approach that fosters open communication with patients and addresses the full scope of their needs. They should promote inclusivity by having open and transparent conversations that culminate in shared decision making; and they should solicit feedback from patients to ensure the information provided is understood.
- PA participants are also working to empower those with SCD to become the type of patient physicians want in their practice. They also want physicians to know that serving those with SCD can be very rewarding, as those patients are very appreciative of providers who truly care for them.

“Lots of layers have to be pulled back and uncovered before change can occur.”

Suggested Improvements: Health Inequities

- Streamlining ED processes by adopting SCD pain management protocols is one approach to improving care quality, customer service and ED wait times for those with SCD. Establishing day-treatment centers, whereby those with SCD can access needed therapies without going through the ED, would be a second approach.
- Ensure hospitals have established SCD pain management protocols in place to guide the treatment of pain crisis episodes.
- While Michigan now requires all licensed health care professionals to complete implicit bias training for initial licensure and renewal, hospitals/EDs are encouraged to implement team-based cultural sensitivity or competency training. Through these trainings, hospitals/ED teams will learn how to effectively communicate with patients (i.e., practice active listening, removing stigmatizing/intrusive language, understanding cultural differences) to better assess and address patient needs.

- Review hospital and ED policies, procedures and processes to ensure they are culturally competent and implement quality improvement initiatives to identify areas of concern or weakness. Make modifications if needed.
- Implement patient experience surveys for those with SCD to determine their satisfaction with the services they received. Implement improvements based upon their feedback.
- Ensure adequate funding is available to support SCD research and advancements in treatment; and to support interventions designed to address the health inequities and disparities experienced by people with SCD and their caregivers.

VII. Conclusions

Through these focus groups, MDHHS has learned much about the lived experiences of Michiganders who have SCD and those who care for them. While the study identified many issues of concern, it also identified concrete actions that, if implemented, can do much to improve the quality of life for focus group participants and the broader communities they represent.

In July, MDHHS will convene a group of stakeholders from across the state for the 2026 SCD Strategic Planning Consensus Summit. Prior to that meeting, stakeholders are encouraged to review the information contained within, as well as other information prepared for the summit. During the summit, stakeholders will select SCD priority areas that are intended to guide state level SCD programming for the next five years. From the priorities selected, MDHHS and its stakeholders will develop the MDHHS 2026 SCD Strategic Plan, a comprehensive public health blueprint for how to best address the needs of individuals (children and adults) with hemoglobinopathies.

MDHHS also plans to share this report broadly with health care providers, school personnel, employers, policy makers, stakeholders and the SCD community. These groups are encouraged to read the report, listen intently to the stories being told and reflect on what role they can play in addressing the concerns expressed.

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