

Issue Analysis:

Hematologist Survey Results & Strategic Planning Priorities for the Michigan Department of Health and Human Services's 2026 Sickle Cell Strategic Plan



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Background

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States and is associated with early mortality and significant morbidity. It primarily affects individuals of African descent, though it also impacts people of Hispanic, Middle Eastern and South Asian ancestry. In Michigan, an estimated 4,000 residents are living with SCD, and approximately 140,000 individuals have sickle cell trait (SCT).

Given the changing landscape and increased attention to SCD across the state, the Michigan Department of Health and Human Services (MDHHS) has determined that updates to its SCD Strategic Plan, originally launched in 2015, are necessary to ensure that its efforts reflect current evidence, best practices and recent lessons learned.

Strategic plan updates are being developed with support from a wide range of stakeholders, institutions, organizations, and communities – all of which continue to be key drivers in expanding SCD care and services across the lifespan in Michigan. Several partner organizations have played important roles in gathering both qualitative and quantitative data that intend to inform strategic priorities moving forward. These efforts include:

- A statewide provider survey launched by Michigan State University's Institute for Health Policy (MSU IHP), targeting hematologists who care for individuals with SCD (detailed in this issue analysis).
- A series of focus groups with patients, caregivers and advocates, hosted and facilitated in collaboration with MSU IHP and the Sickle Cell Disease Association of America – Michigan Chapter (SCDAA-MI).
- A quantitative assessment of the SCD landscape in Michigan, developed by the Susan B. Meister Child Health Evaluation and Research (CHEAR) Center's Michigan Sickle Cell Data Collection (MiSCDC) program.
- A qualitative assessment report led by MDHHS, documenting SCD-related activities and initiatives happening across the state over the past decade.

Together, these components aim to inform the state's updated SCD Strategic Plan – ensuring it builds on past progress, meets current needs and centers the voices of those most impacted.

Purpose

This document presents an issue analysis based on data collected through a statewide survey of practicing hematologists in Michigan. The purpose of the survey was to better understand, from providers' perspectives, the barriers to delivering quality, coordinated and equitable care for individuals with SCD across the lifespan. In addition to identifying care-related challenges, providers were asked to highlight their top priorities for the state to consider as it plans what future initiatives in SCD care, support and infrastructure will look like.

Although the number of survey responses was lower than anticipated, a recognized limitation, the insights gleaned are still valuable. They largely align with findings from other sources, including the patient and caregiver focus groups, the quantitative assessment, and the 2015 strategic plan assessment. MDHHS, in partnership with key stakeholders, provides this analysis as a way to begin aggregating information collected from all sources. It should also serve as a guide for the department's five-year strategic planning initiative aimed at improving health outcomes and quality of life for people living with SCD.

Key Findings from the Hematologist Survey

1) Provider Demographics and Practice Characteristics.

- a) The survey was electronically distributed to 128 hematologists providing care for patients with SCD; 13 responses were received (~10% response rate).
- b) Most responding providers (12 out of 13) were pediatric hematologists; only one respondent reported exclusively treating adults with SCD. This can be seen as a limitation in the scope of this issue analysis.
- c) Practices were geographically distributed across 11 counties, with a concentration in major urban areas.
 - i) According to MiSCDC program data, individuals living with SCD reside in 51 of Michigan's 83 counties. Nearly three out of every five Michiganders with SCD live in Wayne (46.4%), Oakland (9.7%) and Macomb (8.0%) counties. While survey responses were received from providers in Oakland and Wayne counties, there was no participation from providers in Macomb County.
 - ii) It is important to note that providers affiliated with the University of Michigan hospital system were overrepresented in the sample.

2) Clinical Practice and Adherence to Guidelines

- a) The majority of providers follow National Heart, Lung, and Blood Institute (NHLBI) and/or the American Society of Hematology (ASH) guidelines and report routine non-acute follow-up visits.
- b) Hydroxyurea prescribing is widespread, with 92% of responding providers prescribing to both pediatric and adult patients, typically starting between 9 months to 2 years of age, so long as there are no contraindications.
- c) Respondents reported that 51% or more of their patients adhere to hydroxyurea regimens. However, barriers to prescribing hydroxyurea remain, including:
 - i) Parent, family or patient...

- (1) Concerns about risks and/or side effects.
- (2) Concerns about taking too many medications.
- (3) Reporting a lack of time for extra appointments that may be required.
- d) Despite high prescribing rates and reports of patient adherence, MiSCDC program data suggests a gap in the number of prescriptions filled. Only about one in five individuals with SCD (who were consistently enrolled in Medicaid for 12 months) had at least one filled prescription for hydroxyurea.

3) Pain Management and Psychosocial Support

- a) Of all responding providers, 77% create individualized pain management plans (PMPs), but the method of sharing these plans varies:
 - i) 60% use electronic medical record (EMR) only.
 - ii) 30% use EMR and give a hard copy to patient.
 - iii) 10% give a copy only to the patient.
- b) Some hospitals represented in the sample have implemented age-specific, evidence-based pain management protocols for SCD; however, the departments or units where these protocols are implemented vary by site.
 - i) The need for broader implementation of evidence-based pain management protocols is supported by MiSCDC program data, which cites pain as the most common morbidity among people living with SCD.
- c) Non-opioid and non-pharmaceutical pain management strategies appear to be underutilized. While oral hydration, heat application, massage therapy and distraction were the most commonly reported approaches, many other modalities – such as physical or occupational therapy, music, art or drama therapy, relaxation techniques or guided imagery, positioning, and meditation or prayer – were reported less frequently.
 - i) Most responding providers primarily care for pediatric patients, which could limit the types of alternative pain management strategies that are perceived as feasible or age-appropriate for children and young adults. Thus, these alternative strategies could be underreported in the survey data collected.
- d) Behavioral health assessments are routinely conducted, though frequency seemed to differ across reporting providers.

4) Care Coordination

- a) Most practices report having care coordination (CC) or case management (CM) services available for patients and families (85%).
 - i. The most commonly reported CC/CM services include conducting comprehensive assessments of care needs (91%), providing educational materials to patients and families (91%) and referring patients and families to culturally appropriate care and community supports (82%).
 - ii. Less commonly reported CC/CM services include developing a person-centered plan of care (55%), advocating on behalf of the patient or their family (45%) and assigning a case manager to help navigate care (9%).

- b) Teams often included social workers, nurse coordinators and primary hematology staff. However, the inclusion of behavioral health therapists, community health workers, genetic counselors and health educators were less commonly reported across SCD care teams.
- c) Approximately 75% of respondents reported that facilitating patient/family transition from pediatric to adult health care providers is a function of their CC/CM services.
 - i. In partnership with Children’s Special Health Care Services (CSHCS), the department has worked to implement several efforts to improve health care transition, including establishing a permanent transition specialist position, incorporating transition planning into the Maternal Child Health Plan, and requiring Medicaid Health Plans to have approved transition policies.
 - ii. Despite these provider-reported efforts and the work done alongside CSHCS, focus group participants still expressed anxiety about their child leaving the trusted relationship with a pediatric hematologist to establish care with an “unknown” adult hematologist. This suggests that while health care transition support may be available, logistical and emotional concerns seem to remain unaddressed for some families.

Addressing Concerns: Priorities for the Strategic Plan

Survey respondents were asked to identify their top concerns and recommendations for MDHHS, and its stakeholders, to consider as they continue to develop their five-year SCD strategic plan which will be released in September 2025. The responses centered around several recurring themes, touching on systemic, clinical and community-level challenges, as well as posed some potential solutions.

Provider-Related Concerns

One of the most frequently cited concerns was the persistent delay in appropriate treatment and care for patients with SCD when they present to emergency departments (EDs). This is troubling given that MiSCDC program data shows that approximately 50% of individuals with SCD seek care in the emergency department each year, compared to about 30% of individuals without SCD. Provider respondents reported that these delays are driven by a lack of ED provider awareness regarding the unique needs of this patient population, inadequate, institute-specific pain management protocols, and stigma/biases – particularly the ongoing assumption among some ED staff who feel that patients with SCD are drug-seeking. This concern echoed similar feedback gathered during patient and caregiver focus groups, where participants expressed deep frustration with ED care. Many shared that they often delay or avoid seeking emergency care altogether due to anticipated mistreatment or dismissal by hospital staff. In one example, a focus group participant described feeling as though they could not fully take on the role of a patient when seeking care. While others might be able to show up to the hospital and receive the care they need without question, this participant noted feeling like they had to advocate for every aspect of their treatment. They also reflected on the burden of managing providers’ perceptions

during a pain crisis – sharing that even when they were at their worst, they felt pressure to show up as their best self in order to be taken seriously by their care teams.

At the same time, providers recognized that access to alternative treatment settings – such as infusion and day treatment centers – remains limited across Michigan. The lack of such care options forces many patients to rely on the ED for care that could be more comfortably managed elsewhere. One provider noted the need for “*access to infusion centers for rapid hydration*” and the “*establishment of more global (standardized) pain control measures*” both of which could shift the burden away from emergency settings and may improve outcomes.

Patient-Related Concerns

From the perspective of providers, a key concern among patients is a lack of understanding about the seriousness of SCD, its progression and its long-term impacts. However, this concern is somewhat complicated by the fact that many providers (62%) indicated that they use self-developed materials to educate patients – particularly in the context of transitioning from pediatric to adult care. This raises questions about the effectiveness of these resources and whether they are meeting the informational needs of patients and families. One provider noted that simply offering more educational materials is unlikely to solve the underlying issues, stating, “*I think providing more patient and family support would be more helpful than developing educational materials. There are a lot of educational materials available for free, and the greatest need is for case management and care coordination*”. In addition, a responding provider highlighted that low patient health literacy can hinder the aforementioned understanding and adherence, suggesting that well-resourced care coordination teams may be able to help bridge these gaps.

Medication adherence and treatment fatigue were also identified as challenges. This challenge is supported by the earlier reviewed differences in hydroxyurea prescribing and adherence rates. It’s also important to consider how the introduction of new treatments – like cell and gene therapies – might make these issues worse. During stakeholder conversations, many people have pointed out the emotional stress patients face when trying to make big, life-changing treatment decisions. These choices can feel overwhelming, especially when patients don’t have clear information or steady support to help them understand the pros and cons.

Another area of concern centered around missed appointments, which providers attributed, in at least some part, to unreliable or inaccessible transportation.

Community-Related Concerns

At the community level, providers highlighted low public awareness of SCD as a persistent issue. Many noted that stigma and misunderstanding extend beyond the clinical setting, which seems to affect patients in schools, workplaces and other daily environments. During patient and caregiver focus groups, caregivers of school-aged children reported that they frequently have to “handhold” their child’s educators, often serving as the primary source of information about SCD-related needs and accommodations. In one example, a caregiver recalled a time in which an educator gave their child ice packs for joint pain – an

inappropriate treatment choice that is offered to highlight the potential lack of knowledge in the education system. Beyond the classroom, focus group participants also discussed barriers to securing and maintaining employment, and to accessing Family and Medical Leave Act (FMLA) protections, when caring for their child or while they were experiencing a major health crisis. One parent described how they lost their job due to their child's long hospitalizations (i.e., due to having a stroke) and their need to be present at the hospital.

Recommended Priorities for MDHHS

Based on the concerns described above, providers offered several key areas that MDHHS and its partners should prioritize over the next five years.

Access to quality care was cited as a top priority. Providers emphasized the urgent need to expand the number of adult hematology providers and to improve the geographic distribution of SCD care services across the state. Respondents also highlighted persistent territorial tendencies among health care systems that could be creating barriers to coordinated care. While Michigan is home to roughly 600 hematologists/oncologists, only about 30% are treating individuals with SCD, highlighting a shortage in specialized care access for this population.

Improving care in EDs was also identified as essential, particularly through the implementation and consistent use of pain management protocols. Beyond strengthening ED care, providers recommend expanding access to high-quality care through infusion centers, too. One provider punctuated the urgency of this issue by stating: *"We need more doctors and nurses willing and able to care for these complex patients. Build the clinic, then educate medical students and residents and show them the care can be rewarding and effective."* This perspective suggests a potential need for increased funding and incentives to support workforce development.

The second priority posed centers on **care coordination**. Providers advocated for more robust investment in case management and navigation services, including community health workers, health educators and other support roles that can provide equitable wraparound care. These roles were seen as critical for addressing gaps in health literacy, facilitating smoother transitions between pediatric and adult care, and helping families navigate the health care system. While steps are being taken to address care coordination gaps, substantial work remains. With the support of policymakers, MDHHS partnered with the SCDA – MI and Henry Ford Health to establish a Comprehensive Adult Sickle Cell Center. The center aims to reduce disparities by providing accessible and equitable care for all adult patients. MDHHS is eager to see how this initiative will transform the care coordination landscape and quality of care for individuals living with SCD.

Education and awareness emerged as another priority. While some providers cautioned against simply producing more educational materials, there was some agreement that culturally relevant, high-quality and audience-specific resources – particularly for adult patients – are still needed. Efforts to strengthen patient understanding should also include provider education, especially around the realities of SCD in adulthood and how to support patients transitioning out of pediatric systems. Several focus group participants noted that

they were not aware of the expansion of the Children’s Special Health Care Services (CSHCS) program across the lifespan. While MiSCDC program data indicates that CSHCS enrollment among individuals aged 21 and older has increased in recent years, some participants still shared that they were unaware benefits could extend into adulthood or were unclear on how to access those supports. This lack of awareness underscores the need for clearer communication and outreach about available resources and services.

Although approximately 85% of individuals with SCD are enrolled in Michigan Medicaid, respondents indicated **health insurance** is a critical issue to address, citing prior authorization barriers and improved reimbursement for health care systems to make the availability of day hospitals, infusion centers and patient centered medical homes financially viable options. Further learned through focus groups, participants provided varied responses regarding their pharmacy experience, ranging from no issues to experiencing limited medications in stock for prescription refills. Given advances in gene therapy, insurance coverage and medication access/availability, a deeper dive in identifying facilitators and addressing barriers may be needed.

Another recommendation was **better support for behavioral, mental and emotional health**. Respondents emphasized the importance of regularly screening for anxiety or depression and making sure patients can get the help they need (i.e., weaving behavioral health into care coordination systems). Living with a long-term illness like SCD can be very hard, especially when people feel judged or misunderstood. This came up in patient and caregiver focus groups too, where many people talked about feeling stress, sadness or even trauma – not just from the disease itself, but also from how they’ve been treated in the systems of care and society.

Conclusion

This issue analysis provides a snapshot of the current landscape of SCD care in Michigan, based on the surveying of practicing hematologists. While the number of respondents was limited, the findings still point to persistent gaps in access, care coordination, education, and support services that impact both patients and providers. At the same time, they highlight clear opportunities for strengthening the system – such as expanding provider capacity and care team networks, enhancing behavioral health support, and increasing targeted engagement and education for providers, patients and the community at-large. As MDHHS and its partners continue to shape the next five-year SCD strategic plan, this issue analysis is intended to guide meaningful dialogue and inform initiatives to better support individuals living with SCD and their families across the lifespan.