



# Public Health Strategic Plan 2.0 to Address Sickle Cell Disease Across the Lifespan

Fiscal Years 2026 - 2030

## **Authorship**

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## Foundations

**Vision:** In Michigan, people living with sickle cell conditions and their families are heard, valued and have access to optimized unbiased health care and supportive services.

**Mission:** We aim to leverage the lived experience of people with sickle cell conditions, combining the latest science and standards of care, to inform policy, increase knowledge, promote understanding and strengthen systems.

**Values:** Human Dignity, Person-centered, Innovation, and Goal Focused.

## Table of Acronyms

Acute Chest Syndrome	ACS
Center of Excellence	CoE
U.S. Centers for Disease Control and Prevention	CDC
Susan B. Meister Child Health Evaluation and Research Center	CHEAR
Children’s Special Health Care Services	CSHCS
Children’s Hospital of Michigan	CHM
Cell and Gene Therapies	CGT
Centers for Medicare and Medicaid Innovation	CMMI
Detroit Medical Center	DMC
Division of Immunizations	DOI
Emergency Department	ED
Family Medical Leave Act	FMLA
U.S. Federal Drug Administration	FDA
Health Status Assessments	HSA
Hemoglobin	Hgb
Hemoglobinopathy Quality Improvement Committee	HemQIC
Hemoglobinopathy Quality Improvement Program	HemQIP
Henry Ford Health	HFH
Lifecourse Epidemiology & Genomics Division	LEGD
Medicaid Health Plans	MHPs
Michigan Developmental Disabilities Council	MiDDC

Michigan Department of Education	MDE
Michigan Department of Health & Human Services	MDHHS
Michigan Public Health Institute	MPHI
Michigan Rehabilitation Services	MRS
Michigan Sickle Cell Data Collection Program	MiSCDC
Michigan State University's Institute for Health Policy	MSU-IHP
National Heart, Lung, Blood Institute	NHLBI
Newborn Screening	NBS
Non-Emergency Medical Transportation	NEMT
Pediatric Sickle Cell Improvement Program	P-SCIP
Public Health Genomics	PHG
Red Blood Cells	RBCs
Registry and Surveillance for Hemoglobinopathy	RuSH
Sickle Cell Clinic Expansion and Enhancement	SCCEE
Sickle Cell Disease	SCD
Sickle Cell Disease Association of America - Michigan Chapter	SCDAA-MI
Sickle Cell Trait	SCT
Standards of Care	SOC
University of Michigan	UM
Vaso-Occlusive Crisis	VOC

## Executive Summary

Sickle cell disease (SCD) is an inherited disorder of the hemoglobin (Hgb). It is one of the most prevalent genetic disorders in Michigan and has a dramatic impact on the lives of approximately 4,000<sup>1</sup> residents diagnosed with the condition and their families. SCD represents significant public health concerns due to its high disease prevalence, elevated rates of morbidity and mortality, and the disproportionate impact on the health of affected populations. This **Public Health Strategic Plan 2.0 to Address Sickle Cell Disease Across the Lifespan Fiscal Years (FY) 2026-2030**, developed by the Michigan Department of Health and Human Services (MDHHS), continues to build upon the work accomplished in the landmark plan, [Public Health Strategic Plan to Address Sickle Cell Disease Across the Lifespan 2015-2018](#), released in October 2015.

The Department's first-ever SCD strategic plan (2015-2018), set the goals for a decade-long implementation. Initial activities conducted during the plan's original timeframe became the framework for additional activities. Federal grants, legislative allocations and opportunities to obtain Medicaid matching funds for specific projects supported the evolution of multiple initiatives. These efforts were also driven by increasing public awareness of health disparities and inequities that were highlighted during the COVID-19 pandemic. Given the increased attention placed on the health concerns of communities that have been marginalized, SCD activities were designated as a core operational process under the "Public Health Investment" domain of the [2023-2027 MDHHS Strategic Plan](#).

This 2026-2030 SCD Strategic Plan recommends a framework based on the findings of a multi-pronged needs assessment process conducted from June 2024 through May 2025 by the Lifecourse Epidemiology & Genomics Division (LEGD) within MDHHS. LEGD provided the staff and support needed to accomplish this strategic planning project, with contracted assistance from Michigan State University's Institute for Health Policy (MSU-IHP) and the Michigan Public Health Institute's (MPHI) Center for Healthy Communities. This plan provides a set of public health interventions to reduce the burden of SCD in the state by increasing education and awareness, improving access to high-quality health care and disease-modifying therapies, and strengthening public health surveillance.

MDHHS held a Consensus Summit in July 2025 during which the strategic planning team, in collaboration with community partners, identified and prioritized six goals described below. The summit provided a structured decision-making process to identify and rank key issues, strategies, tactics and themes through group consensus. The goals and objectives, which will be described in greater detail later in this report, were designed to promote the integration and expansion of SCD services and resources, while also highlighting the importance of improving patient clinical experiences.

## **Six Goals of the 2026 Strategic Plan**

1. Implement system changes that center the needs of the SCD community through a collaborative approach.
2. Ensure access to quality, integrated sickle cell treatment and support services statewide.
3. Utilize standards of care and implement protocols that improve patient outcomes.
4. Improve prescription of and adherence to disease-modifying therapies.
5. Provide continuous education to increase awareness of information, best practices, and resources for SCD across the state and for priority groups (i.e., people with SCD and their caregivers, health professionals, general public, schools and employers).
6. Establish and track metrics to improve health-related outcomes.

## Acknowledgements

Contributors to 2026 SCD Strategic Planning process include those listed below. A special acknowledgement and heartfelt thank you are extended to everyone - those living with SCD, caregivers, focus group participants, hematologists, pediatricians, workgroup members, advisory committee members, reviewers, and staff, who gave their time and insight to shape this plan over the course of many months. We hope that this plan reflects your experiences and your vision for meaningful improvements.

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## Background Information on Sickle Cell Disease and Sickle Cell Trait

SCD is an inherited disorder that affects the formation of hemoglobin (Hgb), the protein in red blood cells that carries oxygen. The red blood cells (RBCs) become hard, sticky and shaped like a farmer's sickle or a crescent. These sickled cells are less flexible and can block blood vessels, reducing the flow of blood and oxygen. Additionally, these abnormal cells break down more rapidly than normal RBCs, which can lead to a low blood cell count (anemia) and organ damage. SCD primarily affects individuals of African descent, but it is also present in populations from the Mediterranean, Middle East, and parts of Asia.

Statewide, approximately 4,000 Michigan residents live with SCD.<sup>1</sup> The Newborn Screening (NBS) program identifies approximately 62 newborns with hemoglobinopathies per year, and an additional 2,800 infants are born with sickle cell trait (SCT) — having one copy of the sickle cell gene.<sup>2</sup>

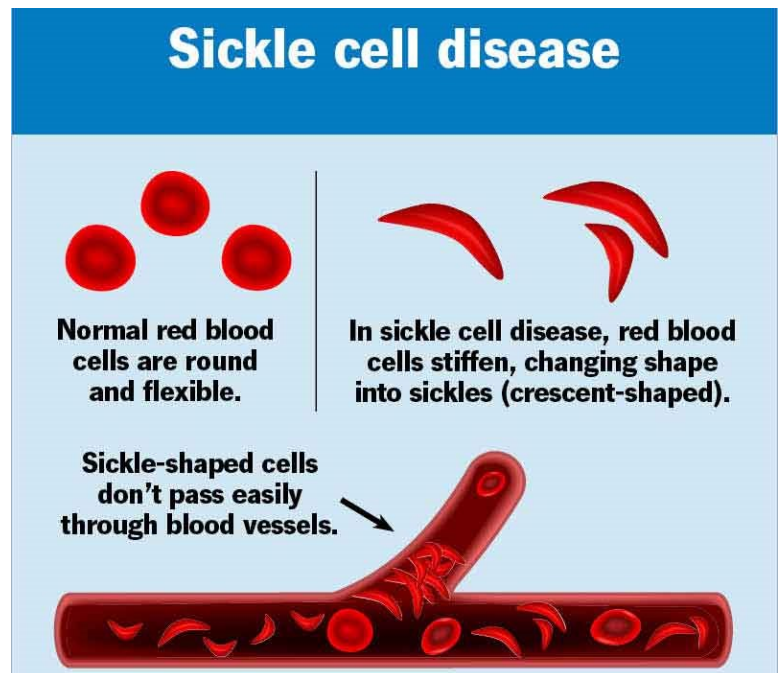
### Complications of Sickle Cell Disease

The hallmark symptom of SCD is sickle cell crisis (vaso-occlusive crisis or VOC), which causes sudden attacks of severe pain. An infection or blockage of blood vessels in the lungs can lead to acute chest syndrome (ACS), another common and serious occurrence.<sup>3</sup> The abnormal shape of RBCs found in patients with SCD contributes to co-morbidities throughout the lifespan including pneumococcal infections and acute spleen sequestrations in infants, pulmonary hypertension, stroke, gallbladder disease, and organ damage. SCD is also associated with premature mortality.<sup>4</sup>

### Sickle Cell Trait

People with SCT can pass the sickle cell gene to their children. However, having the trait is different from having SCD. SCT affects 1 in 13 non-Hispanic Black or African Americans in the United States (U.S.)<sup>5</sup> and occurs when a person inherits a sickle cell gene from just one parent. SCT and SCD inheritance are as follows:<sup>6</sup>

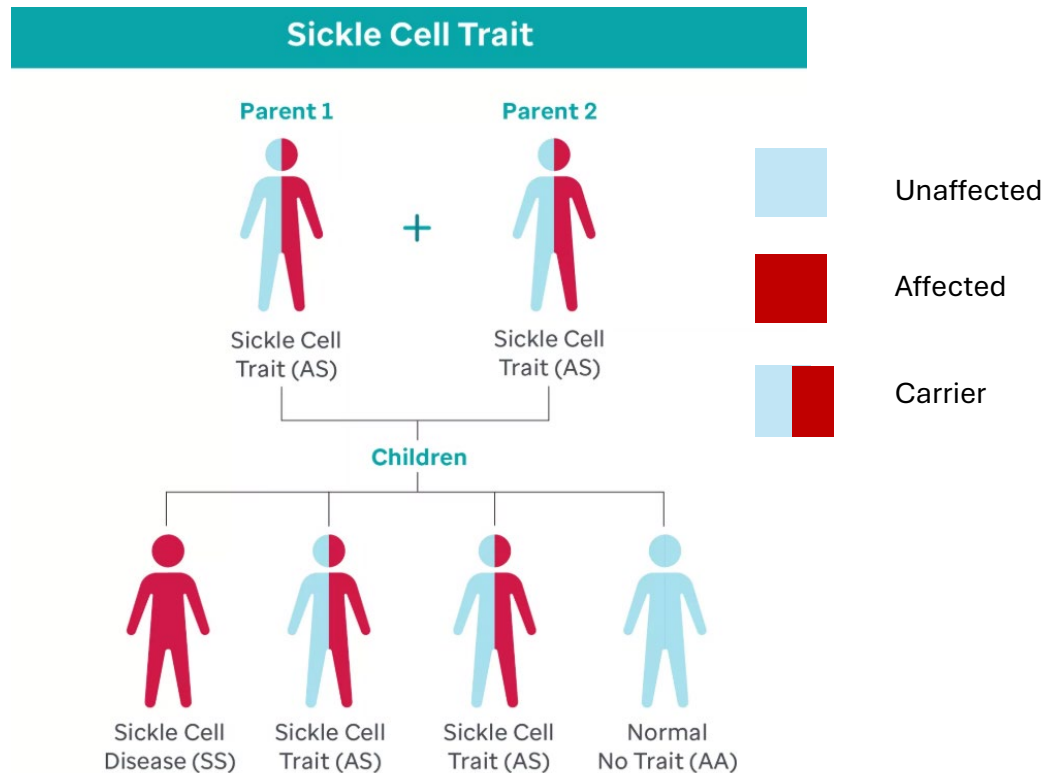
- If both parents have SCT, there is a 50% (1 in 2) chance that any child of theirs will have SCT, if the child inherits the sickle cell gene from one of the parents. These children will not have symptoms of SCD, but they can pass SCT on to their children.



Source: <https://my.clevelandclinic.org/health/diseases/12100-sickle-cell-disease>

- If both parents have SCT, there is a 25% (1 in 4) chance that any child of theirs will have SCD. There is the same 25% (1 in 4) chance that the child will not have SCD or SCT.
- If one parent has SCT, there is a 50% (1 in 2) chance that any child of this parent will have SCT and an equal 50% chance that the child will not have SCT.

In rare cases, environmental conditions — such as low oxygen levels in the atmosphere (<21%) or dehydration — can cause some people with SCT to experience complications, such as pain crises. Additionally, there are a few rare health problems that may affect people with SCT.



Source: <https://together.stjude.org/en-us/medical-care/inherited-risk-genetic-testing/sickle-cell-trait.html>

## **2015-2018 Sickle Cell Strategic Plan Background and Accomplishments**

The LEGD within MDHHS initiated a SCD strategic planning session in 2014. Based upon a comprehensive assessment, the planning process engaged a wide range of partners, including state employees, health care professionals, allied health workers, community-based service representatives, and those with SCD and members of their support system. The process also included a prioritization session and the formation of workgroups, which identified a set of goals, strategies, and tactics to improve and advance awareness, treatment and care of patients with SCD in Michigan. From this work, the [\*\*Public Health Strategic Plan to Address Sickle Cell Disease Across the Lifespan 2015-2018\*\*](#) was developed and released in October 2015.

The overall goal of the plan was to implement public health interventions to reduce the burden of SCD in Michigan through improved awareness, comprehensive transitional care programs, and increased use of community mental health and behavioral health services. Although the Department's first-ever SCD strategic plan was originally intended to span 2015–2018, it ultimately evolved into a decade-long endeavor. Initial activities implemented during the plan's original timeframe became building blocks for additional activities. Federal grants, legislative allocations and opportunities to obtain Medicaid matching funds for specific projects supported the evolution of multiple initiatives.

Additionally, growing concerns about health disparities and inequities — brought to the forefront during the COVID-19 pandemic — also helped fuel these efforts. In response to the increased attention on the health needs of underrepresented populations, SCD activities were designated as a core operational process within the **“Public Health Investment”** domain of the **2023–2027 MDHHS Strategic Plan**.

Since 2015, MDHHS has made progress in improving both the care and treatment for those with SCD including:

- Using the 2015 Registry and Surveillance for Hemoglobinopathy (RuSH) report as a basis for ongoing surveillance work, MDHHS and the [\*\*Susan B. Meister Child Health Evaluation and Research Center\*\*](#) (CHEAR) secured additional U.S. Centers of Disease Control and Prevention (CDC) funding to establish the Michigan Sickle Cell Data Collection (MiSCDC) program.
- Within MDHHS, Children's Special Health Care Services (CSHCS) and Public Health Genomics (PHG) secured legislative support to add SCD to the list of eligible diagnoses included by CSHCS for benefit coverage across the lifespan. As a result of their joint proposal, an additional \$6.65 million in ongoing funding was allocated in FY 22 to expand CSHCS age eligibility through adulthood for those with SCD. A portion of these funds were designated to support the expansion and enhancement of SCD clinics within the state to improve access to affordable SCD-specific care.

- The 2022 and 2023 budgets allocated a total of \$5 million to the Sickle Cell Disease Association of America–Michigan Chapter (SCDAA-MI) to support developing a SCD Center of Excellence (CoE) within the City of Detroit. With those funds, SCDAA-MI formed a partnership with Henry Ford Health (HFH), to establish the Henry Ford Comprehensive Adult Sickle Cell Center. The specialty center features a dedicated multidisciplinary team who work with patients to treat their SCD condition, focusing on the whole individual and working to improve both health outcomes and satisfaction. The center offers state-of-the-art care and treatment, including a comprehensive pain clinic, outpatient acute pain management and access to cutting-edge treatments. The center, with its goal of serving 850 patients with SCD in the next five years, serves as a hub for a growing system of hospitals located in the metro Detroit area and across the state. Oversight of this initiative is provided by the Michigan Coronavirus Task Force on Racial Disparities.
- MDHHS’s Medicaid program implemented a Pediatric Sickle Cell Quality Improvement (P-SCIP) program through the Medicaid Health Plans (MHPs) beginning in FY 2021. Through this program, the eight MHPs that serve Macomb, Oakland and Wayne counties received incentives to improve performance for pediatric patients with SCD. The project currently focuses on improved antibiotic prophylaxis and hydroxyurea utilization and transcranial doppler screenings. The program, now entering its fifth year, has produced promising results. Some of these results include a roughly 30% increase in annual transcranial dopplers (TCD) screenings, elimination of prior authorizations for hydroxyurea (Siklos and Xromi brands), a 16% increase in 300 days of dispensed antibiotics and a 3% increase in 300 days of dispensed hydroxyurea between December 2020 and December 2024. The program is planning to expand to all MHPs serving clients throughout the state of Michigan in the future.
- MDHHS’s Medicaid program has joined with 33 other states to participate in the Centers for Medicare and Medicaid Innovation’s (CMMI) Cell and Gene Therapy (CGT) Access Model. The model improves access to gene therapy treatments for those who are Medicaid eligible and living with SCD. In December 2023, the U.S. Food and Drug Administration (FDA) approved two new gene therapies for the treatment of SCD in patients 12 years and older: Casgevy and Lyfgenia. Both therapies offer one-time needed treatment that genetically modifies the patient’s own blood cells, remediating some of the disease’s devastating outcomes. Michigan’s participation in the program began Jan. 1, 2026 and MDHHS estimates it will receive ten prior authorization requests for these gene therapies from Medicaid beneficiaries who meet the program’s coverage criteria each year.

## Capturing the Voices of Warriors, Caregivers and Advocates: Challenges of Sickle Cell Disease

To truly understand the challenges that people with SCD continue to face, MDHHS and its partners held focus group discussions with people with SCD and their caregivers. The full report is accessible here: [2026 Focus Group Report](#). According to focus group participants, for many who have SCD, day-to-day life is often filled with excruciating pain, time-consuming trips to the ED, stigmatization as “drug seekers,” and a decreased quality of life. This SCD strategic plan addresses these challenges by targeting gaps identified by patients, families, advocacy organizations, health care providers, public health practitioners, and others involved in providing services to individuals with SCD or SCT.

SCD affects all aspects of life for people living with the disease. The debilitating symptoms and complex treatment regimens can limit one’s ability to perform well in school, pursue careers, have a family, and maintain relationships. The disease takes an emotional toll as patients face challenges with the health care system, stigma within society, financial hardships, and worries about the future. Complications of SCD include daily fatigue and decreased cognitive functions, increased risk of disabilities (due to stroke, etc.), as well as long-term, progressive physical, mental and emotional damage.

The difficulties in effectively managing SCD extend far beyond having access to medical treatments. Focus group findings indicate that patients frequently experience challenges navigating the health care system, interacting with health care professionals, accessing treatment, having their symptoms taken seriously and obtaining needed accommodations within their schools and workplaces. Focus group participants identified the following concerns to address challenges over the next five years:

### Education and Awareness

- Lack of general education about the disease.
- Lack of nutrition education and information on how to live an active life.
- Difficulty in identifying trustworthy sources for SCD treatment, self-management and disease progression information.
- Lack of knowledge about community-based resources and referral information, such as:
  - Educational materials to share with school personnel and employers.

*“Sickle cell disease is all encompassing. Everything that I do the thought of sickle cell is attached to it.”*

Focus group participant  
- Lansing

- Information about accommodations for people with SCD at school and/or work that is provided by law.
- Age-appropriate educational materials for children.
- Peer support services.

### **Access to Quality Health Care**

- Lack of knowledgeable providers — especially providers for adults — that are interested in treating those with SCD.
- Lack of care coordination services, especially for adults with SCD.
- Difficulties getting appropriate pain medications when needed.
- Fragmented health care — characterized by poor care coordination and ineffective communication among providers.
- Ineffective health care transition from pediatric to adult services.
- Lack of training in patient centered care and communication across social contexts in emergency departments (EDs) and hospitals.

### **Health Insurance**

- Lack of knowledge concerning eligibility and benefits associated with CSHCS coverage.
- Difficulties in obtaining insurance coverage while unemployed and/or when a person doesn't qualify for Medicaid.
- Unaware of where to obtain health insurance advocacy assistance.
- Inability to navigate prior authorizations and drug formulary issues.

*“Biggest complaint is not being treated with dignity.”*

Focus group participant

-Grand Rapids

Foundational to these issues are the lived experiences of those with SCD who have endured unfair treatment because of their diagnosis. Both participants and patient advocates spoke at length about the persistent stigma faced by those with SCD, particularly the harmful perception of them as drug seekers. This stereotype left many feeling devalued, disrespected and misunderstood.

## The Story of the Data: Sickle Cell Surveillance in Michigan

The Michigan Sickle Cell Data Collection (MiSCDC) program — launched in October 2020 — is a collaborative effort between the CHEAR Center at the University of Michigan (UM) and MDHHS to address knowledge gaps in SCD diagnosis and treatment. Funded by the CDC, Michigan is one of 16 states participating in a national initiative that collects population-based data such as where individuals with SCD live and how they use health care services over time.

To support the development of the SCD Strategic Plan, the MiSCDC program, with assistance from MDHHS staff, prepared the [Quantitative Report of SCD in Michigan](#). Data for the report comes from the *MiSCDC* program's longitudinal, population-based public health surveillance system and leverages multiple data sources to identify individuals with SCD in Michigan and to assess their health care use over time.

### Data findings from 1988-2022<sup>7</sup>

From 1988-2022, a total of 2,285 infants born in Michigan were confirmed through the NBS program to have SCD. Among the confirmed SCD births, 56.4% had sickle cell anemia, 33.2% had Hemoglobin SC disease and 9.8% had sickle beta thalassemia.

### Select findings from 2018-2022

- The average annual population of people with SCD in Michigan was 3,966. During 2022, three out of every five Michigan residents with SCD resided in Wayne (46.4%), Oakland (9.7%), and Macomb (8%) counties; 51 out of 84 counties were home to someone living with SCD.
- On average, people with SCD were 49.3 years when they died (46.2 years for men and 51.7 years for women). The **crude mortality rate**, which measures the total number of deaths in a population without adjusting for age or other factors, was substantially higher among people with SCD. During 2022, the crude mortality rate for people with SCD was **1.8 times higher than Michigan's general population** and **1.7 times higher than Michigan's Black population**, indicating a greater overall risk of death.
- Over half of people with SCD had at least one ED visit per year, averaging 2.6 ED visits per person across all ages. People with SCD aged 30-39 years had the highest number and average of ED visits per person. In comparison, the average number of ED visits among the U.S. population aged 18-44 was 0.4 ED treat-and-release visits per person in 2022.
- The proportion of individuals with SCD enrolled in any Medicaid program was approximately 85%, with half enrolled in a full coverage plan for 12 months.
- Approximately three out of five people with SCD did not have a hematologist visit within a year. It is recommended that those with SCD should have at least one visit with a

hematologist every year; two or more hematology visits in a year have been associated with higher uptakes of life-saving preventive services.

- Among children with SCD, completion of the primary immunization series was over 80%, higher than the overall population average. However, rates of influenza and COVID-19 immunization among people with SCD were substantially lower compared to the overall population.
- Approximately one in five individuals with sickle cell disease had at least one filled prescription for hydroxyurea. Among those with at least one filled prescription, the quantity dispensed, on average, was sufficient to cover half of the year. Less than 5% of people with SCD received any new disease-modifying medications (Endari, Oxbryta, Adakveo).
- Most children with SCD had at least one filled prescription for antibiotics within the year. The proportion of children that did not have any antibiotic prescriptions filled varied from 10% to 15.9% between 2018 and 2022.
- Less than half of children with SCD received a transcranial doppler screening annually.

## **2026 Strategic Plan: Purpose and Process**

Given the changing environment and growing attention placed on SCD by researchers, policy makers, advocacy groups, and community partners, MDHHS determined that updates to its existing SCD Strategic Plan were necessary. The 2026 plan aims to build on partnerships and make the most of federal funding by aligning efforts across priority areas. These approaches are deemed essential in assuring resources are used effectively and strategic goals are achieved. The 2026 planning process included two phases: assessment and plan development.

### **Assessment**

Conducting a community needs assessment was the first phase in the SCD strategic planning process. Through the needs assessment, community partners learned about SCD initiatives, including Michigan's past efforts, current landscape and future direction. Additionally, the needs assessment helped to identify key resources, as well as gaps and/or barriers that must be addressed. Finally, the assessment provided the foundation for the objectives, benchmarks, outcomes, and other indicators necessary for measuring change over time which will be included in the evaluation plan. The SCD needs assessment involved the collection, analyses and review of both quantitative and qualitative data. For the SCD Strategic Planning update, reports, documents and presentations were developed and considered.

- A. [\*\*\*Quantitative Report of SCD in Michigan – A Report from the MiSCDC program.\*\*\*](#) This report, developed by the MiSCDC program, provides statistical data about people living with SCD, including detailed demographic, health status, and health care use data.
- B. [\*\*\*Focus Group Report – the 2026 SCD Strategic Plan.\*\*\*](#) This report contains synthesized information collected during six focus groups. Five of the focus groups, which included people with SCD, and their parents and caregivers, were conducted in-person in Detroit, Benton Harbor, Grand Rapids, Lansing and Saginaw. A sixth, virtual focus group, included patient advocates that work directly with these groups. Combined, these focus groups captured the views and practices of populations affected by SCD and identified strategies to improve SCD/SCT programming for people of all ages. Participants responded to an agreed upon set of questions that were designed to gather concerns, perceptions and their lived experience in accessing health care, using health insurance, and obtaining health information and medications. Additionally, the focus groups highlighted the impact that social drivers of health (SDoH) have on those living with sickle cell conditions as they care for themselves and their families.
- C. [\*\*\*MDHHS 2025 Hematology Survey Results Issue Analysis.\*\*\*](#) This analysis provides data collected through a survey sent to practicing hematologists in Michigan who serve SCD patients. The purpose of the survey was to better understand, from the providers' perspectives, the barriers to delivering quality, coordinated and equitable care for those

with SCD. In addition to identifying care-related challenges, providers were asked to highlight their top priorities for consideration by the state when planning future initiatives for SCD care, support and infrastructure. Although the survey response rate was lower than anticipated — a limitation that affects its overall usefulness — the insights gathered are still valuable and align with findings from other reports, including the patient and caregiver focus groups, the quantitative assessment and the 2015-2018 Assessment report.

**D. [Assessment Report: 2015-2018 Public Health Strategic Plan to Address SCD Across the Lifespan](#).**

This report provides an overview of a decade’s worth of collaborative public health work achieved by a broad-based group of community partners who worked to improve the health outcomes of those living with SCD in Michigan and the systems of care that serve them. Using the CDC’s 10 Essential Services framework, the report identifies 187 activities that have been completed since the initial plan was released. Some of these activities represent large endeavors, such as establishing a Center of Excellence and the age-expansion of CSHCS across the life span for those with SCD. Others, while smaller (i.e., the creation of a handout or toolkit), have addressed a specific, identified need. Each of these efforts have helped Michigan move upstream as community partners work to address systemic and structural barriers to health and health equity, and downstream to meet urgent needs and alleviate disparities associated with SCD. Collectively, the report serves as an environmental scan to help community partners understand the broader landscape that could impact long-term success.

**E. Other Informational Sources.** In addition to these four comprehensive documents, two other informational pieces were reviewed:

1. **A Qualitative Exploration of Prenatal Care for Individuals Living with SCD.** This 2025 Northwest University graduate student project sought to understand the psychosocial impact of high-risk pregnancy and SCD-related prenatal care on people living with SCD in the Midwest. The aims of this study were:
  - a. Describe experiences with SCD-specific prenatal care, given the complex needs of people living with SCD who are carrying pregnancies; and
  - b. Identify the barriers and facilitators to SCD-specific prenatal care according to recommended guidelines.
2. **Medicaid’s New Gene Therapy Model for Patients with SCD: Understanding the Centers for Medicare & Medicaid Services (CMS) Cell & Gene Therapy Access Model.** This presentation provides a high-level overview of the new CMS Access Model available to eligible Medicaid enrollees who have SCD. It answers key questions about what cell and gene therapies are covered by Medicaid, their benefits for patients, which facilities are participating in the model, and where to go for additional information.

## Plan Development

Once the assessment phase was completed, the plan development phase was initiated. MDHHS convened two separate community partner meetings, facilitated by MPHI, to develop key components of the plan.

A. **Vision/Mission/Values:** The SCD Strategic Planning Executive Committee, a group of internal and external partners who provided oversight for the entire process, met to develop a shared mission, vision and values statement. As a result of their efforts, group consensus was reached on the following:

1. **Vision** – A vision statement represents a picture of the ideal condition as it relates to SCD in Michigan. It is a short, unifying statement that reminds the people of the efforts they are striving to accomplish and helps to guide important decisions. The following vision statement was developed:

### **SCD 2026 Strategic Plan Shared Vision Statement:**

**In Michigan, people living with sickle cell conditions and their families are heard, valued and have access to optimized, unbiased health care and supportive services.**

2. **Mission** – The mission statement is more specific than the vision statement. It expresses the "what and how" of the SCD efforts, describing what needs to happen to make the shared vision a reality. While the vision statement inspires people to dream, the mission statement should inspire them to take action. The following mission statement was developed:

### **SCD 2026 Strategic Plan Shared Mission Statement:**

**We aim to leverage the lived experience of people with sickle cell conditions, combining the latest science and standards of care, to inform policy, increase knowledge, promote understanding and strengthen systems.**

3. **Values** – The values reflect core principles and/or philosophical ideals that are used to both inform and guide the decisions and behaviors of the planning team and others associated with the plan's development and implementation. The following four values were identified and adopted:

### **SCD 2026 Strategic Plan Shared Value Statements:**

- **Human Dignity – Unbiased, compassionate, respectful, and equitable care and support.**
- **Person-centered – Empowered self-advocacy that focuses on the values, needs and preferences of each individual.**

- **Innovation – Leverage science and best practices to improve accessibility and transform service delivery.**
- **Goal Focused – Actions that are accountable and transparent, driven by data and are sustainable over time.**

B. **Strength, Opportunities, Weaknesses and Challenges (SWOC) Analysis.** Upon completion of the vision, mission and values statement, MDHHS staff met to review the various reports and to conduct a SWOC analysis. During the SWOC analysis, staff explored internal and external factors, including organizational capabilities and known barriers. They also reviewed potential opportunities and expected challenges — all of which were documented and provided, along with copies of the assessment reports and summary information — to community partners in preparation of the Consensus Summit.

C. **Consensus Summit.** On July 14, 2025, MDHHS virtually convened a group of 39 SCD community partners to select the 2026 SCD Strategic Plan priorities. Prior to the meeting, registered participants were asked to review the assessment reports described above, which were provided in three different formats: full report, report brief, or recorded presentation. Participants were instructed to choose from the available formats and thoroughly review the materials provided. Completing this “pre-work” ensured a consistent baseline of foundational knowledge among all attendees prior to the summit. Trained facilitators from the Michigan Public Health Institute (MPHI) led the group through a series of discussions, using a nominal group technique. The group identified several priorities during the time allotted, which were then synthesized and condensed into six goal areas. These statements were shared with participants, who were then asked to provide additional comments.

## 2026 Strategic Plan Goals

The Consensus Summit offered key community partners from across the state an opportunity to reflect on the findings of the SCD Strategic Planning Assessment and the information provided in its reports. Using this information, participants were asked to brainstorm innovative and substantial actions that could be implemented to fulfill and achieve the group’s shared mission, vision and values. Upon conclusion of the meeting, six goals were identified.

1. **Implement system changes that center the needs of the SCD community through a collaborative approach.** Throughout the assessment phase of the SCD strategic planning process, a very crucial part was listening to the voices of people living with SCD and their family members. Summit participants agreed that this was a strength of the planning process, and it should be foundational to the evolving work ahead. While there are many approaches that could be used to center the needs of the SCD community, consensus participants identified the following:

- Ensure that care planning is individualized, and reflects the needs, values and preferences of those receiving care.
- Promote participatory decision-making and informed consent.
- Sponsor health professional trainings that enhance professional competency skills and focus on the lived experiences of patients.
- Encourage the inclusion of those with SCD when providing peer support services and/or as board members for policy/advisory groups.

*“Whatever bias or stigma you have – that’s fine – but I did not choose this for me so now we are here and let’s figure this out.”*

Focus group participant  
- Lansing

2. **Ensure access to quality, integrated sickle cell treatment and support services statewide.** Summit participants, cognizant of CSHCS age-eligibility expansion, and the potential impact associated with federal Medicaid changes due to the passage of H.R. 1 of 2025, agreed that adequacy of health insurance was an important access to care issue that must continue to be addressed in the 2026 SCD Strategic Plan.

They also identified a lack of providers willing and able to treat patients with SCD as a significant factor contributing to “health care deserts” (i.e., areas where services are not available) within certain areas of the state. For some adults with SCD, the lack of access to providers has led to ED overutilization as they attempt to manage complications of their disease. Unfortunately, the lack of continuity in care received in the ED contributes to diminished health outcomes. To address these issues, participants identified the need for

improvements in the following areas: integration of primary and specialty services, as well as access to infusion and/or, day treatment centers, non-emergency medical transportation (NEMT), and behavioral health services.

- 3. Utilize standards of care (SOCs) and implement protocols that improve patient outcomes.** The adoption and implementation of SCD SOCs and clinical protocols are key for operationalizing evidence-based medicine and transforming health care. SCD-specific SOCs and protocols help to ensure consistent management of acute and chronic complications; reduce disparities in care; improve health status outcomes; and support the use of known prevention and early intervention strategies.

Consensus participants discussed the need to improve both ED and hospital responses for vaso-occlusive crisis (VOC) management, including waiting time for evaluation, pain medication administration, and discharges/admissions. They also identified the need for individual pain management plans that are accessible by patients, caregivers and medical providers both within and across health care systems. They recognized the importance of broad-based collaborations, which include patients, providers, hospitals and health plans, who join to implement quality improvement initiatives that monitor results, incorporate feedback and/or incentivize providers for improving outcomes.

- 4. Improve prescription of and adherence to disease-modifying therapies.** Consensus participants acknowledged that there have been some advances in the treatment for SCD during the past 40 years, including the use of hydroxyurea to reduce pain crisis. Since then, more disease-modifying therapies have emerged (i.e., Endari, Oxbryta, Adekveo (crizanlizumab). Additionally, curative and genetic therapies have also been identified, such as allogeneic stem cell transplant and the newly FDA approved Casgevy and Lyfgenia medications. Whether used alone or in combination, these therapies can help to reduce the frequency of pain crisis, mitigate anemia, protect vital organs, and potentially increase years of life.

Despite these advances, many people with SCD may be uninformed, unable to access and/or do not follow medication protocols. Consensus summit participants agreed that the SCD strategic plan should focus its efforts to ensure that people with SCD have the information they need about disease-modifying therapies, so they can make informed choices about which ones to consider and how to use them effectively. In addition, they expressed the need to ensure that the processes for obtaining therapies should be sufficiently flexible, locally available, affordable and readily accessible for those who are eligible.

*“No care in the health care system for SCD.”*  
Focus Group Participant  
-Grand Rapids

5. **Provide continuous education to increase awareness of information, best practices and resources for sickle cell disease across the state and for priority groups.**

Consensus participants agreed that continuous education is essential for system change and health improvement. Through education, individuals can be empowered to self-manage their condition and adhere to treatment protocols; the stigma associated with SCD can be reduced and replaced with knowledge and understanding; and quality health care can be achieved.

Participants understood that education and awareness must encompass many different modalities, including interactive and digital tools, social media, and traditional print and visual media. They also understood that to be impactful, messages must be designed to target specific groups, such as individuals with SCD and/or SCT, parents/caregivers, school personnel, employers, health professionals, policy makers and the public. Additionally, consensus participants recommended that the strategic plan incorporate the use of technology in its educational programming to maximize effectiveness and streamline its delivery in transformative ways.

6. **Establish and track metrics to improve health-related outcomes.** Consensus participants appreciated the MiSCDC program's efforts and recognized its valuable contributions. This program aims to improve the lives of those in Michigan with SCD by collecting and analyzing data that can be used to inform policy changes, improve health care services, support the development of new treatments and raise awareness and educate community partners. Consensus participants support its expansion as it seeks to add data sets to the surveillance system, evaluate SCD initiatives and publish novel studies regarding SCD findings and trends for program planning purposes.

## 2026 Sickle Cell Strategic Plan Partners

The MDHHS's LEGD will continue its long-term collaboration with internal and external partners to improve the health of individuals with SCD. Benefits from the partnerships below will include leveraging and maximizing resources, utilizing existing expertise, and increasing capacity.

- **Children's Special Health Care Services (CSHCS):** A program within the MDHHS that serves children and some adults with special health care needs and their families. CSHCS helps those with chronic health conditions by providing coverage and referrals for specialty services, family centered services to support primary caretakers, community-based services to help caregivers care for children at home, and service coordination to coordinate the services of many providers who work within different agencies. In October 2021, Michigan expanded CSHCS benefit coverage to include people living with SCD over 21 years of age with the goal of improving health outcomes and reducing health disparities for this population.
- **Family Center for Children and Youth with Special Health Care Needs (Family Center):** The Family Center is a statewide parent-direct program within CSHCS whose primary purpose is to help families navigate the CSHCS system of care and to ensure that its policies and procedures reflect the needs of those it serves. Through its *Parent-to-Parent Support Network*, the Family Center provides emotional support and information statewide to families of children with special health care needs. It also helps families identify community resources and organizations; offers virtual learning opportunities on a variety of topics; and grants camp and conference scholarships for parents and youth interested in learning more about their child's chronic condition and how to live with it.
- **Henry Ford Comprehensive Adult Sickle Cell Center:** The Comprehensive Adult Clinic offers a broad array of health care services to those with SCD residing in the Detroit area, including multi-disciplinary team care, pain management, day treatment appointments, adult transition services, specialty referrals, and preventive and holistic care, such as mental health and social service referrals.
- **Michigan Hemoglobinopathy Quality Improvement Committee (HemQIC):** This committee consists of pediatric and adult hematologists, nurses, NBS and laboratory staff who review the LEGD system for diagnosis and treatment services provided to newborns and children with hemoglobinopathies detected through Michigan's NBS Program, other states or later diagnosis. This includes the development of diagnostic and medical management protocols, short and long-term follow-up protocols and database management.

- **Michigan Sickle Cell Data Collection Program: MiSCDC** is a collaboration between University of Michigan-CHEAR and MDHHS. Funded by CDC, the data it collects and analyzes is used to inform policies and to ensure effective allocation of resources.
- **MDHHS's Medicaid:** A joint federal-state health care program designed to assist low-income individuals and families, including children, pregnant women, seniors, and people with disabilities. It covers a wide range of services such as medical visits, dental/vision services, prescription medications, mental health and substance use treatment, NEMT, and long-term care services. More recently, MDHHS's Medicaid has begun to focus specifically on those with SCD. Through its partnership with a Michigan Medicine Research Team on the P-SCIP initiative, it works to incentivize and oversee select Medicaid Health Plans to improve preventive-care measures for children with SCD. Additionally, MDHHS's Medicaid has also joined the CMMI Access to Cell and Gene Therapy Model to make available FDA newly approved gene therapies to eligible participants with SCD. MDHHS's Medicaid also provides administrative matching funds for SCD-funded grant initiatives, as appropriate and when allowable.
- **Newborn Screening (NBS):** NBS is a public health program that finds babies with rare but serious disorders that require early treatment to prevent disability or death. The Michigan NBS program tests for more than 50 medical conditions, including SCD. The program works with hospitals and midwives to make sure babies are screened shortly after birth and if diagnosed with a disorder receive proper treatment. Each year, approximately 62 Michigan-born infants are confirmed to have SCD and 2,800 are identified with SCT.
- **Sickle Cell Clinic Expansion and Enhancement Clinic (SCCEE) Partners:** Since fiscal year FY22, MDHHS has received funding allocations to distribute to hematology clinics who have successfully completed an application process. Funding priorities for current awardees include projects that focus on access to care, medication adherence and quality improvement initiatives. Beginning in FY25, MDHHS will embark on a new SCD grant funding opportunity cycle which will span five years and reflect the priorities found in the 2026 SCD Strategic Plan. Through these grants, MDHHS seeks health care projects that are quantifiable, based on evidence and best practices, and results in system improvements that benefit those with SCD.
- **Sickle Cell Disease Association of America, Michigan Chapter (SCDAA-MI):** The SCDAA-MI provides statewide education, assistance, and advocacy for people living with SCD throughout the lifespan. The agency offers a range of services including counseling, support groups, referrals for financial and medical help, college and employment assistance, and financial support/camp scholarships for children wishing to attend summer each year.

Since 1987, through a contract with MDHHS, the SCDA-MI assures that newborns with sickle cell conditions identified through the state's NBS program receive comprehensive diagnostic, educational, counseling, social work, laboratory testing and treatment services.

- **Specialty Clinics:** Hematology clinics in Ann Arbor, Detroit, Flint, Kalamazoo, and Grand Rapids that provide multi-disciplinary care for sickle cell and thalassemia patients.

## 2026 Sickle Cell Strategic Goals, Objectives, Strategies, and Tactics

After completing all planning process activities and the identification of the 2026 SCD Strategic Plan goals, MDHHS developed the following objectives, strategies and tactics to meet the needs of the SCD community, each mapped to the plan’s priorities.

**GOAL 1:** Implement system changes that center the needs of the SCD community through a collaborative approach.

**OBJECTIVE 1A:** By September 2030, center the needs of the SCD community by implementing coordinated efforts with partners to advance understanding of the full impact of SCD and SCT on individuals and society.

A key aspect of the strategic planning process is actively listening to and integrating the voices of those with SCD and their lived experiences. One of the strengths of this strategic plan lies in its ability to incorporate this valuable information into its goals, strategies, and tactics. By sharing their lived experiences, those with SCD will be empowered to contribute to the development of a comprehensive, empathetic, and culturally-sensitive care system that aligns with the needs and preferences of those it serves. Through this goal, MDHHS aims to foster trust in research, address stigmatization in health care and ensure participatory decision-making in care and treatment. The strategies selected are designed to guarantee that these voices are not only heard but also play an active role in shaping the future of SCD care in Michigan.

**STRATEGY 1A.a:** Ensure that the lived experience of people with SCD is shared broadly and amplified to promote condition awareness and understanding.

KEY PARTNERS	TACTICS	YEAR
MDHHS (LEGD, CSHCS, Family Center), SCDA-MI, MiSCDC	<b>(1A.a.1)</b> Implement an education campaign to share the lived experience of people with SCD (i.e., story boards, photoblogs, videos, social media, news releases, PSAs, lobby TV signage, etc.)	Ongoing

**STRATEGY 1A.b:** Increase capacity within MDHHS to incorporate SCD into its public health programming.

KEY PARTNERS	TACTICS	YEAR
MDHHS (LEGD, CSHCS, Family Center) SCDAAMI, University of Michigan (MiSCDC)	<b>(1A.b.1)</b> Leverage existing groups to assure broad representation of people with SCD, their families and/or caretakers in the development and/or selection of program specific materials, policies, approaches, feedback (community participatory input/feedback)	Ongoing
MDHHS (LEGD, CSHCS, Family Center) SCDAAMI, SCCEE clinics	<b>(1A.b.2)</b> Support the development of peer support systems that are age-appropriate and provide opportunities for people to share their experiences and learn from others.	Ongoing

**GOAL 2:** Ensure access to quality, integrated sickle cell treatment and support services statewide.

**OBJECTIVE 2A:** By Sept. 30, 2030, improve access to care by establishing and enhancing organized care in at least five health care systems operating in Michigan to ensure both clinical and non-clinical supportive services are available to at least 75% of people living with SCD.

SCD is an inherited, chronic disease that can lead to complex medical conditions, frequent hospitalizations and premature death. It requires life-long care and treatment by a team of well-trained medical professionals, which includes specialists, primary care providers, nurses, social workers, behavioral health specialists and patient advocates who work to ensure those with SCD receive needed treatment and support services. To date, Michigan has taken a multi-faceted approach that improves both access to comprehensive care and the adequacy of health care insurance coverage for those services. While this approach is working, more can be done. The strategies and tactics identified in the 2026 Strategic Plan seek to build upon past successes, focusing efforts on enhancing care coordination services, supporting health insurance enrollment and retention and advancing quality care initiatives.

**STRATEGY 2A.a:** Explore existing Medicaid authorities to improve the system of support services for patients with SCD and their families.

KEY PARTNERS	TACTICS	YEAR
MDHHS Medicaid, SCDA-MI, SCCEE clinics	<b>(2A.a.1)</b> By May 30, 2026 establish a referral process to connect at least 25 clients per quarter with a community health worker, ensuring they receive assistance in accessing health care and social services, and review progress biannually to improve outcomes.	1
MDHHS CSHCS, SCCEE clinics	<b>(2A.a.2)</b> Promote the CSHCS Children’s Multi-disciplinary Specialty (CMDS) clinic model to five SCD/Hematology clinics to advance and support multidisciplinary approaches for SCD treatment and care coordination services.	1, 2
MDHHS (CSHCS, Medicaid, LEGD)	<b>(2A.a.3)</b> Explore options for adding SCD diagnoses to Michigan’s existing chronic disease health home eligibility criteria so to strengthen client’s access to primary care, improve their ability to receive care coordination and health education services, and promote holistic, multi-disciplinary support.	1, 2, 3
MDHHS (Medicaid, LEGD) HFH, SCDA-MI	<b>(2A.a.4)</b> Support the continued development and ongoing sustainability of the legislatively funded HFH Comprehensive Adult Sickle Cell Clinic as it serves up to 850 clients and expands its services.	Ongoing

**STRATEGY 2A.b:** Ensure access to adequate health benefits that provide coverage to services that people with SCD need.

KEY PARTNERS	TACTICS	YEAR
MDHHS (CSHCS, LEGD, Medicaid), MiSCDC, SCDA-MI, SCCEE clinics	<b>(2A.b.1)</b> Implement a comprehensive outreach strategy to inform those with SCD of CSHCS age eligibility expansion to increase enrollment to at least 75% of eligible population.	1

KEY PARTNERS	TACTICS	YEAR
MDHHS (CSHCS, Medicaid), SCDA-MI	<b>(2A.b.2)</b> Explore the use of health insurance advocates to help clients navigate insurance enrollment, coordination of benefits, and denials.	Ongoing
MDHHS (CSHCS, LEGD, Medicaid), MiSCDC	<b>(2A.b.3)</b> Develop and promote at least two non-emergency medical transportation (NEMT) resources for those with SCD to ensure their ability to access transportation assistance.	1

**STRATEGY 2A.c:** Issue funding opportunities to support up to five health care facilities to improve access to quality health care services.

KEY PARTNERS	TACTICS	YEAR
MDHHS – LEGD, SCCEE Clinics, HFH	<b>(2A.c.1)</b> Support expansion and enhancements of clinical services in the following areas: network development, health care transition, day treatment, and infusion services.	Ongoing
MDHHS – LEGD, SCCEE Clinics, HFH	<b>(2A.c.2)</b> Support the development and implementation of quality improvement initiatives for patients receiving SCD services within clinical settings.	Ongoing
MDHHS – LEGD, SCCEE Clinics, HFH	<b>(2A.c.3)</b> Explore establishing at least two mentorship opportunities (i.e., team, apprenticeship, residency formal, informal, virtual) for health professionals that assist other health professionals and students in learning about the SCD condition and its treatment options.	Ongoing
MDHHS (CSHCS, Medicaid, LEGD) SCCEE Clinics, HFH	<b>(2A.c.4)</b> Monitor access to behavioral health services for those with SCD and their caregivers.	Ongoing

**GOAL 3:** Utilize standards of care and implement protocols that improve patient outcomes.

**OBJECTIVE 3A:** By Sept. 30, 2030, 80% of SCCEE funded health care organizations will adopt and implement standards of care and/or protocols that strengthen the evidence base for interventions, using quality indicators to monitor improvements.

The incorporation of SOCs and protocols that reflect evidence-based clinical guidelines and step-by-step directions are important treatment considerations that can help guide providers in their medical decision-making and the care they render. Standards and protocols play a vital role in promoting patient safety and achieving optimal outcomes. These tools help to ensure that care is delivered consistently and promptly, which can significantly improve treatment effectiveness. Standardizing clinical steps and patient interactions via the use of SOCs and protocols can help to instill trust and confidence in the provider, and reduce disparities due to implicit bias. The following strategies and tactics reflect the use of SOCs and protocols in ways that will lead to measurable care improvements.

**STRATEGY 3A.a:** Expand and enhance the sickle cell improvement program to incentivize Medicaid health plans in improving the quality of care for those with SCD.

KEY PARTNERS	TACTICS	YEAR
MDHHS (Medicaid, CSHCS, LEGD) MHP, University of MI	<b>(3A.a.1)</b> Expand the P-SCIP program in the areas of prophylaxis antibiotics and hydroxyurea usages and TCD screening to additional areas within the state.	Ongoing
MDHHS (CSHCS, Medicaid, LEGD) SCCEE Clinics, HFH	<b>(3A.a.2)</b> Explore implementing the SCIP for adults, which would include incentivizing health plans to improve care for adult patients with SCD in health care transition.	Ongoing

**STRATEGY 3A.b:** Support the development/adoption of SCD protocols by EDs and measure their effectiveness over time.

KEY PARTNERS	TACTICS	YEAR
MDHHS (LEGD, CSHCS, Medicaid) specialty clinics, hospitals, HFH	<b>(3A.b.1)</b> Support the development and implementation of an ED SCD improvement initiative that assures the adoption of pain management protocols (including wait time, time of first medication administration, etc.), SCD provider education, patient feedback and ongoing monitoring.	Ongoing

**STRATEGY 3.A.c.** Support MDHHS SCD-funded projects in adopting/implementing evidence-based standards and/or protocols.

KEY PARTNERS	TACTICS	YEAR
MDHHS (LEGD, CSHCS, Medicaid) specialty clinics, hospitals, HFH	<b>(3A.c. 1)</b> Support the adoption/implementation of evidenced-based standards and/or protocols in five participating learning collaborative partners.	1-3

**GOAL 4:** Improve prescription of and adherence to disease-modifying therapies.

**OBJECTIVE 4A:** By Sept. 30, 2030, increase the number of Medicaid beneficiaries with SCD who had at least one filled prescription for hydroxyurea from 20% to 30% and the number of people with SCD who had received new disease-modifying medications from less than 5% to 7.5%.

Disease-modifying therapies offer relief from many of the complications caused by SCD. These therapies have been shown to reduce the frequency and severity of pain crises, resulting in less ED visits and fewer hospitalizations. Some medications have been shown to reduce organ damage, while others are known to mitigate anemia and reduce red blood cell destruction (hemolysis). Collectively, the use of disease-modifying therapies has been associated with improved quality of life and greater well-being in those with SCD. In December 2023, two new gene-based therapies (Casgevy and Lyfenia) were approved by the FDA which, for some, may offer potential cure. MDHHS’s Medicaid program has begun working to ensure these disease-modifying therapies are available to those with SCD who live in Michigan. The Strategic Plan acknowledges, supports and builds on these efforts by offering the following strategies and tactics.

**STRATEGY 4A.a:** Support the development and implementation of the cell and gene therapy access model within MDHHS’s Medicaid.

KEY PARTNERS	TACTICS	YEAR
MDHHS (LEGD, CSHCS, Medicaid), MiSCDC	<b>(4A.a.1)</b> Advise and collaborate with MDHHS’s Medicaid program as they implement the CMMI CGT Access model to eligible participants and offer newly approved disease-modifying therapies.	Ongoing

**STRATEGY 4A.b:** Support the development and implementation of models and tools to assist with the use of disease modifying therapies, including treatment decision-making and ongoing monitoring.

KEY PARTNERS	TACTICS	YEAR
MDHHS - LEGD, SCCEE clinics	<b>(4A.b.1)</b> Support the use of disease-modifying therapies (i.e., hydroxyurea, L-glutamine, crizanzumab, Casgevy, Lyfenia and others) within hematology clinics by providing decision-making aids that can assist patients in understanding their treatment options.	Ongoing
MDHHS (Medicaid, CSHCS, LEGD), MHPs	<b>(4A.b.2)</b> Work with MDHHS’ Managed Care Plan Division to incorporate SCD medication review/adherence into its reporting and review processes.	2

**GOAL 5:** Provide continuous education to increase awareness of information, best practices, and resources for SCD across the state and for priority groups (i.e., people with SCD and their caregivers, health professionals, general public, schools and employers).

**OBJECTIVE 5A:** By Sept. 30, 2028, conduct SCD education and awareness campaigns (i.e., presentations, webinars, social media, educational resources, medical grand rounds and other approaches) to strengthen the self-advocacy skills of those diagnosed with SCD and their caregivers through multi-faceted approaches that focus on reproductive health and social drivers of health.

Improving education and awareness was a fundamental aspect of the previous strategic plan and continues to be a priority today, with an additional focus on self-advocacy. The addition of self-advocacy to this objective underscores the importance of encouraging those with SCD and their communities to become more engaged, empowered and vocal. By implementing the identified strategies and tactics, MDHHS’s intention is that people with SCD learn how to participate in their own health care and grow in their ability to make informed decisions, while taking an active role in amplifying the causes and concerns they share. MDHHS believes that through education and awareness, policy and access to care issues can be addressed, clinical care improved, and stigmatization and implicit bias reduced.

**STRATEGY 5A.a:** Develop educational resources to be utilized by those with SCD and SCT to improve their health.

KEY PARTNERS	TACTICS	YEAR
MDHHS - LEGD, SCDA-MI, CHM	<b>(5A.a.1)</b> Support the development of an electronic application (app) that would provide SCD resources (i.e., educational, advocacy, treatment and pain plan, medication reminders, etc.).	1, 2, 3
MDHHS (LEGD, Medicaid, CSHCS)	<b>(5A.a.2)</b> Develop and implement pre/post-conception health resources to be used during reproductive years.	1, 2, 3
MDHHS - LEGD, SCDA-MI	<b>(5A.a.3)</b> Devise and implement a protocol and materials to notify people with SCT, who are entering reproductive age, that genetic counseling is recommended.	1, 2, 3

**STRATEGY 5A.b:** Develop educational materials and programs to assist students with SCD in achieving success.

KEY PARTNERS	TACTICS	YEAR
MDHHS - LEGD, MDE, SCDA-MI	<b>(5A.b.1)</b> Develop and provide sample protocols and educational materials to teachers, school nurses and administrators to help them understand the impact of SCD on students and families and the types of accommodations that are available to them.	1, 2
MDHHS - LEGD, MDE, SCDA-MI	<b>(5A.b.2)</b> Develop and promote age-appropriate educational materials for students living with SCD.	1, 2
MDHHS (CSHCS, LEGD), MDE, SCDA-MI	<b>(5A.b.3)</b> Encourage and support the development of peer support services in schools to reduce isolation experienced by students with SCD.	1, 2

**STRATEGY 5A.c:** Develop SCD informational materials for employers and employees that promote awareness and assist them in understanding the accommodations that, by law, are available to those with SCD.

KEY PARTNERS	TACTICS	YEAR
MDHHS-LEGD, SCDA-MI, MI Rehabilitation Services (MRS)	<b>(5A.c.1)</b> Assist employers in accessing SCD information and special accommodations needed by employees diagnosed with SCD or who care for a family member with SCD.	1, 2
MDHHS - LEGD, SCDA-MI, Michigan Developmental Disabilities Council (MiDDC)	<b>(5A.c.2)</b> Develop materials to assist those with SCD in completing and submitting requests in accordance with the Family Medical Leave Act (FMLA).	1, 2

**GOAL 6:** Establish and track metrics to improve health-related outcomes.

**OBJECTIVE 6A:** Between Oct. 1, 2026, through Sept. 30, 2030, leverage MiSCDC program’s integrated data system to collect and link data sources to characterize the burden of disease, outcomes, and the needs of people with SCD across the life span and use this information to monitor SCD improvements statewide.

Over the years, Michigan has developed robust data capabilities that have proven to be invaluable in its program and policymaking activities. The establishment of the MiSCDC and its integrated data system, which links data sets together, strengthens the state’s data infrastructure while providing a more complete understanding of who is living with SCD and how their care can be improved. Supporting the continuation of these efforts is critical to the overall success of the plan, which will rely on the MiSCDC program to monitor and evaluate interventions, while continuing to assess needs and identify opportunities for change. By maintaining and expanding the MiSCDC program, Michigan will have continued access to the information it needs to make data driven decisions related to SCD.

**STRATEGY 6A.a:** Expand the state SCD public health surveillance systems.

KEY PARTNERS	TACTICS	YEAR
MDHHS-LEGD, MiSCDC	<b>(6A.a.1)</b> Maintain the MiSCDC program by expanding funding resources to include federal, state, private and philanthropic funds.	Ongoing

MDHHS-LEGD, MiSCDC	<b>(6A.a.2)</b> Incorporate Medicare and commercial insurance data into the MiSCDC program data set.	Ongoing
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**STRATEGY 6A.b:** Leverage public health surveillance data in order to identify best practices for care delivery and outcomes.

KEY PARTNERS	TACTICS	YEAR
MDHHS-LEGD, MiSCDC, SCCEE Clinics	<b>(6A.b.1)</b> Provide clinic snapshots that monitor patient outcomes to clinics participating in the MiSCDC program.	Ongoing
MDHHS-LEGD, MiSCDC	<b>(6A.b.2)</b> Publish novel studies regarding SCD findings and trends in Michigan, as well as promote the use of data in program planning.	Ongoing
MDHHS-LEGD, MiSCDC, SCCEE Clinics	<b>(6A.b.3)</b> Assist with program evaluation of SCCEE clinics, including monitoring performance indicators.	Ongoing
MDHHS-LEGD, MiSCDC, SCDA-MI	<b>(6A.b.4)</b> Assist with development and administration of the Health Status Assessment (HSA) survey through SCDA-MI.	1,2

## **Next Steps: Implementation and Collaborations**

This plan reflects the knowledge, skills, expertise, and passion of a dedicated group of action-oriented people and agencies. MDHHS LEGD will continue to lead the implementation of the plan with participation and collaboration from internal public health programs: MDHHS Public Health Administration and Health Services Administration, SCDA-MI, the MiSCDC program, HemQIC, the SCCEE funded SCD Clinics, other Specialty Clinics, community groups, and people living with SCD and their caregivers. From these partners, an SCD strategy team will be formed and will meet at least twice per year to maintain open communication, as well as to review plan updates. During the first year, the strategy team will develop communication, project management and evaluation plans. These plans will be used to keep community partners informed, track efforts, and monitor progress, improvements and decision making. As part of the evaluation, key metrics will be identified, tracked and incorporated into an online dashboard available on the MDHHS website.

Several aspects of the plan are already in the implementation phase and the department is well positioned to deliver services that support those with SCD and their caregivers. LEGD is committed to continued involvement in these programs, including:

- Ongoing cooperation and technical assistance with the Health Services Administration's Managed Care Plan Division as it moves forward with its SCD-related initiatives:
  - The CMMI Cell and Gene Access Model which makes available affordable SCD disease-modifying therapies to eligible Medicaid recipients; and
  - The P-SCIP, a UM based research project that incentivizes MHPs to improve care and outcomes for children with SCD.

LEGD will continue to meet with staff from these programs and offer guidance, technical support and resources throughout their implementation phases.

LEGD will also continue to work closely with CSHCS to ensure that the funding provided by the Michigan legislature as part of its SCD age-eligibility expansion efforts is awarded to clinical projects that address the needs of those with SCD, improve their access to care and treatment and advance the quality of the health care that patients with SCD receive. LEGD will continue to promote CSHCS with its clients and support and assist with the age-eligibility expansion outreach efforts to adults with SCD.

LEGD will foster new collaborations with MDHHS's Medicaid Policy Division, with the aim of improving care quality and reducing hospitalizations and unnecessary ED visits for those with SCD. The focus of the new projects will be to employ sustainable, integrated clinical services, enhance existing care coordination services, and educate clients about Medicaid, its enrollment, renewal and benefit requirements.

LEGD will continue its collaboration with the SCDA-MI, the MiSCDC program and HemQIC to update and administer the health status assessment (HSA) survey, a tool developed to measure access to care, disease complications, health care use, financial status, and educational status among people in Michigan with SCD. Over the last several years, the HSA has provided self-reported information on patients, in an effort to learn more about Michigan's population with SCD, obtain feedback on educational initiatives provided by the SCDA-MI, and facilitate conversations among patients and their families about important health issues related to SCD. The HSA will continue to be included as part of the regular follow-up for all SCD patients detected via NBS.

LEGD will promote and support the legislatively funded Henry Ford Comprehensive Adult SCD Clinic as it becomes fully operationalized and accredited. LEGD will continue to provide technical assistance, help to facilitate partnerships, establish provider networks, update state policymakers, and communicate evaluation findings and lessons learned.

LEGD will continue its partnership with the CHEAR Center to maintain and expand the MiSCDC program, as it strives to improve the lives of those with SCD by using data to inform policy development, improve health care services and guide treatment. Building on the past success of this robust public health surveillance system, Michigan now has the capabilities needed, including established benchmarks and reliable data sources, to measure the plan's progress over time and evaluate the impact of its interventions.

## Appendix A: Key Milestones in Sickle Cell Disease Discoveries and Advances

The past 115 years of sickle cell research have resulted in landmark discoveries that ushered in the era of molecular genetics.<sup>8</sup> In the United States, SCD affects an estimated 90,000 to 100,000 people, the majority of whom are Black or African Americans.<sup>9</sup> All states screen newborns for SCD. The condition occurs in approximately one out of every 500 Black or African American births and one out of every 36,000 Hispanic births.<sup>6</sup> In addition, more than 2 million people in the United States have SCT.<sup>8</sup>

<b>1910</b>	Dr. James B. Herrick published first description of sickled cells in blood sample of 20-year-old dental student from Grenada. Term “sickle cell anemia” was coined based on published paper.
<b>1933</b>	Scientists tested 2,500 Black or African Americans in Memphis; determine SCT and SCD are separate entities.
<b>1940</b>	Researchers suggested the exchange of oxygen for carbon dioxide occurring in small blood vessels may cause RBCs to sickle and block blood vessels.
<b>1948</b>	Dr. James Neel suggested low concentration of sickled cells in blood from newborns with SCD was due to high levels of fetal Hgb in their RBCs.
<b>1949</b>	Dr. Linus Pauling revealed that SCD is due to abnormal Hgb protein molecule. Term “molecular disease” was coined.
<b>1949 - 1950</b>	Inheritance of SCD was independently described by two teams. It was determined that sickle cell genes are needed from both parents to produce SCD. Receiving the gene from one parent produces SCT.
<b>1957</b>	Scientists showed abnormality of sickle Hgb is due to an amino acid substitution in protein, making SCD the first genetic disorder for which the molecular basis was known.
<b>1971</b>	Dr. Charles Whitten established the Sickle Cell Detection Center in Detroit, Michigan. This organization later became the SCDA-MI, which eventually grew in size and scope and now provides services statewide.
<b>1972</b>	National Sickle Cell Anemia Control Act provided for the establishment of voluntary SCD screening; counseling; public and professional education; and research and training in diagnosing, treating, and controlling the disease.  A milder variation of SCD was found in Saudi Arabia associated with increased levels of fetal hemoglobin. The finding suggests that increasing fetal hemoglobin levels could help alleviate the disease.

<b>1974</b>	Feasibility of NBS for SCD was demonstrated. The method was developed for prenatal diagnosis by sampling fetal blood from the umbilical vein.
<b>1978</b>	New York became the first state to screen for SCD; prenatal method to diagnose SCD using DNA samples reported. The National Heart, Lung, Blood Institute (NHLBI) launched multicenter study with 4,000-plus individuals from newborns to age 70. First study to document clinical course of disease from birth to adulthood.
<b>1984</b>	Several teams independently demonstrated that hydroxyurea increases fetal Hgb levels. Bone marrow transplant performed to treat a child with leukemia also cures the child's SCD.
<b>1986</b>	A NHLBI study showed penicillin as a preventive measure in children with SCD ages 3 months to 5 years old that reduced the incidence of Streptococcus pneumonia infection, a major cause of childhood death, by 84%. This practice later becomes widely adopted.
<b>1987</b>	National Institutes of Health Consensus Development Panel recommends screening all U.S. newborns for SCD and giving penicillin to all affected infants by three months of age.
<b>1987</b>	Michigan legislature adds SCD to the state NBS panel and state health department establishes contract with the SCDA-MI to coordinate follow-up services for babies detected with SCD.
<b>2005</b>	The Stroke Prevention Trial in Sickle Cell Anemia (STOP) was a pivotal clinical trial that demonstrated the effectiveness of chronic transfusion therapy in preventing strokes in children with SCD.
<b>2010</b>	The Registry and Surveillance System for Hemoglobinopathies (RuSH) pilot project was implemented by the Centers for Disease Control and Prevention (CDC) to collect state-specific, population-based data on people with sickle cell disease (SCD) and thalassemia. The two-year pilot project was supported and conducted in collaboration with the National Institutes of Health's National Heart, Lung, and Blood Institute (NHLBI).
<b>2014</b>	An expert panel of the NHLBI released new guidelines for managing SCD.
<b>2014</b>	MDHHS-LEGD released the Sickle Cell Disease Newborn Screening Surveillance Report celebrating 27 years of sickle cell screening.
<b>2015</b>	MDHHS-LEGD released its <b>Public Health Strategic Plan to Address Sickle Cell Disease Across the Lifespan 2015-2018</b> , Michigan's first SCD Strategic Plan.

<b>2017</b>	FDA approves hydroxyurea to reduce the frequency of painful crises and the need for blood transfusions in pediatric patients with sickle cell anemia.
<b>2019</b>	MDHHS-LEGD received a one-year CDC-funded cooperative agreement to plan a statewide SCD surveillance program.
<b>2020</b>	MDHHS-LEGD and UM CHEAR Center submitted a joint application to the CDC to join the Sickle Cell Data Collection (SCDC) program. As part of the cooperative agreement, the MiSCDC program seeks to address knowledge gaps in SCD and disease management by studying the long-term trends in diagnosis, treatment, and health care access for people with SCD.
<b>2021</b>	MDHHS-LEGD and CSHCS submitted a joint proposal to expand the CSHCS age-eligibility through the lifespan for those with SCD to help ensure adequate insurance coverage for related treatments. Additional funds were also allocated to improve access to care through the expansion and enhancement of SCD services.
<b>2022/ 2023</b>	Michigan legislature allocated funding to establish a SCD Center of Excellence in the City of Detroit.
<b>2022</b>	SCDAA-MI entered into partnership with Henry Ford Health to establish a SCD Comprehensive Adult clinic that features state of the art care for those living in Michigan with SCD.
<b>2022</b>	MDHHS LEGD issued the first Sickle Cell Clinic Expansion and Enhancement (SCCEE) Request for Proposal and awarded \$300,000 to three organizations to improve access, medication adherence and health care quality.
<b>2023</b>	MDHHS LEGD issued the second SCCEE Request for Proposal and awarded an additional \$200,000 to two organizations to improve access to care and transcranial doppler screenings among pediatric patients.
<b>2023</b>	FDA approved two new gene therapies, Casgevy and Lyfgenia, for the treatment of SCD in eligible patients 12 years and older.
<b>2025</b>	MDHHS-Health Services Administration joined the CMMI's Cell and Gene Therapy Model Access program to ensure those qualifying individuals with SCD and receiving Medicaid have access to affordable gene therapies with their potential curative effects.
<b>2026</b>	MDHHS-LEGD released its second 2026-2030 Strategic Plan for SCD.

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