OKLAHOMA
Health Care Authority

Independent Evaluation of Sickle Cell Disease Management within the SoonerCare Population – *2025 Update*

LEGISLATIVE REPORT IN COMPLIANCE WITH SB 1467

Prepared by the Pacific Health Policy Group for:

State of Oklahoma
Oklahoma Health Care Authority

JANUARY 2026

INDEPENDENT EVALUATION

The Pacific Health Policy Group (PHPG) in 2022 conducted an independent evaluation of the SoonerCare program's performance in covering members with sickle cell disease. This report presents a third annual update to our initial study findings and recommendations. PHPG is solely responsible for the content of this report.

PHPG is a national consulting firm with locations in the states of Arizona, California, Illinois, Oklahoma and Vermont. PHPG specializes in the development and evaluation of programs to serve Medicaid beneficiaries with special health care needs.

PHPG wishes to acknowledge the cooperation of the Oklahoma Health Care Authority in obtaining the necessary data for completion of the evaluation. PHPG also wishes to acknowledge the contributions made by Supporters of Families with Sickle Cell Disease in preparation of the report.

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COMMONLY-USED ABBREVIATIONS & ACRONYMS

ABD	Aged, Blind, Disabled
CCM	Chronic Care Management (unit within the OHCA)
DUR	Drug Utilization Review
FDA	Food and Drug Administration
CGT	Cell and Gene Therapy
HAN	Health Access Network
HbSC	Hemoglobin C
HbSS	Hemoglobin S
HIE	Health Information Exchange
HMP	Health Management Program
HRSA	Health Resources and Services Administration
HRSN	Health Related Social Needs (see also SDOH)
MCE	Managed Care Entity
OHCA	Oklahoma Health Care Authority
OU	Oklahoma, University of
PCMH	Patient Centered Medical Home
RFP	Request for Proposals
SCD	Sickle Cell Disease
SCT	Sickle Cell Trait
SDOH	Social Determinants of Health (see also HRSN)
SFY	State Fiscal Year

A. EXECUTIVE SUMMARY

Introduction

Sickle cell disease (SCD) is the most prevalent inherited blood disorder in the United States. There are an estimated two million Americans with the sickle cell trait (SCT), meaning that the individual inherited the sickle cell gene from one parent. There are approximately 100,000 Americans who have inherited the SCD gene from both parents and have been diagnosed with sickle cell anemia or another disease within the SCD group.

Sickle cell disease is present at birth, with symptoms often appearing in the first year of life and worsening over time. Children and adults with SCD are at greater risk of infection than the general population, including a heightened risk of pneumonia. Children and adults with SCD also can be at heightened risk for stroke, among other complications.

Many people with SCD receive health care services through their state Medicaid program. In Oklahoma, the SoonerCare Program, in a typical year, covers around 500 members with SCD and another 800 to 900 with sickle cell trait.

The SCD population is not evenly distributed throughout the State. Most reside in Oklahoma and Tulsa Counties, which together are home to over 300 members with SCD. The next most populated counties are Canadian, Cleveland, Comanche and Muskogee, each with between 10 and 30 persons. There are 32 counties with at least one, but fewer than 10 members with SCD; 39 counties have no members with SCD.

Prior to 2024, most Medicaid members in Oklahoma were enrolled in SoonerCare Choice, the OHCA's primary care case management model. In April 2024, the majority of non-disabled members transitioned into SoonerSelect, the State's new Medicaid managed care program. The SoonerSelect private managed care entities (CEs) serve slightly over 50 percent of members with SCD, with the remainder almost evenly distributed between SoonerCare Choice and SoonerCare Traditional, which covers Medicare/Medicaid dual eligibles and persons receiving long term care.

A variety of new prescription drugs and interventions have been developed for SCD treatment in recent years, raising life expectancy for those with some form of the condition. In December 2023, the US Food and Drug Administration approved gene and gene-editing therapies for people with SCD that also offer the potential for a cure.

Despite these advances, SCD can be a devastating and difficult-to-manage condition for the patient and his or her family. In addition to other health risks and complications, people with SCD may experience severe pain crises brought on by clotting of the abnormally shaped red blood cells.

Patients in crisis often require intensive and continuous opioid-based pain medications that must be administered parenterally (e.g., by intravenous method). The medications must be provided either in an emergency room or inpatient setting, where the patient can be monitored and the dosage increased as necessary to achieve pain relief. One SoonerCare member with SCD described the experience of an acute pain crisis as being, *"like shards of glass running through your system."*

SB 1467 Study Scope

During the 2022 regular session, the Oklahoma Legislature enacted Senate Bill (SB) 1467, which was signed into law by the Governor on May 2, 2022. Section 1A of SB 1467 directed the OHCA to:

> *"… conduct an annual review of all medications and forms of treatment for sickle cell disease and services for enrollees with a diagnosis of sickle cell disease. The purpose of the annual review is to determine if the available covered medications, treatments, and services are adequate to meet the needs of enrollees with a diagnosis of sickle cell disease, and whether the Authority should seek to add or recommend additional medications, treatments, or services."*

The OHCA retained the Pacific Health Policy Group (PHPG) to conduct an independent evaluation in accordance with SB 1467 requirements. PHPG is a national consulting firm that specializes in development and evaluation of programs to serve Medicaid populations with special needs.

PHPG organized the study scope to align with the Legislature's specific areas of inquiry. The evaluation methods were selected to obtain the data necessary to inform findings and recommendations across the areas defined in SB 1467. They included: interviews with members, providers and program stakeholders; analysis of Medicaid eligibility and paid claims data; and review of national best practices, among other activities.

PHPG applied the data and related analysis toward answering the following questions:

- *Do SoonerCare members with SCD have access to all necessary services, including access to knowledgeable Patient Centered Medical Home (PCMH) providers?*
- *Do Oklahoma emergency room providers have the appropriate training and resources to care for members in crisis?*
- *Do SoonerCare members with SCD have appropriate supports to navigate the health care system?*
- *How can the program be strengthened?*

PHPG issued a report in December 2022. The report, "Independent Evaluation of Sickle Cell Disease Management within the SoonerCare Population" was submitted by the OHCA to the Legislature in January 2023. The report is available on the OHCA website at: SoonerCare SCD Evaluation - January 2023.pdf (oklahoma.gov).

PHPG's initial study provided information on the characteristics of the SoonerCare population with SCD and on the current standard-of-care for treatment of the disease. It also contained findings and recommendations within each of the above-noted areas of inquiry.

SB 1467 included a provision for annual updates to the original study, to be delivered on or before the anniversary of the initial study due date. This is the third annual update.

The implementation of SoonerSelect in April 2024 has introduced significant changes to the Medicaid program and provides new opportunities for improving the care and quality-of-life of members with SCD. This update examines how the OHCA, SoonerSelect Care Entities, major providers of care to people with SCD and the State's leading advocacy organization (Supporters of Families with Sickle Cell Disease) are collaborating to implement PHPG recommendations to improve access and quality of care.

More specifically, this report:

- Provides current (SFY 2025) information on the characteristics of the population with SCD (demographics and service use) and advances in treatment of the disease.
- Shares member perceptions of the delivery system, as gathered through structured surveys and Town Hall meetings.
- Discusses continuing barriers to care, notwithstanding positive steps taken by the OHCA and its partners since issuance of the initial report.
- Provides information on the OHCA's strategy to reduce or remove these barriers, with significant activity planned for 2026.

Characteristics and Service Use among SoonerCare Members with SCD

PHPG identified 478 SoonerCare members with SCD in SFY 2025, based on paid medical claims (a minimum of two claims were required to be counted). Slightly more than 40 percent of the members (207 people) were under the age of 20; this included 32 older adolescents aged 17 to 19 approaching the transition from child to adult coverage. There were 261 adults aged 20 to 64 and another 10 aged 65 and over.

SoonerCare Choice and Traditional members with SCD had average annual medical claim costs of about $44,000 each in SFY 2025. By comparison, the average expenditure per

SoonerCare member program wide in SFY 2024 (most recent year available) was under $6,000. (SoonerSelect CEs receive a fixed per member monthly payment based on age, gender and aid category. PHPG limited the utilization and expenditure analysis this year to SoonerCare Choice/Traditional members whose costs are reimbursed by the OHCA on a fee-for-service basis.)

SoonerCare members with SCD who experience a pain crisis must be treated in a hospital setting, either in the emergency room or as an inpatient. Medications are administered parenterally and require continuous monitoring.

Seventy percent of SoonerCare Choice/Traditional members with SCD had at least one inpatient stay in 2025. Nearly all these members were hospitalized for treatment of an SCD-related complication, such as an acute pain crisis.

Eighty percent of SoonerCare Choice/Traditional members had at least one emergency room visit in SFY 2025. Over the entire year, these members sought care in the emergency room an average of about 11 times each, or nearly once per month.

The emergency rooms at OU Health Sciences Center in Oklahoma City and Saint Francis Hospital in Tulsa have evidence-based protocols for treatment of patients in crisis, as well as at least some providers who are familiar with how to treat the condition. However, as PHPG documented in previous studies, most emergency room physicians see only one or two cases per year.

ER physicians with infrequent contact accounted in aggregate for nearly 1,000 encounters during the three-year period reviewed in the initial study. Their unfamiliarity with the needs of patients with SCD was found to be a barrier to effective treatment.

PHPG surveyed members regarding their emergency room experiences and participated in a virtual Town Hall with members organized by Supporters of Families with Sickle Cell Disease. Both groups of members raised concerns about emergency room care for patients in crisis. One Town Hall participant spoke for many others when she said, *"We have to wait until it (pain) gets extreme to get help."*

There are preventive steps that people with SCD can take, with medical support, to avert an oncoming pain crisis; hydration therapy is one example. An emerging best practice in other states is to make such services and other supports available through day centers that specialize in serving patients with SCD. (These can be free standing centers or repurposed space within existing facilities.) The OHCA and its partners are exploring the feasibility of piloting a day center in Oklahoma City within the next 12 months.

Another best practice is for members and their regular physicians to complete a "pain management action plan" with information on medication and other treatment needs.

Members can take these action plans with them to the emergency room and ask attending physicians to use them when ordering interventions.

Care Management for Members with SCD

Individuals with complex/chronic diseases such as SCD often require care from multiple medical specialties, as well as behavioral health services, to cope with what is a life-long condition. Navigating the health care system without support can lead to fragmented care or gaps in care, as well as patient discouragement.

Medicaid beneficiaries often face additional, non-clinical hurdles to accessing care. These factors, known as "health related social needs" (HRSN) or "social determinants of health" (SDOH) can include housing insecurity, food insecurity, difficulty making utility payments and lack of reliable transportation, among others. A person with significant HRSN/SDOH needs may, by necessity, regard his or her health care, particularly preventive services, as a lesser priority.

The OHCA contracts with Supporters of Families with Sickle Cell Disease to assist members with HRSN/SDOH needs. Supporters of Families with Sickle Cell Disease is a comprehensive, community-based organization serving individuals and families living with sickle cell and thalassemia disease and trait in Oklahoma. The organization is based in Tulsa but works on behalf of families throughout the State. (It also advocates for members seeking care, particularly during crisis episodes.)

One recognized best practice for managing complex care needs is through establishment of a member-centered interdisciplinary care team. The team typically includes representatives from all specialties relevant to the individual's health needs, as well as a designated care manager (nurse or social worker) to coordinate the team's activities. As suggested by its name, the team places the member at its center, and she or he retains autonomy for choosing the preferred course of care.

Individuals enrolled with an interdisciplinary care team typically receive a comprehensive assessment, followed by creation of a care plan that addresses both clinical and non-clinical (HRSN/SDOH) priorities. HRSN/SDOH needs may be managed by a Community Health Worker trained in this task.

The interdisciplinary care team model also is well-suited for facilitating a member's transition from pediatric to adult care. The team can assist the member in making the transition and can itself evolve, in terms of composition, from pediatric to adult care providers.

The OHCA has taken steps in the past two years to identify and assist members reaching adulthood, but the issue remains salient. One young adult member at a Town Hall spoke

about her experience and said, *"The problem I see with people who have sickle cell, as soon as you hit 18 or 21, you have nowhere to go – you go straight to the hospital and are treated like a drug addict going to get high…for starters we need to know the stuff we have to take for our health care and learning how to talk to the doctors – communicating what we need and being advocates for ourselves."*

There are multiple pathways through which SoonerCare members with SCD can receive care management today. Children and adolescents who are seen at the OU Jimmy Everest Center have access to an interdisciplinary care team in accordance with best practices.

The OHCA conducts annual outreach to all members with a sickle cell diagnosis and provides care management to the costliest members with SCD through its Chronic Care Management unit; the agency also contracts with two university-sponsored "Health Access Networks" to provide care management to members with SCD who are patients within their provider networks. The OHCA also operates the SoonerCare Health Management Program, under which it contracts with a care management vendor to serve high-risk SoonerCare Choice members with complex/chronic conditions, including a small number of members with SCD.

SoonerSelect CEs are required to offer an initial health screening to all new enrollees, and to perform a comprehensive clinical and SDOH assessment on those identified as having special needs, a category that would include members with SCD. The assessment is to be used to develop a comprehensive, interdisciplinary care plan, to be overseen by a designated care manager.

The number of members in PHPG's survey who reported having a care manager rose in 2025 from the prior year but still was fewer than one-quarter of respondents. (It is likely that some members were offered but declined to enroll in care management.) The OHCA and its partners recognize this remains an opportunity for improvement in care delivery.

Findings & Recommendations

Findings

As documented in this and earlier reports, patients and families with SCD face numerous potential health disparities/barriers to care. Patients living outside of major metropolitan areas may not have local access to a hematologist with specialized knowledge of the condition, necessitating lengthy travel for care.

Emergency room providers unfamiliar with SCD may be reluctant to take aggressive steps to manage the pain of patients in crisis. This can prolong the episode and the patient's level of distress.

Adolescents approaching adulthood may be confronted with the need to change providers, if their current provider restricts his or her practice to pediatric patients. SoonerCare members also face a change in benefits when they reach age 19, including a limit on monthly prescription medications and specialist visits, absent prior authorization.

As a life-long chronic condition, SCD requires a comprehensive approach to care. Patients and families with social stresses and needs may be ill-equipped to manage day-to-day care needs without additional support.

Development of Recommendations

In the initial 2022 report, PHPG made recommendations to improve access to covered services; strengthen emergency room physician training; and expand resources and adequacy of supports for members to navigate the health care system. PHPG added in 2024 a recommendation to expand preventive care capacity within the framework of a day center model.

The OHCA began implementation of several of the recommendations in 2023 and 2024 but paused others while it implemented the SoonerSelect program. The OHCA believed it would be more effective to have the SoonerSelect CEs in place when developing a comprehensive strategy for improving care.

In 2025, the OHCA, in partnership with the SoonerSelect CEs, Supporters of Families with Sickle Cell Disease and major providers, including OU's Jimmy Everest Center, formed a Task Force to develop a broad-based care improvement strategy for members with SCD. The Task Force created three smaller work groups to implement PHPG's recommendations: Provider-Focused Work Group, Member-Focused Work Group and (Delivery) Systems Change Work Group.

Provider-Focused Work Group

The Provider-Focused Work Group includes representatives from the SoonerSelect CEs, one of which (through its parent company) has developed an online SCD training module for primary care providers. The module offers a foundational overview of SCD management, explores navigating sickle cell disease in clinical practice, including its epidemiology, pathophysiology, diagnosis, and common complications. Clinicians will evaluate current and emerging therapies and evidence-based strategies to improve management and prevention of SCD-related complications. Providers who complete the training will earn continuing education credits.

The Provider-Focused Work Group also has begun to develop an individualized pain management action plan template for adults, modeled on an existing template that OU Jimmy Everest uses for children. The action plan will be completed by the member's

physician, with his/her participation. It will address medication needs and include instructions for providers and emergency rooms to follow in managing the crisis. The goal is for members to carry the action plans with them but also ultimately to make them available to providers through the Health Information Exchange.

Member-Focused Work Group

The Member-Focused Work Group has begun to coordinate creation of interdisciplinary care teams for members with SCD. Planning meetings are underway with the two leading centers of care (OU Jimmy Everest and Saint Francis) to support SoonerCare Choice/Traditional members and are to expand to include the SoonerSelect CE care management teams. The CEs will be responsible for SoonerSelect members while the OHCA will work with its HAN and SoonerCare HMP partners to address care management for other SoonerCare beneficiaries.

The Work Group also has addressed the need for pediatric-to-adult transition of care planning. The OHCA CCM and all three SoonerSelect CEs have established care management outreach plans to affected members. The OHCA conducts outreach to all members with sickle cell disease aged 17 to 21, regardless of cost or utilization, with a targeted focus on transitional care needs. OU Jimmy Everest and Saint Francis also have formal transition-of-care protocols that are implemented at each visit beginning at age 12.

Systems Change Work Group

The Systems Change Work Group is taking the lead in developing preventive care capacity under the day center model. The Work Group is considering a pilot in Oklahoma City with potential expansion to Tulsa. Pilot development activities include consulting with national experts, exploring partnerships with infusion centers and examining funding options.

Conclusions

Members and advocates continue to identify provider capacity issues and lack of training on SCD care, particularly during pain crises, as significant barriers to care. However, the OHCA and its partners have made advances in the past year, with much of it focused on planning for 2026.

The coming year should see significant progress as the recently developed plans are implemented. If the Work Group initiatives have the intended effect of reducing long-standing barriers to care, the potential exists for improving the quality-of-life of all Oklahomans with Sickle Cell Disease or Trait.

B. STUDY PURPOSE & SCOPE

1. Study Purpose (Senate Bill 1467)

During the 2022 regular session, the Oklahoma Legislature enacted Senate Bill (SB) 1467, which was signed into law by the Governor on May 2, 2022. Section 1A of SB 1467 directed the OHCA to:

> *"… conduct an annual review of all medications and forms of treatment for sickle cell disease and services for enrollees with a diagnosis of sickle cell disease. The purpose of the annual review is to determine if the available covered medications, treatments, and services are adequate to meet the needs of enrollees with a diagnosis of sickle cell disease, and whether the Authority should seek to add or recommend additional medications, treatments, or services."*

Section 1B of SB 1467 provided additional direction for the evaluation scope and methods. Specifically, the evaluation should examine:

1. *The extent to which healthcare transitional programs covered under the state Medicaid program prepare, transfer, and integrate emerging adults into the adult care setting from a pediatric setting;*

2. *The extent to which emergency department providers are adequately trained and otherwise prepared to treat and manage sickle cell patients presenting with vaso-occlusive crises including but not limited to the extent to which providers follow clinically validated algorithms and protocols regarding such treatment and management;*

3. *The extent to which sickle cell patients covered under the state Medicaid program are entitled to receive the same standard of care when referred or transferred to an out-of-state facility, and the extent to which the state reimburses such patients for reasonable interstate travel costs; and*

4. *Any additional areas identified by the Authority that impact the care and treatment of individuals in this state living with sickle cell disease or sickle cell trait.*

2. Study Scope (Initial and Updates)

Initial Study

The OHCA retained the Pacific Health Policy Group (PHPG) to conduct an independent evaluation in accordance with SB 1467 requirements. PHPG is a national consulting firm that specializes in development and evaluation of programs to serve Medicaid populations with special needs. PHPG serves as evaluator of the SoonerCare waiver programs under which most Medicaid beneficiaries with sickle cell disease (SCD) receive care[1].

PHPG conducted the initial study from May to December 2022; the study scope was defined in accordance with the Legislature's specific areas of inquiry. The evaluation methods were selected to obtain the data necessary to inform findings and recommendations across the areas defined in SB 1467.

The initial study included six data collection methods:

1. Literature review
2. Provider, care manager and stakeholder interviews
3. Member interviews (structured survey)
4. Analysis of Medicaid eligibility and paid claims data
5. Review of OHCA Drug Utilization Review (DUR) Board activities
6. Review of OHCA coverage policies and managed care strategy

PHPG applied the data and related analysis toward answering the following questions:

- *Do SoonerCare members with SCD have access to all necessary services, including access to knowledgeable Patient Centered Medical Home (PCMH) providers?*
- *Do Oklahoma emergency room providers have the appropriate training and resources to care for members in crisis?*
- *Do SoonerCare members with SCD have appropriate supports to navigate the health care system?*
- *How can the program be strengthened?*

PHPG issued a report in December 2022 entitled, "*Independent Evaluation of Sickle Cell Disease Management within the SoonerCare Population*". The report was submitted by the OHCA to the Legislature in January 2023 and is available on the OHCA website at: SoonerCare SCD Evaluation - January 2023.pdf (oklahoma.gov).

[1] These include the SoonerCare Choice Section 1115 Demonstration and the SoonerSelect 1915b managed care waiver.

PHPG's initial report provided information on the characteristics of the SoonerCare population with SCD and on the current standard-of-care for treatment of the disease. The report also contained findings and recommendations within each of the above-noted areas of inquiry.

First and Second Updates (2023 and 2024)

SB 1467 included a provision for annual updates to the original study, to be delivered on or before the anniversary of the initial study due date. Specifically:

> *"On or before January 15, 2023, and on or before January 15 each year thereafter, the Authority shall submit a report to the President Pro Tempore of the Senate and the Speaker of the House of Representatives for distribution to the appropriate subject matter committees that details the Authority's findings from the annual review required by this section and any recommendations to the Legislature based upon those findings."*

PHPG limited the 2023 report to an update of member demographics and a discussion of actions taken with respect to original report recommendations. This was done in anticipation of forthcoming changes to the SoonerCare program and their expected impact on members with SCD.

In April 2024, the majority of SoonerCare members, including those with SCD, were transitioned to the SoonerSelect program, under which risk-based Care Entities assumed responsibility for providing health services and care management to their enrollees. There are three statewide CEs participating in SoonerSelect. (Members in the Aged, Blind and Disabled (ABD) eligibility category without Medicare remained in the SoonerCare Choice program[2], while those with Medicare and/or in long term care remained in the SoonerCare Traditional program.)

Considering this shift, PHPG conducted a comprehensive evaluation similar in scope to the initial 2022 study, including through surveys of SoonerCare members who transitioned to SoonerSelect and participation in a Town Hall meeting. The 2024 surveys and Town Hall meeting took place in the early months of the SoonerSelect transition. Many members were still learning about the changes to their health coverage and had yet to form opinions of their Care Entities.

[2] SoonerCare American Indian members eligible for SoonerSelect have the option to enroll or remain in SoonerCare Choice.

Third Update (2025)

Members with SCD enrolled in SoonerSelect have now had more than a year of experience with the program. PHPG and Supporters of Families with Sickle Cell Disease collaborated in gathering information on member perceptions of the program, as well as those of members still served through SoonerCare Choice.

More specifically, the 2025 report:

- Provides current information on the characteristics of the population with SCD (demographics and service use) and advances in treatment of the disease.
- Includes findings from the latest round of surveys conducted with SoonerCare members who transitioned to SoonerSelect, as well as members who remain enrolled in the SoonerCare Choice or SoonerCare Traditional programs.
- Presents information from a December 2025 virtual Town Hall meeting of Oklahomans with SCD, organized and facilitated by Supporters of Families with Sickle Cell Disease.
- Describes outreach and care management responsibilities and activities of the OHCA and its partners, including SoonerSelect CEs and OHCA staff, as well as community-based partners such as Supporters of Families with Sickle Cell Disease.
- Documents the steps taken to date by the OHCA, CEs and community-based partners to act on PHPG recommendations and discusses next steps for improving quality and overcoming barriers-to-care.

Sections C and D of the report address PHPG findings. Section E discusses the OHCA's strategy for implementing PHPG's recommendations and updates their status.

C. CHARACTERISTICS & TREATMENT OF PERSONS WITH SCD

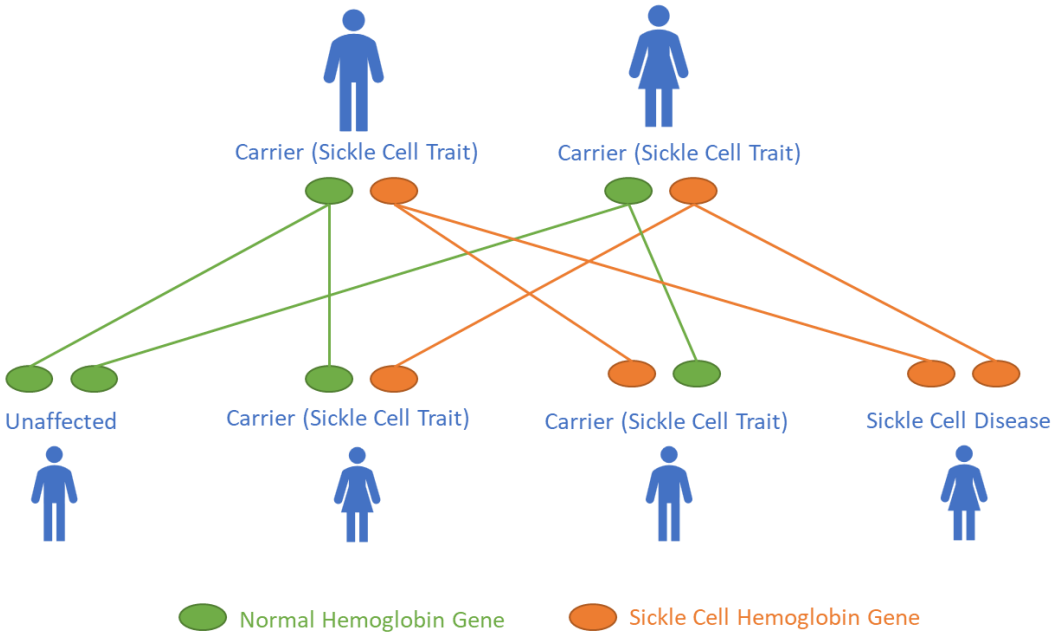
1. Characteristics of Persons with SCD

Sickle Cell Disease Types and Prevalence

Sickle cell disease refers to a group of blood disorders, usually inherited, of which Hemoglobin S (HbSS), also known as sickle cell anemia, is the most common. SCD is concentrated within (although not exclusive to) the African American community, where it occurs in one of every 365 births[3], making it the most prevalent inherited blood disorder in the United States.

There are an estimated two million Americans with the sickle cell trait (SCT) in the United States, meaning that the individual inherited the sickle cell gene from one parent. SCT occurs in approximately one of every 13 African American births. A child whose parents carry the SCD gene has a three-in-four chance of being born either with SCT or SCD (Exhibit C – 1).

Exhibit C – 1 – Sickle Cell Trait and Disease Risk



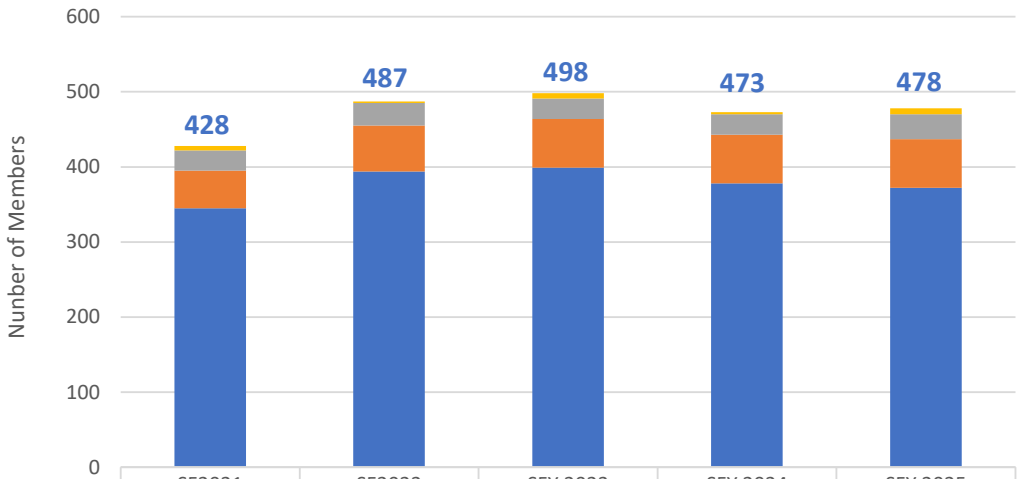
[3] Source: Data & Statistics on Sickle Cell Disease | CDC. SCD occurs in one of every 16,300 births to Hispanic Americans and less frequently among individuals of Asian, Mediterranean and Middle Eastern lineage.

There are approximately 100,000 Americans who have inherited the SCD gene from both parents and have been diagnosed with sickle cell anemia or another disease within the SCD group[4]. Other SCD conditions include Hemoglobin C (HbSC) and HbS beta thalassemia, as well as several rarer types. Sickle cell anemia, in which an abnormal form of hemoglobin causes red blood cells to become rigid and sickle-shaped, is usually the most severe form of SCD.

Many people with SCD receive health care services through their state Medicaid program. (Nationally, it is estimated that 50 percent of people with SCD are enrolled in Medicaid.[5])

During each of the last five state fiscal years (SFY 2021 – SFY 2025[6]), the SoonerCare program covered between 428 and 498 members with SCD (Exhibit C – 2).

Exhibit C – 2 – SoonerCare Members with SCD by State Fiscal Year[7]



	SF2021	SF2022	SFY 2023	SFY 2024	SFY 2025
Other SCD	6	2	7	3	8
Thalassemia	27	30	27	27	33
Sickle Hemoglobin	50	61	65	65	65
Sickle Cell Anemia	345	394	399	378	372

[4] Sickle cell disease: MedlinePlus Genetics

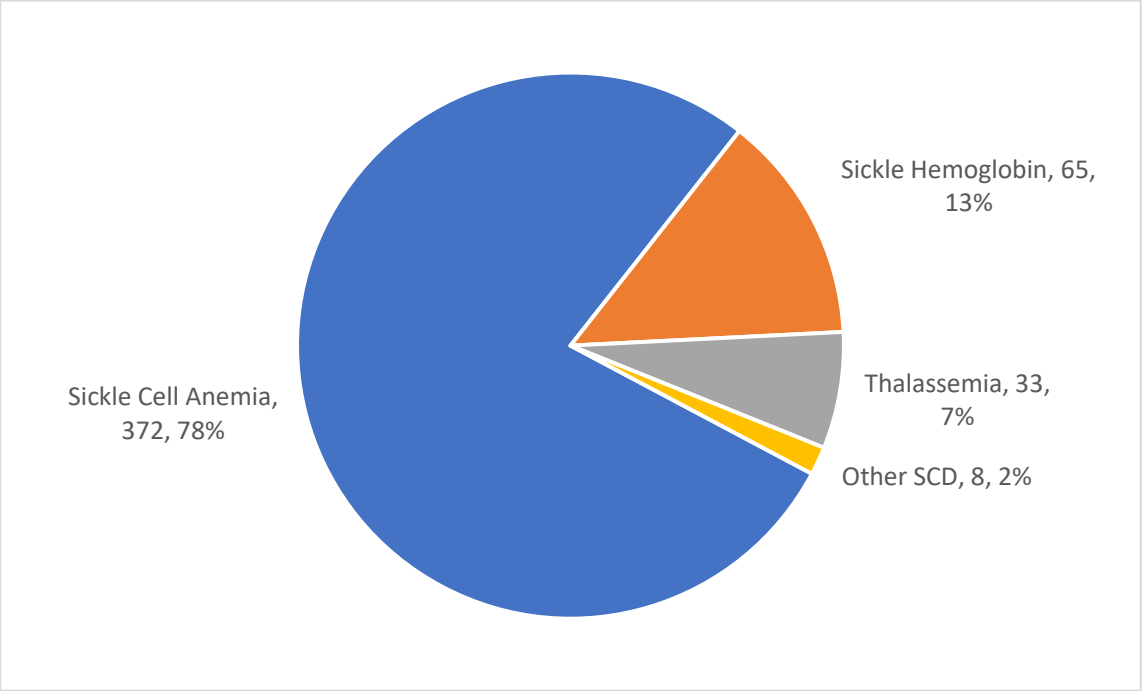
[5] 1 https://www.cms.gov/files/document/sickle-cell-disease-action-plan.pdf

[6] State fiscal years run from July to June.

[7] PHPG adhered to OHCA guidelines for identifying members with chronic health conditions. A member was included in the analysis data set for a particular year if she or he had at least two paid claims with a sickle cell disease diagnosis code. Because the member count is service-dependent, some of the year-over-year variation may be due to fluctuations in the number of eligible persons presenting for care. In addition, the expiration of COVID-era procedural disenrollment suspensions in SFY 2024 likely contributed to the drop in members that year.

Nearly 80 percent of SoonerCare members with SCD in 2025 were diagnosed with sickle cell anemia, while other SCD conditions occurred with less frequency (Exhibit C – 3).

Exhibit C – 3 – SoonerCare Members with SCD by Category (SFY 2025)



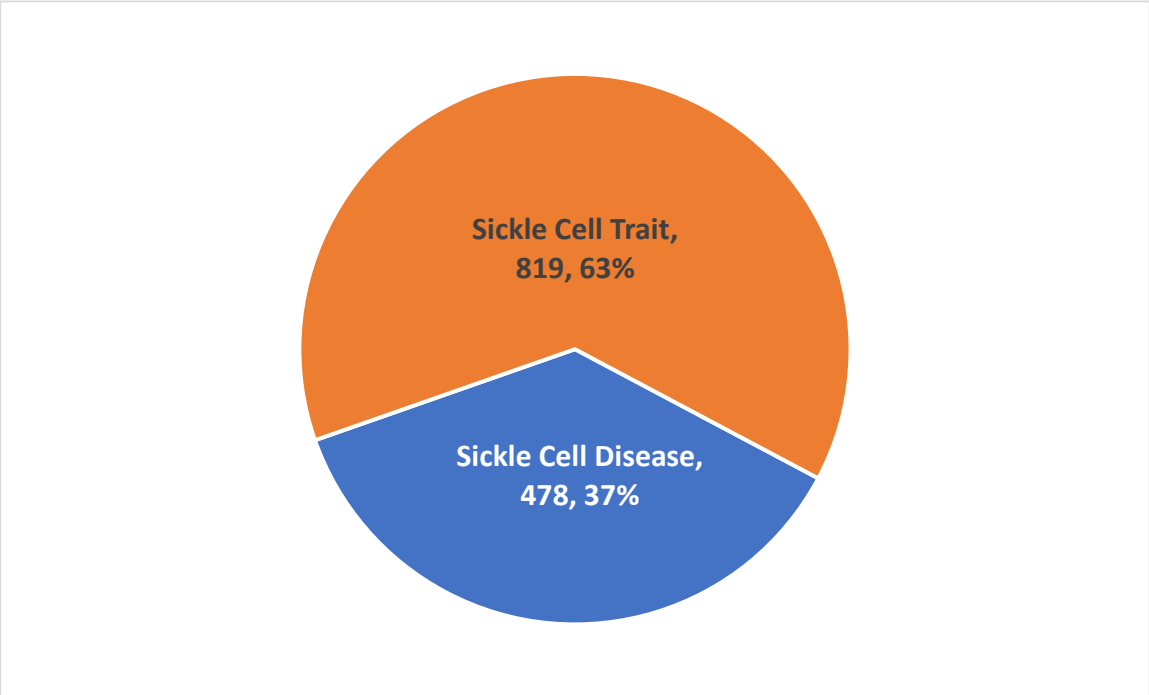
In addition to members with SCD, there were over 800 SoonerCare members in 2025 with sickle cell trait[8] (Exhibit C – 4 on the following page). While individuals with SCT typically do not experience the same health issues as those with SCD, they do face risks.

Under certain conditions, persons with SCT can experience health complications that include muscle breakdown (rhabdomyolysis); reduced blood supply to the spleen (ischemia/infarction); increased pressure in the eye (glaucoma) following eye injuries; and a rare form of kidney cancer (renal medullary carcinoma)[9].

[8] For this count, PHPG included members with only one claim associated with the diagnosis. This lesser standard was used on the presumption that members with no symptoms could have a claim coded for SCT as part of an annual exam. The count of members with two or more claims was 379.

[9] Sickle Cell Trait - Hematology.org

Exhibit C – 4 – SoonerCare Members with SCT or SCD (SFY 2025)



Sickle Cell Disease – SoonerCare Member Demographics

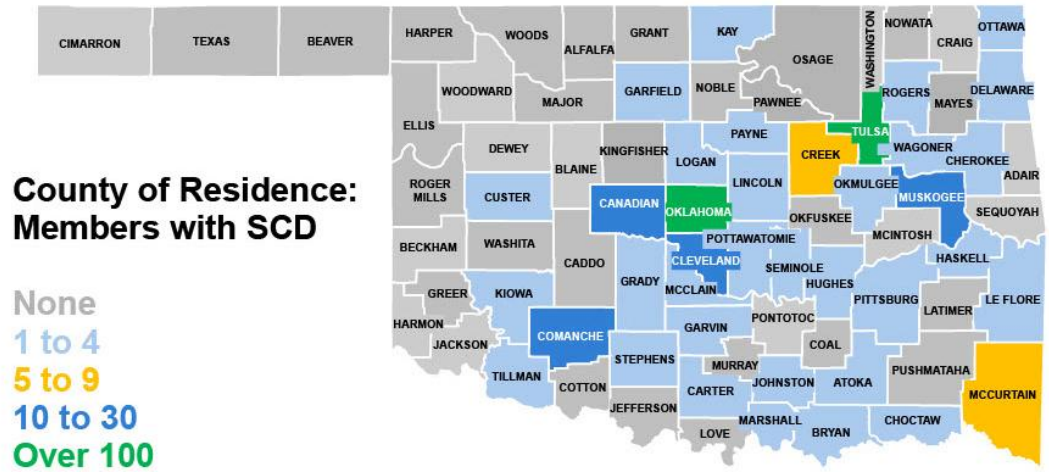
PHPG analyzed SFY 2025 eligibility data to profile the demographic characteristics of SoonerCare members with SCD, including places of residence, age ranges, gender and race/ethnicity. The profile is presented starting on the following page.

County of Residence

SoonerCare members with SCD are not evenly distributed throughout the State. Most reside in Oklahoma and Tulsa Counties, which together are home to over 300 members with SCD (Exhibit C – 5 on the following page).

The next most populated counties are Canadian, Cleveland, Comanche and Muskogee, each with between 10 and 30 members. There are 32 counties with at least one, but fewer than 10 members with SCD; 39 counties have no members with SCD.

Exhibit C – 5 – SoonerCare Members with SCD by County of Residence (SFY 2025)



Oklahoma County contains nearly 40 percent of SoonerCare members with SCD. The top five counties, as a group, account for approximately 80 percent of all members with SCD (Exhibit C – 6).

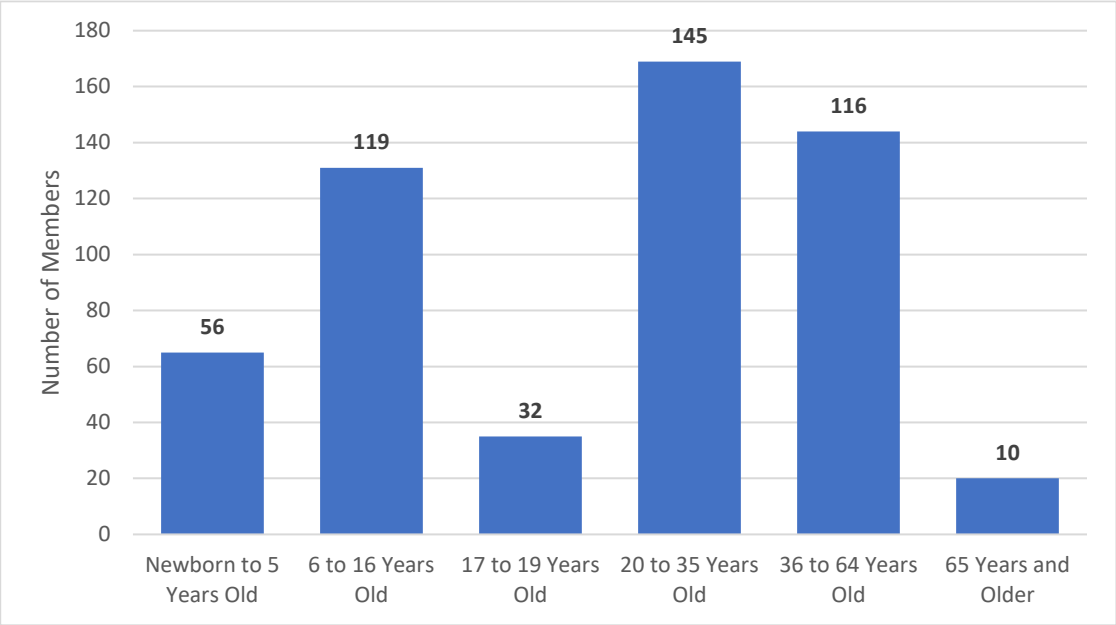
Exhibit C – 6 – SoonerCare Members with SCD – Top Counties (SFY 2025)

County	Number of Members	Percent of Total	Cumulative Percentage
Oklahoma	190	39.7%	39.7%
Tulsa	139	29.1%	68.8%
Cleveland	24	5.0%	73.8%
Comanche	18	3.8%	77.6%
Canadian	15	3.1%	80.7%
Muskogee	12	2.5%	83.2%
Other Counties/Out of State	80	16.8%	100.0%
Total	**478**	**100.0%**	**100.0%**

Age Ranges

Forty-three percent of members with SCD in SFY 2025 were under the age of 20; this included 32 older adolescents ages 17 to 19 approaching the critical transition from child to adult coverage. Adults age 20 to 64 accounted for 55 percent of members while adults 65 and over made-up the remaining two percent (Exhibit C – 7 on the following page).

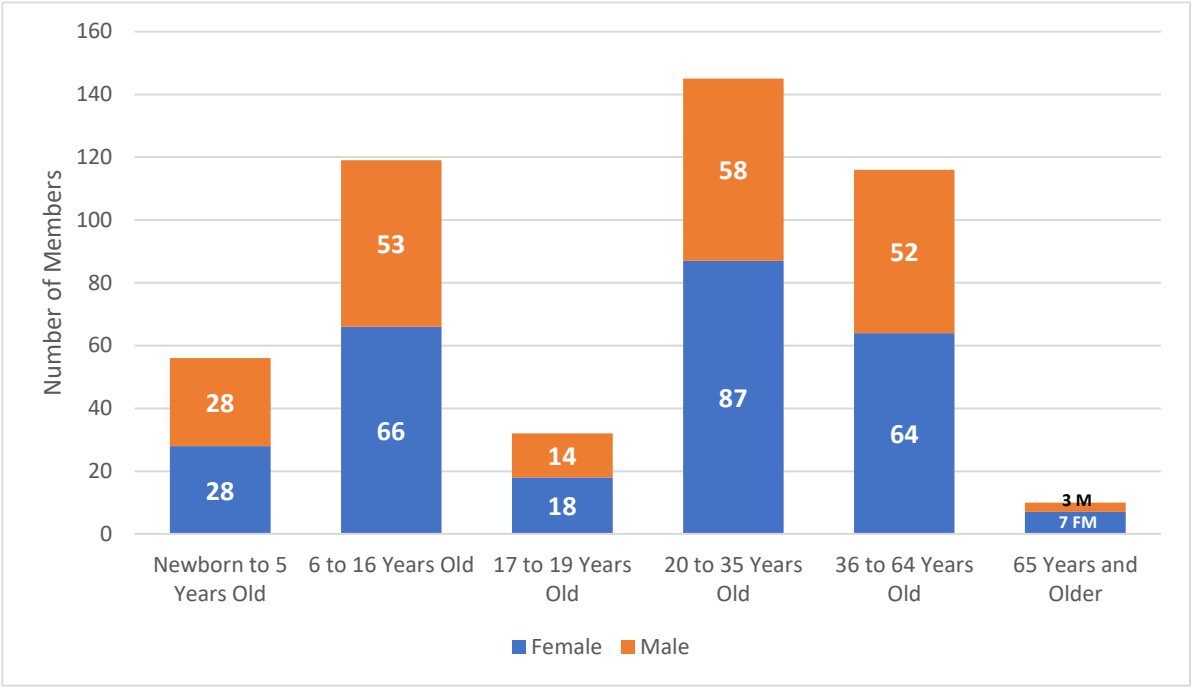
Exhibit C – 7 – SoonerCare Members with SCD by Age Range (SFY 2025)



Age and Gender

Females with SCD accounted for 57 percent of members in SFY 2025 and outnumbered males in all age cohorts except the youngest (Exhibit C – 8).

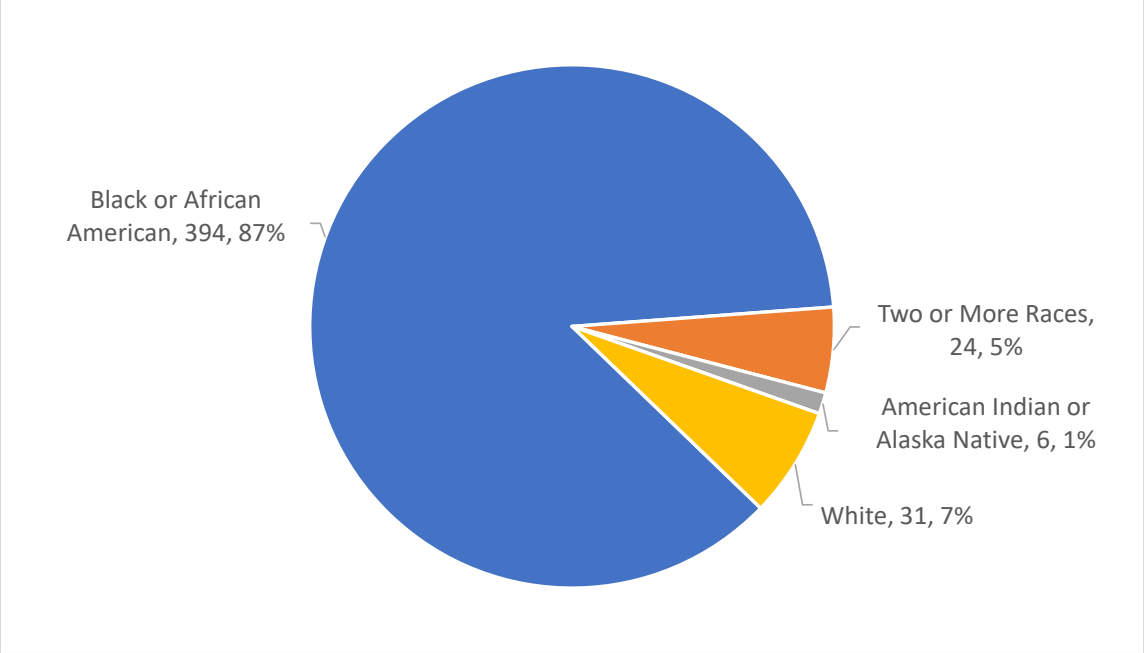
Exhibit C – 8 – SoonerCare Members with SCD by Age Range and Gender (SFY 2025)



Race (Self-Reported)

African Americans comprised 87 percent of members with SCD in SFY 2025, based on self-reported race; they also presumably are represented within a large portion of the "two or more races" cohort (Exhibit C – 9).

Exhibit C – 9 – SoonerCare Members with SCD by Race (Self-Reported)[10]



The next section discusses treatments for people with SCD, including recent medical advancements. It also profiles expenditure trends and service use among SoonerCare members.

[10] Twenty-three members declined to state their race.

2. Treatment of Persons with SCD

Sickle Cell Disease Complications and Treatments

Sickle cell disease is present at birth, with symptoms often appearing in the first year of life and worsening over time. Children and adults with SCD are at greater risk of infection than the general population, including a heightened risk of pneumonia. In addition to being vaccinated, children with sickle cell anemia and severe forms of thalassemia are recommended to take penicillin daily until at least age five.

Children and adults with SCD also can be at heightened risk for stroke, which is identifiable through a special type of ultrasound (transcranial Doppler ultrasound). Stroke risk can be reduced through administration of frequent blood transfusions. Transfusions also are used to address episodes of severe anemia.

The transfusions themselves can cause side effects such as iron overload, which pose the risk of damage to the heart, liver, kidneys and other organs. Blood transfusions typically are accompanied by iron chelation therapy to reduce excess iron in the body[11].

Medications

A variety of prescription drugs have been developed for SCD treatment and can be used for young children and adolescents. These include, among others[12]:

Hydroxyurea – this medication was approved in the 1980s and reduces the development of abnormally-shaped red blood cells. It can be prescribed, starting at age two.

L-glutamine – this is an amino acid that supports the body's fight against infections. It also helps to reduce damage to blood cells. L-glutamine treatments can be prescribed starting at age five.

Crizanlizumab – this medication reduces the risk of blood cell clumping or clotting. It can be prescribed starting at age 16.

[11] This is not an exhaustive listing of SCD-related complications, which can be damaging to many body systems.
[12] The list in a previous report included Voxelotor, which is marketed under the brand name Oxbryta, and is intended to restore red blood cells to their normal shape. The drug was removed from the marketplace in September 2024 due to concerns over patient safety.

There also are new medications in clinical trials or awaiting FDA approval[13]. Etavopivat, a pyruvate kinase (PK) activator that may inhibit the sickling process, is in a phase III trial scheduled for completion in 2026. Osivelotor, a hemoglobin S polymerization inhibitor, is being evaluated in a phase III clinical trial as a potential chronic treatment for SCD.

Bone Marrow/Stem Cell Transplants

In addition to medications, people with SCD may be candidates for bone marrow or stem cell transplants. These procedures offer the potential for a cure but also have high risks and potential serious side effects. They also require a donor who is a close genetic match to the patient, such as a sibling.

Cell and Gene Therapy

In December 2023, the US Food and Drug Administration approved gene and gene-editing therapies for people with SCD that also offer the potential for a cure. The approved therapies are priced at over $2 million per patient and are not yet widely available but could transform treatment of SCD in future years[14].

In July 2025, Oklahoma became one of 33 states and the District of Columbia to participate in CMS' Cell and Gene Therapy (CGT) Access Model. Under the model, participating states receive guaranteed discounts and rebates from participating CGT manufacturers if the therapies fail to deliver their promised therapeutic benefits. The Model also includes optional federal support of up to approximately $10 million per state for implementation, outreach and data tracking activities.

The introduction of new medications and treatments in recent decades has resulted in reduced mortality rates among younger people with SCD. Nationally, from 1979 to 2017 (most recent year available), the median age at death increased from 28 to 43 years. Over that same period, SCD-related death rates among Black children younger than five years of age declined, from 2.05 deaths per 100,000 to 0.47 deaths per 100,000.

Despite these advances, SCD can be a devastating and difficult-to-manage condition for the patient and his or her family. In addition to other health risks and complications, people with SCD may experience severe pain crises brought on by clotting of the abnormally shaped red blood cells.

Patients in crisis often require intensive and continuous opioid-based pain medications that must be administered parenterally (e.g., by intravenous method). The medications

[13] Last year's report mentioned a new P-selection inhibitor (Inclacumab) that was undergoing a phase III trial to determine its safety and efficacy in reducing vaso-occlusive crises. Results of the trial were announced in August 2025 and, unfortunately, found that the drug did not outperform the placebo.

[14] For a detailed recounting a recent patient's experience with gene therapy, see: First Sickle Cell Gene Therapy Patient, 12, Leaves Hospital - The New York Times (nytimes.com)

must be provided either in an emergency room or inpatient setting, where the patient can be monitored and the dosage increased as necessary to achieve pain relief.

One SoonerCare member with SCD who participated in a 2022 Town Hall described the experience of an acute pain crisis as being, "*like shards of glass running through your system*."

SoonerCare Paid Claims Analysis

Methodology

As noted earlier (and discussed in more detail later in the report), the majority of the SoonerCare population transitioned to the SoonerSelect managed care program in April 2024. The SoonerSelect Care Entities (CEs) are paid a per member per month (PMPM) premium intended to cover all medical costs.

The CEs are responsible for paying provider claims and then submitting electronic "encounter" records that duplicate the information on the claims. During the program's first year, the OHCA and CEs worked collaboratively to finalize the encounter reporting process and improve the reliability and completeness of the data[15].

Aged, Blind and Disabled (ABD) beneficiaries did not transition to SoonerSelect. American Indian beneficiaries in the SoonerCare Choice program were given the option to enroll in SoonerSelect or remain in SoonerCare Choice or SoonerCare Traditional; most elected not to change programs.

PHPG's 2025 paid claims analysis was limited to the portion of the population that remained outside of SoonerSelect. This included 220 of the 487 members with SCD enrolled in Medicaid.

The ABD population overall is older and costlier than the SoonerSelect population. Those members with SCD who remain outside of SoonerSelect likely also have higher average service use and costs than the SoonerSelect cohort. However, the gap between the two SCD populations may be relatively small, given that most members with SCD (regardless of eligibility type) have ongoing care needs, while many other SoonerSelect beneficiaries are healthy children/adolescents and young adults.

PHPG will review the completeness of encounter data prior to next year's evaluation and, if appropriate, will report findings for all populations, including SoonerSelect members.

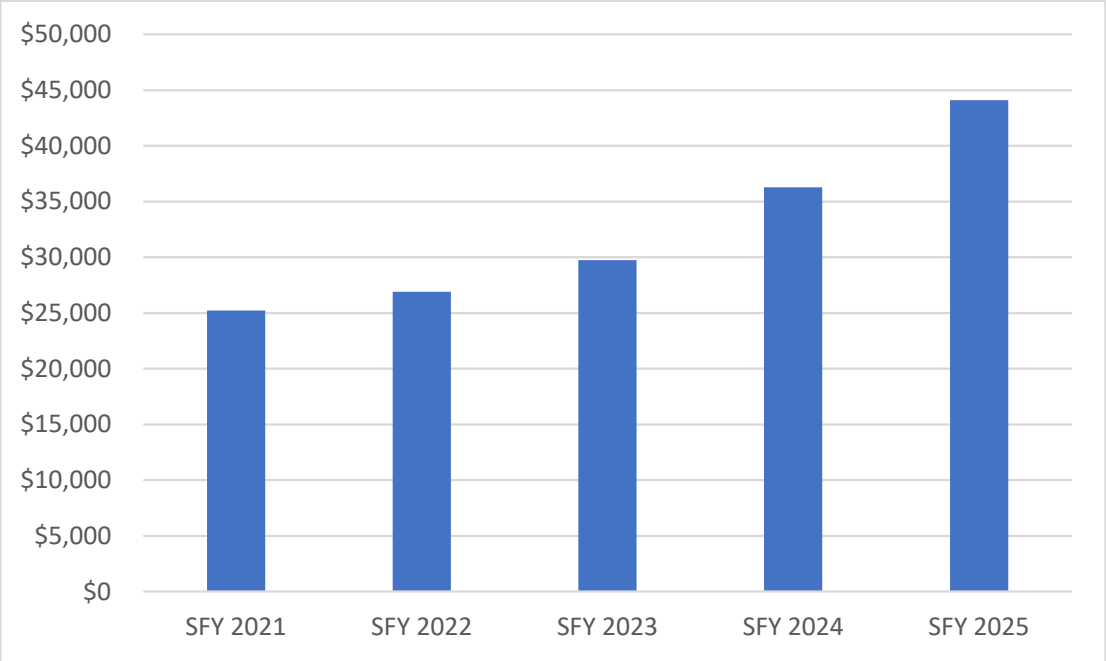
[15] It is common for new managed care programs to have incomplete encounter data reporting during the first year. Oklahoma is not an outlier in this respect.

Expenditures

SoonerCare Choice and Traditional members had average annual medical claim costs of $44,087 in SFY 2025 (Exhibit C – 10). By comparison, the average expenditure per SoonerCare member program wide in SFY 2024 was $5,792[16].

Caution should be exercised when comparing 2025 costs to prior years, due to the exclusion of SoonerSelect members. A portion of the increase from 2024 to 2025 may be attributable to the change in member mix.

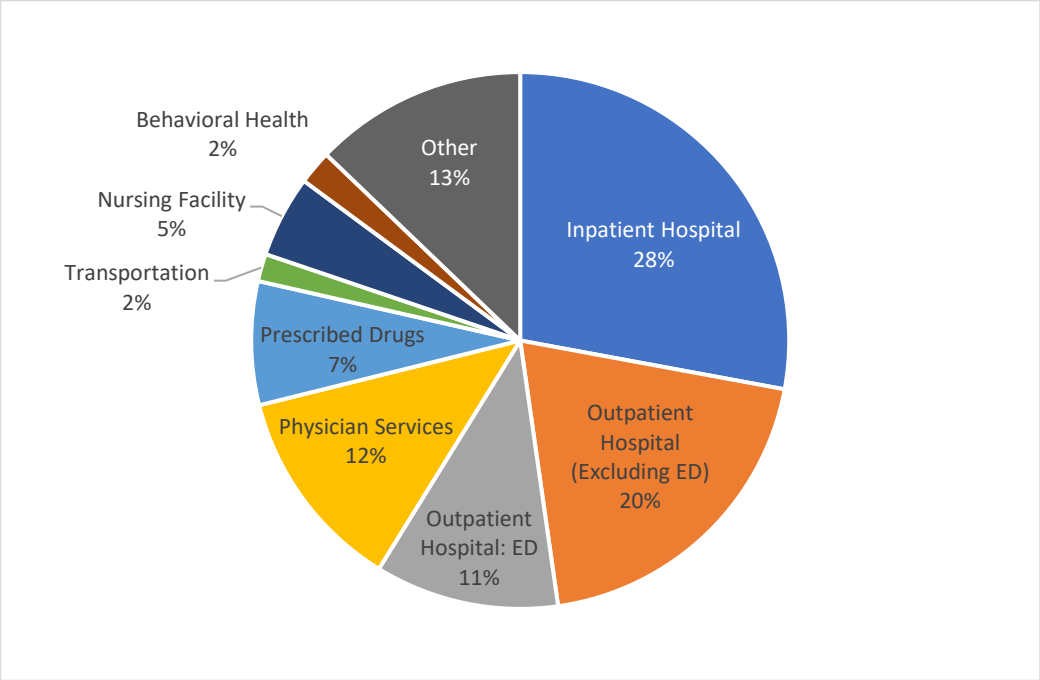
Exhibit C – 10 – Average Annual Expenditures per Member – SFY 2021 to SFY 2025



The largest service category, in terms of paid claims, was inpatient hospital, followed by outpatient hospital (non-emergency room), physician services, emergency room visits and prescribed drugs (Exhibit C – 11 on the following page).

[16] Source: Historic Category of Member Services and Expenditures (oklahoma.gov). Figure for SFY 2025 not yet available.

Exhibit C – 11 – Expenditures by Service Category (SFY 2025)



Although the average expenditure per SoonerCare Choice/Traditional member in 2025 was over $44,000, there was a wide range between low- and high-cost members. The top eight percent of members averaged nearly $200,000 each and accounted for over 55 percent of total expenditures. Conversely, the bottom 20 percent of members accounted for less than one percent of total expenditures (Exhibits C – 12 and C – 13).

Exhibit C – 12 – Expenditures per Member by Expenditure Range (SFY 2025) – Chart

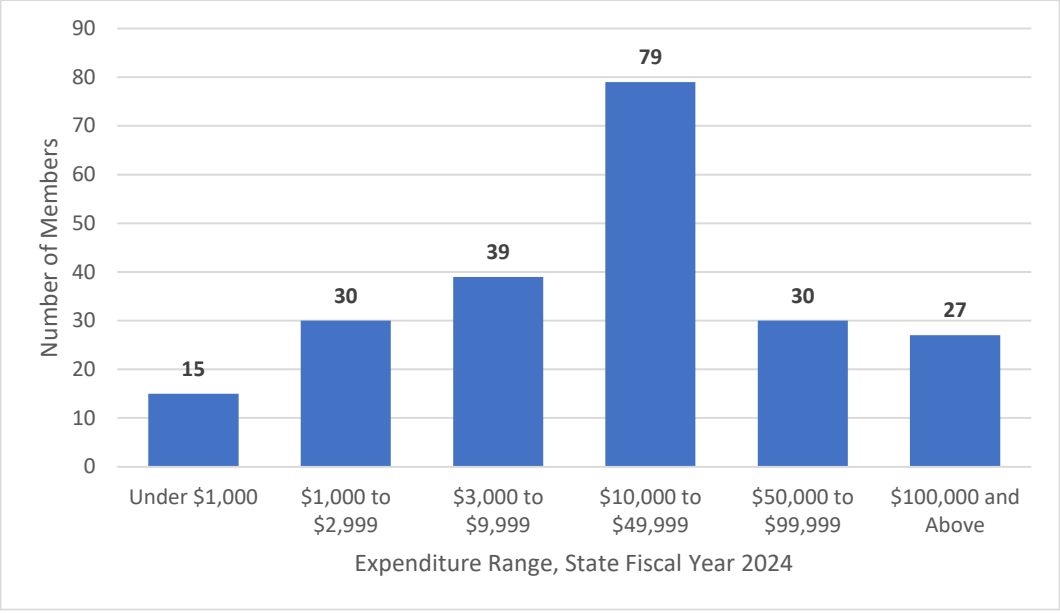


Exhibit C – 13 – Expenditures per Member by Expenditure Range (SFY 2025) - Table[17]

Expenditure Range	Number of Members	Percent of Members	Average Per Member	Percent of Expenditures
Under $1,000	15	6.8%	$491.32	0.1%
$1,000 to $2,999	30	13.6%	$1,855.30	0.6%
$3,000 to $9,999	39	17.7%	$5,989.34	2.4%
$10,000 to $49,999	79	35.9%	$25,314.52	20.6%
$50,000 to $99,999	30	13.6%	$67,970.38	21.0%
$100,000 and above	27	12.3%	$198,672.82	55.3%
Total	**220**	**100.0%**	**$44,089.72**	**100.0%**

Physician Services

Most members with SCD saw a Patient Centered Medical Home provider at least once in SFY 2025. The average number of visits per member was considerably higher, particularly for adult members seeing internists (Exhibit C – 14).

Exhibit C – 14 – PCMH Provider Type Activity (SFY 2025)[18,19]

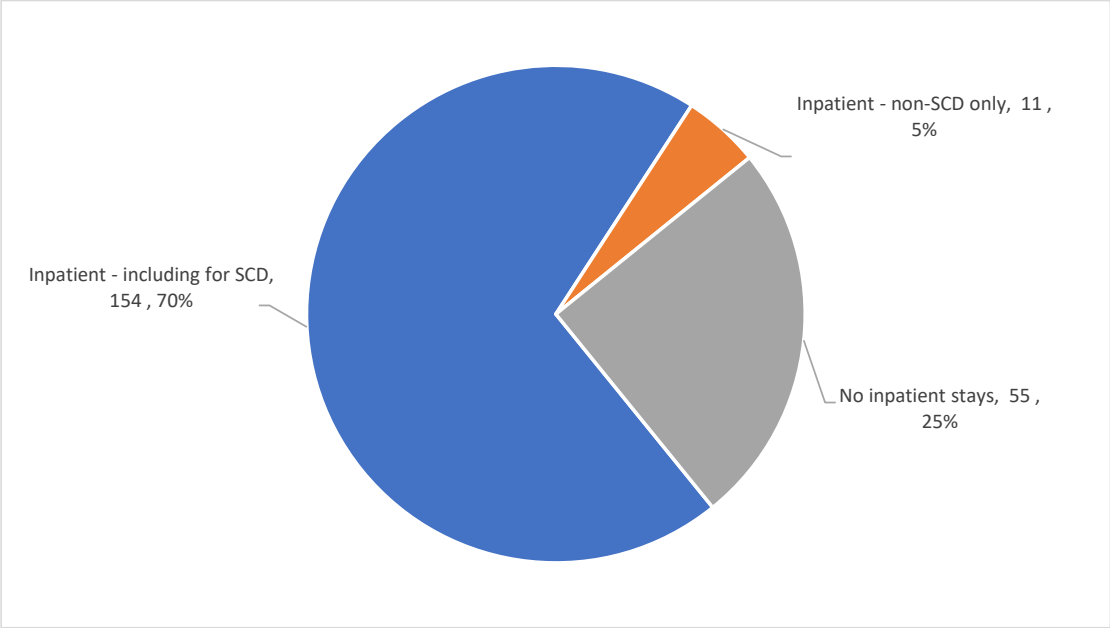
Primary Care Provider Type	Number of Members	Number of Visits	Average Per Member	Percent of Members
Family Practitioner	142	621	4.4	30.1%
General Pediatrician	86	852	9.9	18.2%
Internist	128	1,457	11.4	27.1%
General Practitioner	34	156	4.6	7.2%

Members saw a variety of specialists, the most common of which were hematology/oncology providers. The hematology/oncology providers treating members with SCD are concentrated in Oklahoma City and Tulsa, with smaller numbers practicing elsewhere, including Lawton and Muskogee.

[17] SoonerCare Choice and Traditional members only. The OHCA pays SoonerSelect CEs a fixed PMPM amount per member based on age, gender and aid category.
[18] Member count is not unduplicated. Members who saw multiple physician types are shown within each category to provide an accurate total visit count.
[19] SoonerSelect members are not included in the data. However, the OHCA evaluates SoonerSelect CE performance with respect to ensuring members receive their recommended schedule of primary care visits.

Seventy-five percent of SoonerCare Choice/Traditional members with SCD had at least one inpatient stay in SFY 2025. Nearly all the members with inpatient stays were hospitalized at least once for treatment of an SCD-related condition, such as an acute pain crisis (Exhibit C – 15).

Exhibit C – 15 – Inpatient Hospital Stays – 1 or More (SFY 2025)



Emergency Departments

SoonerCare members with SCD who experience a pain crisis must be treated in a hospital setting, either in the emergency room or as an inpatient. Medications, including opioids, are administered parenterally and require continuous monitoring.

Oklahoma was one of the first states to be affected severely by the opioid crisis. It also was one of the first to take concerted action in response, both legislative (through the State's Anti-Drug Diversion Act) and in policy.

The OHCA in the past decade implemented a strategy for lowering gradually the opioid dosage that providers could prescribe most patients without prior authorization. The OHCA also expanded its contract with the SoonerCare Health Management Program (HMP) vendor to include pain management education for providers with a history of prescribing opioids more extensively than their peers.

One unintended consequence of the campaign to reduce inappropriate use of opioids has been to make it more difficult for members with SCD to receive necessary medication

when experiencing a pain crisis. Providers unfamiliar with the nature of the disease can be reluctant to accede to a patient's urgent request for prescription pain medication.

In its 2021 regular session, the Oklahoma Legislature addressed the pain management needs of people with conditions like SCD through passage of SB 57, which amended the State's Anti-Drug Diversion Act. At the recommendation of the patient advocate community, new language was inserted that states:

> *"Nothing in the Anti-Drug Diversion Act shall be construed to require a practitioner to limit or forcibly taper a patient on opioid therapy. The standard of care requires effective and individualized treatment for each patient as deemed appropriate by the prescribing practitioner without an administrative or codified limit on dose or quantity that is more restrictive than approved by the Food and Drug Administration (FDA)."*[20]

The SB 57 language removed a statutory barrier to treating members with SCD, and OHCA coverage policy aligns with the statute. However, the experience of members with SCD who seek treatment in an emergency room still varies based on the knowledge of providers about their condition and their recognition (or lack thereof) of the need to prescribe very high doses of pain medication. This finding was part of PHPG's initial report to the legislature in January 2023 and continues to be the case today. (See Member Perceptions in next section for more on this topic.)

In SFY 2025, 176 out of 220 SoonerCare Choice/Traditional members with SCD, or 80 percent, had at least one emergency room visit. By comparison, 38 percent of all SoonerCare members visited the emergency room in SFY 2023[21].

The total population sought care in the emergency room an average of 8.5 times each; the subset with one or more visits sought care an average of 10.6 times each. These results were driven in part by the top 15 members (those with over 30 visits), who accounted for approximately 50 percent of all emergency room activity (Exhibit C – 16).

Exhibit C – 16 – Emergency Room Visit Activity (SFY 2025)

Number of Visits	Number of Members	Number of Visits	Average Per Member	Percent of Visits
1 Visit	35	35	1.0	1.9%
2 – 3 Visits	45	109	2.4	5.8%
4 – 8 Visits	47	269	5.7	14.4%
9 – 15 Visits	20	221	11.1	11.9%

[20] Section 2.K of the Act.
[21] Emergency Department FF SFY2023.pdf. Most recent year available.

Number of Visits	Number of Members	Number of Visits	Average Per Member	Percent of Visits
16 – 30 Visits	14	295	21.1	15.8%
31 – 50 Visits	7	278	39.7	14.9%
Over 50 Visits	8	657	82.1	35.2%
Total	**176**	**1,864**	**10.6**	**100.0%**

The emergency rooms at OU Health Sciences Center and Saint Francis have evidence-based protocols for treatment of patients in crisis, and at least providers who are familiar with how to treat the condition[22]. (These hospitals serve as major centers for treatment of SCD in the two largest metropolitan areas, as discussed below.)

However, as PHPG documented in the first two annual reports, most emergency room physicians see only one or two cases per year. These "low incidence" providers nevertheless account for hundreds of visits each year.

SoonerCare Delivery System and Care Management

Delivery System

Individuals with SCD often require support from multiple specialties, with hematology typically serving as the nexus for their care. The SoonerCare program is open to all licensed and qualified physicians in the State.

As noted, Oklahoma has two sites that serve as the lead providers for treatment of people with SCD, including SoonerCare members. They are the Jimmy Everest Center at Oklahoma University (OU) Children's Hospital in Oklahoma City and, to a lesser extent, the pediatric hematology program at Saint Francis Health System in Tulsa.

The OU program was created in 1993 and, at the time of PHPG's original study, reported having served approximately 200 patients during the previous two-year period (2021 – 2022), over 80 percent of whom were covered through SoonerCare. The program is interdisciplinary and includes hematologists, behavioral health professionals, a pharmacy liaison, a pediatric nurse practitioner and a nurse coordinator/care manager.

Services include, but are not limited to, a dedicated infusion unit and in-house pharmacy that stocks all newly approved FDA medications and a bone marrow transplant program. Center staff provide support at the pediatric emergency room and to hospital inpatients.

[22] Advocates for members with SCD shared anecdotes with PHPG that suggest protocols based on national standards are not always followed.

Jimmy Everest provides care for SCD patients until age 21. The center assists with transitioning the patients to adult care as early as age 13; adults go either to the OU Cancer Center or to a local provider that sees adults.

The OU program also is part of a multi-state provider consortium headed by Washington University (St. Louis, MO) that meets regularly to review emerging trends and best practices. The consortium receives funding to support its activities from the federal Health Resources and Services Administration (HRSA). OU is part of the HRSA SCD Southwest Region.

The Saint Francis program, while smaller, reported during PHPG's initial study that it serves 90 patients at any point in time. The program is located within the hematology/oncology department and includes both physicians and a nurse coordinator. Program hematologists also support Saint Francis emergency room physicians, as needed.

Notwithstanding the services at Saint Francis, both members and advocates consider Tulsa to have a shortage of hematologists willing to treat members with SCD.

Supporters of Families with Sickle Cell Disease

Supporters of Families with Sickle Cell Disease is a comprehensive community-based organization serving individuals and families living with sickle cell and thalassemia disease and trait in Oklahoma. The organization is based in Tulsa but works on behalf of families throughout the State. It receives funding through the HRSA grant for the Southwest Region. The organization also has a contract with the OHCA.

The OHCA contract outlines three major goals: Improve quality of life, creating successful working and living interaction for those with sickle cell diseases and traits; improve health outcomes related to sickle cell disease; and realize cost savings through outreach and education efforts targeting sickle cell diseases and traits.

The organization's scope-of-work for the OHCA includes[23]:

- Identifying and educating the Oklahoma sickle cell community individuals eligible for Medicaid medical assistance and carriers of sickle cell diseases and traits;
- Collaborating with OHCA Chronic Care Management on members with sickle cell disease needing additional community-based supports;
- Coordinating statewide collaborative efforts with key organizations in order to identify current resources: current Sickle Cell research and any other key Sickle Cell Entities (national and/or local);

[23] Condensed from original language for space and readability; updated to reflect changes since original execution. The OHCA will be issuing an RFP in 2026 for the next contract cycle.

- Creating a free-standing website that is full of resources and an interactive source for sickle cell disease individuals, carriers and their families;
- Enhancing social media presence based on target population, using data and analytics to guide work in this area: Facebook, Twitter, Instagram, Snapchat, and Constant Contact Email Newsletter;
- Pursuing a strong relationship with state agencies for sickle cell disease-hematology for further community reach: Determining existing and current outreach; determining how this outreach can be enriched and further developed; coordinating and developing a sickle cell disease Outreach Plan and targeting Cell Disease audiences, including members and providers with a youth component for member outreach;
- Training providers regarding the sickle cell disease Outreach Plan;
- Working with clinicians to educate on industry best practices;
- Providing SCD collaboration between patients, families, clinicians; and
- Focusing on compliance critical to medication and treatment plans.

Following implementation of SoonerSelect in 2024, the contract for Supporters of Families with Sickle Cell Disease has been limited to SoonerCare Choice and Traditional members. The organization has sought, so far unsuccessfully, to sign a contract with each of the SoonerSelect CEs to provide similar types of support to their members.

Care Management – Best Practices

Individuals with complex/chronic diseases such as SCD often require care from multiple medical specialties, as well as behavioral health services, to cope with what is a life-long condition. Navigating the system without support can lead to fragmented care or gaps in care, as well as patient discouragement.

As outlined in previous reports, one recognized best practice for managing complex care needs is through establishment of a member-centered interdisciplinary care team capable of offering holistic, integrated care[24]. The team typically includes representatives from all specialties relevant to the individual's health needs, both interventionist and palliative, as well as a designated care manager (usually a nurse or social worker) to coordinate the team's activities. As suggested by its name, the team places the member at its center, and s/he retains autonomy for choosing the preferred course of care.

[24] For a discussion of the benefits of the interdisciplinary team model, see: Implementation of an Interdisciplinary, Team-Based Complex Care Support Health Care Model at an Academic Medical Center: Impact on Health Care Utilization and Quality of Life, Implementation of an Interdisciplinary, Team-Based Complex Care Support Health Care Model at an Academic Medical Center: Impact on Health Care Utilization and Quality of Life | PLOS ONE

Medicaid beneficiaries often face additional, non-clinical hurdles to accessing care. These factors, referred to either as "health related social needs" (HRSN) or "social determinants of health" (SDOH), can include housing insecurity, food insecurity, difficulty making utility payments and lack of reliable transportation, among others. A person with significant HRSN/SDOH needs may, by necessity, regard their health care needs, particularly preventive health care, as a lesser priority.

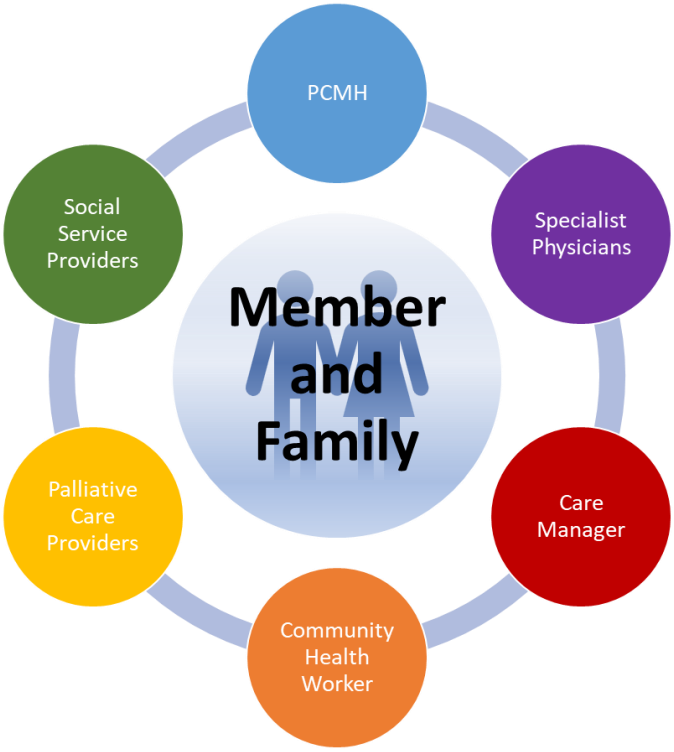
Individuals enrolled with an interdisciplinary care team typically receive a comprehensive assessment, followed by creation of a care plan that addresses both clinical and non-clinical (social) needs. Preventive and therapeutic services are addressed, with preventive services for members with SCD encompassing condition-specific interventions, such as hydration therapy or blood transfusions (as applicable). HRSN/SDOH needs may be managed by a Community Health Worker trained in this task[25].

The interdisciplinary care team can facilitate the transition from pediatric to adult care by assessing a member's readiness to transition, planning for the transition and facilitating the transfer. Peer support can also be made available, if desired by the member.

The composition of the team can evolve concurrently, with adult providers replacing their pediatric counterparts as appropriate (Exhibit C – 17 on the following page).

[25] For a description of the CHW function within an interdisciplinary care team, see: Addressing Social Determinants of Health through Community Health Workers: A Call to Action, HHC-CHW-SDOH-Policy-Briefi-1.30.18.pdf (cthealth.org)

Exhibit C – 17 – Interdisciplinary Care Team Model



There also is a growing body of research on the value of using mobile applications (smart phone technology) to support monitoring of patients with chronic conditions, including SCD. A 2018-2019 Agency for Healthcare Research and Quality-funded randomized study conducted at Duke University on 59 patients with SCD being discharged from the hospital found that:

> *Patients using SMART had significantly less acute care utilization and were more likely to return for follow up visits. The use of a simple technology solution such as a mobile app to record symptoms, allowed symptoms such as pain to be reviewed remotely. Daily review of pain scores remotely provided the medical team with the ability to text specific patients believed to be at risk due to increasing pain. To aid in follow up, SMART also included the ability to have a reminder for an appointment 'pop-up'. Technology reminders also led to patients being more likely to return as scheduled for their appointment as compared to standard-of-care (control group)[26].*

A mobile app could have particular appeal to younger members with SCD. Individuals who both are enrolled with an interdisciplinary care team and equipped with a mobile app would be well supported when navigating the health care system.

[26] SMART Mobile Application Technology Utilization in the Treatment of Sickle Cell Disease Post Day Hospital Discharge - Full Text View - ClinicalTrials.gov

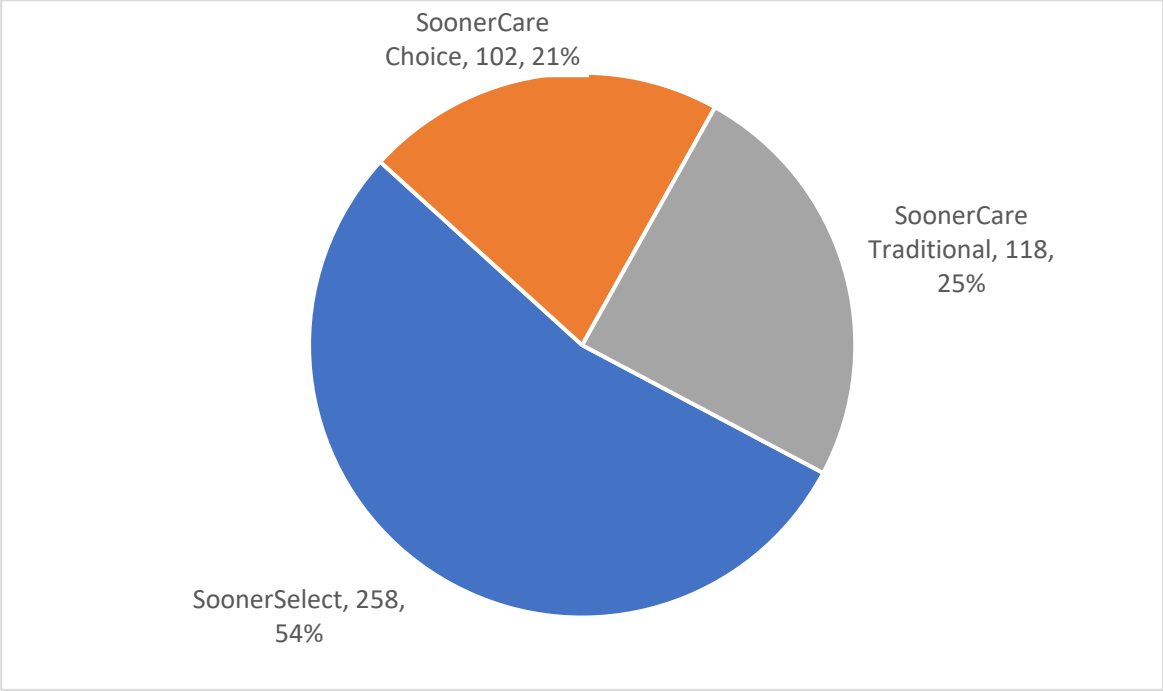
Care Management in the SoonerCare Program

Prior to 2024, most Medicaid members in Oklahoma were enrolled in SoonerCare Choice, the OHCA's primary care case management model. SoonerCare Choice enrollees select a primary care provider to serve as their patient centered medical home, or PCMH. The PCMH is responsible for coordinating the member's care needs, including specialist referrals. Members who require consultation with a specialist generally first must obtain a referral from their PCMH.

As noted earlier, the SoonerCare program underwent a major transition in April 2024 with the implementation of SoonerSelect risk-based managed care. The SoonerSelect CEs serve non-disabled children and adults, including persons eligible because of Medicaid expansion. The MCEs are responsible for all Title-XIX medical, behavioral health and social services. Slightly over 50 percent of members with SCD are now enrolled with one of the three private managed care entities participating in the program.

The remaining members are divided almost evenly between the SoonerCare Choice PCMH program and the SoonerCare Traditional program. SoonerCare Choice serves Aged, Blind and Disabled members who are not eligible for Medicare, as well as American Indians who have opted out of SoonerSelect. SoonerCare Traditional serves members dually-eligible for Medicaid and Medicare and the long-term care population (Exhibit C – 18).

Exhibit C – 18 – SoonerCare Members with SCD by Program (SFY 2025)



SoonerSelect CEs are required to assess the needs of their members at time of enrollment and to offer care management to those who need it. In its SoonerSelect Request for Proposals, the OHCA emphasized the importance of care management for members with SCD by requiring respondents to describe how they would manage the needs of a hypothetical member with SCD experiencing a pain crisis.

The OHCA conducts annual outreach to all members with a sickle cell diagnosis and has both internal programs and contracts with outside organizations to provide enhanced care management to SoonerCare Choice and Traditional members with complex conditions such as SCD. These include: the OHCA Chronic Care Management (CCM), SoonerCare HMP and SoonerCare Health Access Networks (HANs).

The SoonerCare CCM is located within the OHCA and is staffed by nurses who provide telephonic care management to participating members (participation is voluntary). The CCM routinely analyzes paid claims data to identify members at highest risk for adverse health outcomes and invites these members (or parents/caregivers of the members) to participate. The two criteria for enrollment are $50,000 or more in paid claims during the prior 12 months and five or more emergency room visits. In SFY 2025, the CCM provided care management to 98 members with SCD, up from 63 members in the prior year.

CCM nurses assist with clinical needs, including prior authorizations, transportation and specialist appointments. Nurses inquire about social service needs (e.g., housing or food insecurity) at time of enrollment and make referrals as appropriate. Nurses also reach out to members or parents/caregivers of adolescent members to facilitate the transition from pediatric to adult coverage.

The SoonerCare HMP is a vendor-operated care management program that provides a mix of in-person and telephonic care management to SoonerCare Choice members with complex/chronic health conditions. The HMP is holistic and does not target specific health conditions. The program serves approximately 6,000 participants per year, a small number of whom have SCD. (In SFY 2025, nine members with SCD were enrolled in the SoonerCare HMP.)

The SoonerCare HANs are non-profit, administrative entities that work with affiliated providers to coordinate and improve the quality of care provided to SoonerCare Choice members. The HANs employ care managers to provide telephonic and in-person care management to members with complex health care needs who are enrolled with affiliated PCMH providers.

The OHCA contracts with two HANs: University of Oklahoma SoonerHAN and Oklahoma State University HAN. The HANs' combined enrollment prior to SoonerSelect exceeded 300,000, of which approximately 4,000 received care management over the course of a year. HAN enrollment was reduced substantially with implementation of SoonerSelect,

but the HAN-affiliated physicians continue to treat a large portion of the SoonerCare Choice ABD population[27].

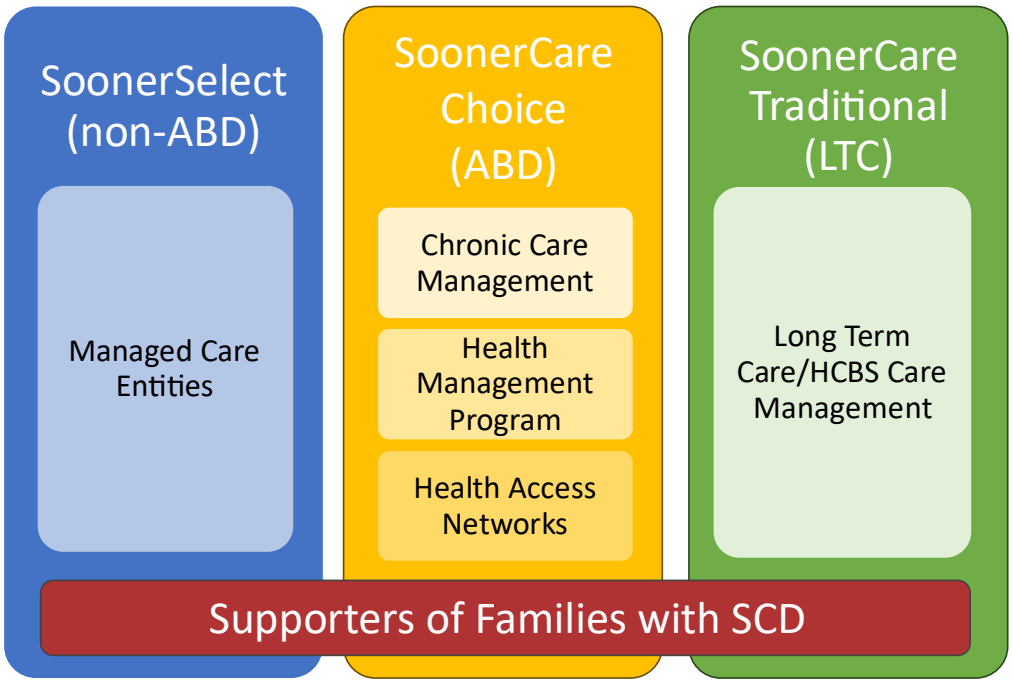
The HANs historically have provided care management to a small number of members with SCD, identified through data analytics or physician referral. In SFY 2025, there were approximately 60 members with SCD aligned with a HAN-affiliated PCMH provider.

A small number of members with SCD are eligible for long term care and are enrolled in one of the OHCA's home- and community-based "waiver" programs[28] or receive care in an institutional setting. These members receive care management as a component of their long-term care eligibility.

Supporters of Families with Sickle Cell Disease also offers support to all members, regardless of eligibility type. The organization has a formal contractual relationship with the OHCA and has sought to execute contracts with the CEs.

Exhibit C – 19 summarizes the various care management models and programs available to SoonerCare members with SCD.

Exhibit C – 19 – SoonerCare Care Management Models



[27] The two HANs also contract with one of the SoonerCare CEs and continue to serve a portion of the SoonerSelect population through these contracts.

[28] The term "waiver" refers to the authority under which the home- and community-based services (HCBS) programs operate. States must obtain a waiver of traditional Medicaid rules that cover long term care only in an institutional setting. The largest Medicaid HCBS waiver is the state's *AD*vantage program for frail elders and adults with physical disabilities.

Sickle Cell Disease – Barriers to Care

As documented in the previous reports, patients and families with SCD face numerous potential health disparities/barriers to care. Patients living outside of major metropolitan areas may not have local access to a hematologist with specialized knowledge of the condition, necessitating lengthy travel for care.

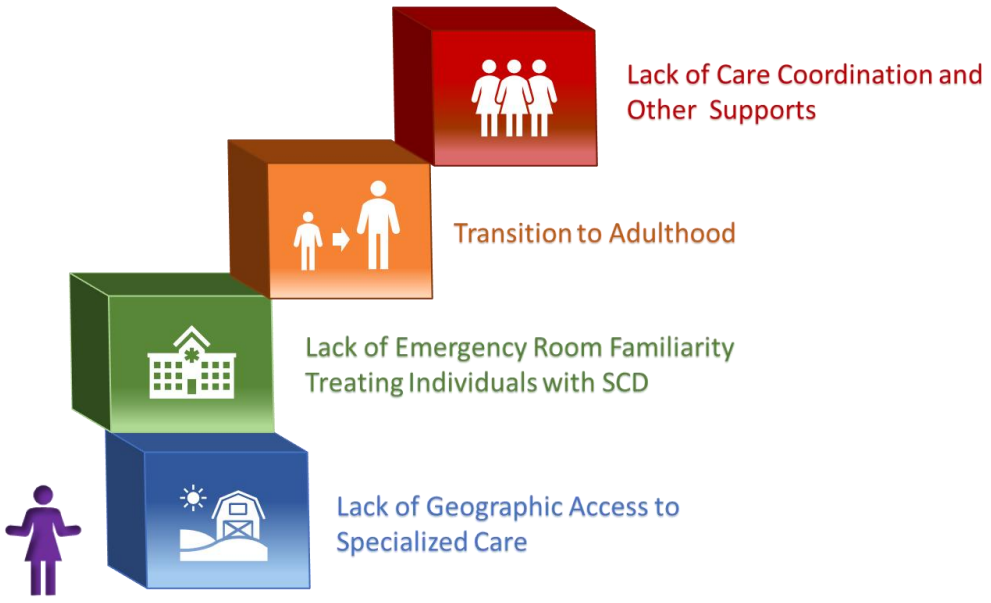
Emergency room providers unfamiliar with SCD may be reluctant to take aggressive steps to manage the pain of patients in crisis. This can prolong the episode and the patient's level of distress.

Adolescents approaching adulthood may be confronted with the need to change providers, if their current provider restricts his or her practice to pediatric patients. SoonerCare members also face a change in benefits when they reach age 19, including a limit on monthly prescription medications and specialist visits, absent prior authorization[29].

As a life-long chronic condition, SCD also requires a comprehensive approach to care. Patients and families with social stresses and needs may be ill-equipped to manage day-to-day care needs without additional supports.

All of these barriers, alone or in combination, can exacerbate a patient's condition, while also placing strains on the family (Exhibit C – 20).

Exhibit C – 20 – Examples of Health Disparities/Barriers to Care



[29] SoonerSelect CEs may waive adult benefit limits as a "value-added" benefit.

PHPG explored member perceptions of care through a structured telephone survey conducted in November 2025. Supporters of Families with Sickle Cell Disease held a virtual Town Hall meeting on December 18, to hear about the experiences of members throughout the State. (PHPG, OHCA and SoonerSelect CE representatives also attended.) Findings from the survey and Town Hall are presented in the next section.

D. MEMBER PERCEPTIONS OF CARE

1. *Data Collection*

Survey Data Collection

PHPG developed a structured member survey instrument during the first annual evaluation and updated it in 2024 to account for the SoonerSelect program. The updated survey was used again in 2025. The survey, which was conducted by telephone, inquired about:

- Regular source(s) of care
- Experience with care management, if any
- Types of sickle cell-related services received and satisfaction with care
- Emergency room use and satisfaction with care
- Transition-of-care for members aging into adulthood
- Suggestions for improving access to, and quality of care

PHPG mailed advance letters to every household with a SoonerCare member with SCD before placing calls. Surveyors made multiple contact attempts over a 30-day period, including in the evening and on weekends. (The advance letter also included a toll-free number that members could call at any time to participate in the survey.)

Forty-three surveys were completed with adult members or the parents/caregivers of members under age 18. The respondents included 40 people with sickle cell anemia and three with thalassemia.

The results were analyzed for respondents in total and by program of enrollment. Eighteen respondents were enrolled in SoonerSelect and the other 25 in SoonerCare Choice or Traditional. Differences between SoonerSelect and the other two populations are noted where applicable.

Town Hall Meeting

Supporters of Families with Sickle Cell Disease organized a virtual Town Hall meeting on the evening of December 18, 2025, and extended invitations to sickle cell families and stakeholders across Oklahoma. Over 100 people attended the meeting, including

patients, family members, advocates, front line staff (nurses and community health workers) and representatives of the SoonerSelect CEs. (PHPG and OHCA representatives attended as observers.)

The topics covered were like those addressed in the survey, but the format allowed for a more in-depth exploration of individual experiences than is possible through a structured survey. The Town Hall format also facilitated sharing of ideas for how services could be improved.

Town Hall participant comments are interspersed in the findings below, along with data from the member survey.

2. Findings

Regular Source of Care

Forty-one of the 43 survey respondents (95 percent) confirmed that they have a regular provider, either a primary care physician or hematologist. This was an improvement from the 81 percent who reported having a regular provider in last year's survey. The remaining two reported using the emergency room as their regular source for care (Exhibit D – 1).

Exhibit D – 1 – Regular Source of Care

Source	*All Respondents*	*SoonerSelect*	*SoonerCare Choice/ Traditional*
Family Practice	48.8%	38.9%	56.0%
General Internist	2.3%	--	4.0%
Pediatrics	39.5%	55.6%	28.0%
Hematology	4.7%	--	8.0%
Emergency Room	4.7%	5.5%	4.0%
TOTAL	**100.0%**	**100.0%**	**100.0%**

Most respondents with a primary care provider also reported having another doctor, usually a hematologist, to help manage their care. SoonerSelect members were more likely to have a specialist, in addition to a primary care provider (Exhibit D – 2 on the following page).

Overall, 33 of the 43 respondents (77 percent) reported having a specialist provider in addition to a primary care provider. (Best practice is to have both provider types, to ensure regular preventive care needs are met.) This also was an improvement of last year's survey, when 57 percent reported having both provider types. The improvement was concentrated in the SoonerSelect population.

Exhibit D – 2 – Specialist in addition to Primary Care Provider

Specialist	*All Respondents*	*SoonerSelect*	*SoonerCare Choice/ Traditional*
Yes - Hematology	58.1%	66.7%	52.0%
Yes- Other (e.g., Oncology)	18.6%	22.2%	16.0%
No	23.3%	11.1%	51.8%
TOTAL	**100.0%**	**100.0%**	**100.0%**

Eight survey respondents (seven SoonerSelect members and one SoonerCare Choice member) reported having a non-physician care manager to assist with obtaining needed services and addressing other sickle-cell related needs. Although the number was low, it was up from last year's survey, when only two members reported having a care manager.

It is possible that some respondents with care managers answered "no" to this question because they are unfamiliar with the concept by that name. It also is likely that some members were offered but declined to enroll in care management.

However, it appears that, despite some improvement, the great majority still lack (or believe they lack) this resource. Care management is a best practice for individuals with complex/chronic health conditions such as sickle cell disease.

The OHCA identified SCD care management as a priority during the SoonerSelect procurement and evaluated offerors on their expertise serving members with SCD. PHPG asked the seven SoonerSelect members additional questions about the nature of their care management support. Survey respondents reported receiving help across a range of activities (Exhibit D- 3 on the following page)[30].

[30] PHPG also asked these questions to the one SoonerCare Choice member with a care manager. The member answered "yes" to each of the activities.

Exhibit D – 3 – Care Manager Activities (SoonerSelect Members)

Activity – Did your care manager…	*Yes Received*	*Did not Receive or Don't Know*
Ask questions about health problems related to SCD	100.0%	--
Discuss treatment options with you	85.7%	14.3%
Help you to make and keep health care appointments with specialists	85.7%	14.3%
Help you create or update a pain management action plan	57.1%	42.9%
Discuss what to do if you experience a sickle cell crisis	85.7%	14.3%
Review your medications with you and help you to manage them	85.7%	14.3%

Respondents also were asked to rate their satisfaction with each of the activities they reported as occurring. All seven consistently reported being very satisfied.

Sickle Care Preventive Tests & Services

Survey respondents were asked whether they had received a variety of recommended sickle cell-related preventive tests and services. Exhibit D – 4 on the following page presents the percentage who answered "yes" to each service.

The most common types of preventive care received were blood pressure, heart and lung checks. The portion who reported receiving the pneumococcal vaccine nearly doubled from last year's survey, increasing from 16 percent to 30 percent.

In addition to the specific tests and services, respondents were asked whether they had a treatment plan for pain, which is a recommended best practice. Nearly 80 percent answered "yes". However, some members may be conflating a formal treatment plan, which can be furnished to emergency room providers, with less formal advice they received from their doctor. (Formal pain management treatment plans are a best practice for people with SCD.)

Exhibit D – 4 – Received Service – Percent answering "Yes"

Service	*All Respondents*	*SoonerSelect*	*SoonerCare Choice/ Traditional*
Daily penicillin[31]	11.6%	22.2%	4.0%
Hydroxyurea	41.9%	66.7%	24.0%
Transcranial Doppler (Head) X-Ray	23.3%	50.0%	4.0%
Blood pressure checked	95.3%	100.0%	92.0%
Retinas examined	58.1%	50.0%	64.0%
Kidneys checked	69.8%	88.9%	56.0%
Lungs checked	74.4%	83.3%	68.0%
Heart checked	72.1%	72.2%	72.0%
Received pneumococcal vaccine	30.2%	22.2%	36.0%
Received blood transfusions	44.2%	33.3%	52.0%
Received chelation therapy	4.7%	--	8.0%
Have a treatment plan for pain control	79.1%	83.3%	76.0%

[31] Daily penicillin is recommended for young children, which likely explains the higher percentage among SoonerSelect members. Most SoonerCare Choice/Traditional members are adults.

Satisfaction with Aspects of Care & Overall Program

Survey respondents next were asked to rate their satisfaction with various aspects of care and with the SoonerCare program overall. Results are presented below in Exhibit D – 5 on the following page. For ease of presentation, only aggregate responses are shown; however, SoonerSelect and SoonerCare Choice/Traditional satisfaction rates were similar on most attributes.

Exhibit D – 5 – Satisfaction with Aspects of Care (non-Emergent) and Program

Service/Program	*Very Satisfied*	*Somewhat Satisfied*	*Somewhat Dissatisfied*	*Very Dissatisfied*	*Don't Know*
Finding doctors who know sickle cell disease	46.5%	32.6%	4.7%	14%	2.3%
Being able to schedule appointments when needed	69.8%	14.0%	7.0%	7.0%	2.3%
Getting the right services and treatments	72.1%	9.3%	7.0%	4.7%	7.0%
Getting the right medications	74.4%	16.3%	2.3%	4.7%	2.3%
Getting extra support & help to manage sickle cell disease	60.5%	20.9%	7.0%	7.0%	4.7%
Being listened to and understood (non-pain related)[32]	72.1%	14.0%	4.7%	7.0%	2.3%
Being listened to and understood (pain related)	72.1%	14.0%	4.7%	7.0%	2.3%
Overall satisfaction with care team	74.4%	11.6%	7.0%	4.7%	2.3%
Overall satisfaction with health plan (Select) or program (others)	74.4%	23.3%	--	--	2.3%

PHPG also inquired about the same aspects of care in last year's survey. There was no clear trend between the two years; satisfaction rates were higher for some measures in 2024 and for others in 2025. Overall satisfaction with the health plan/program improved modestly in 2025, with the percent rating themselves "very satisfied" increasing from 69 percent to 74 percent and the percent rating themselves "very or somewhat dissatisfied" falling from five percent to zero.

[32] Although this measure and the next have the same aggregate results, individual respondents rated their satisfaction with the two activities differently.

The great majority of respondents in both survey samples were at least "somewhat satisfied" with the various aspects of care. However, the OHCA stives to achieve high levels of "very satisfied" ratings across all components of the SoonerCare program.

Using this standard, the program aspects showing the greatest opportunities for improvement include "finding doctors who know sickle cell disease" and "getting extra support and help to manage sickle cell disease".

These findings are supported by information shared at the 2024 and 2025 Town Hall meetings[33]. Many Town Hall participants expressed frustration with the lack of knowledge among physicians outside of Jimmy Everest about sickle cell disease and its symptoms:

> *"I had to switch (my son's) primary care doctor because it felt like I was educating her. He now goes to Jimmy Everest and they've been really great with him." – 2025 Town Hall participant*

> *"The lack of knowledge providers have just blows my mind…I have had providers ask me if I'm a health professional – no, but I do research." – 2025 Town Hall Participant*

> *"That's the main problem – there's nowhere to go. You may get a doctor who has an idea about the disease (and you) are kind of a guinea pig then." – 2024 Town Hall participant*

Members who do not fit the "classic" profile of a sickle cell patient (i.e., are not African American) and members with less common forms of sickle cell disease described the additional challenge of receiving appropriate treatment from providers whose knowledge is limited:

> *"I never imagined it would happen because sickle cell is a 'black disease' but this disease sees no race…it's out there for everybody." – 2024 and 2025 American Indian Town Hall participant*

> *"If you don't have a certain type of sickle cell, a lot of times it's skated over…(and) they don't believe you (regarding pain)." – 2024 Town Hall participant*

> *"Doctors don't think thalassemia patients have pain but they do. I spent 10 hours in urgent care." – 2024 Town Hall participant*

[33] Some comments have been condensed or edited lightly for clarity.

Two providers and a patient advocate acknowledged the need for more education than occurs today:

> *"One of the gaps I see, as a provider (Advanced Practice Registered Nurse and clinic CEO), is education. There's not a lot discussed about sickle cell. Since this is a disease that affects people of color, more needs to be done with education. You have to have the opportunity to get the education. As you become better educated, you'll be able to provide more competent care." – 2025 Town Hall participant*

> *"We (physician assistant students) do not get education about sickle cell for our patients. Hematology talked about sickle cell for only about 30 minutes; it should be covered for a couple days in order to get an understanding. The education part was just not there." – 2025 Town Hall participant*

> *"I spoke to some school nurses, and they said they don't get enough information on how to treat children who are in crisis. They have asked to get training." – 2025 Town Hall Participant*

Families receiving care at Jimmy Everest had the most positive comments, reflecting the value of being seen by providers who understand the disease. This stands in contrast to what many see as a lack of knowledgeable providers in Tulsa and rural parts of the State:

> *"We moved with our son from Arizona in 2021. We went to three different (Tulsa) hospitals and were channeled back to the same one hematologist. How can he adequately support all these 'sicklers'? We ended up having to relocate our son back to Phoenix so his medical group could continue his pain medication and therapies. My son said, 'I don't want to die here (in Arizona).' He came back. He lost hope but we put him in the OU system. Night and day difference between the care you get in Tulsa and the care you get at OU. There shouldn't be such a difference." – 2025 Town Hall Participant*

> *"There should be more community healthcare workers, especially in rural areas. Most of the care is in Oklahoma City and Tulsa. Some areas are four to five hours away. We're only an hour away but sometimes my daughter had to stay in the hospital because of the distance." – 2025 Town Hall Participant*

In 2024, the OHCA and advocates began exploring options for expanding the availability of routine/preventive services outside of a hospital setting (this is a national best practice and also was a PHPG recommendation in 2024). Progress is being made, as discussed in the next section. Town Hall participants in both years strongly endorsed this concept:

"The day center – that's a very good idea. Just going into the ER with my daughter scares me." – 2025 Town Hall participant

"I have to fight with my doctors almost every week to go to outpatient infusion. Just for two days a week. And if those two days don't work, I have to wait seven days and so have to go to the ER." – 2025 Town Hall participant

"We need a facility that specializes in keeping people with sickle cell hydrated and there needs to be a different rule (regarding pain treatment) for sickle cell patients." – 2024 Town Hall participant

Emergency Room Experience

Members with sickle cell disease rely on hospital emergency rooms to treat their pain when experiencing a crisis. The effectiveness of this treatment has been a longstanding source of dissatisfaction and was identified as a significant opportunity for improvement in the previous annual reports.

Survey respondents were asked about their frequency of use of the emergency room over the past 12 months and their satisfaction with the care received (if applicable). Twenty-nine of the 43 respondents reported visiting the emergency room at least once in the past 12 months for any reason (67 percent). The percentage was similar between SoonerSelect and SoonerCare Choice/Traditional respondents (72 and 64 percent, respectively).

Survey respondents averaged slightly over seven visits apiece, although the largest segment (12 respondents) stated they visited the emergency room once or twice. The highest reported count by a survey respondent was 50 visits in the past 12 months.

Exhibit D – 6 on the following page presents satisfaction ratings on various aspects of emergency room care. Once again, only aggregate responses are shown; satisfaction rates were similar between SoonerSelect and SoonerCare Choice/Traditional respondents.

Significant numbers of survey respondents rated themselves as only "somewhat satisfied" or as "dissatisfied" on each aspect of care, as well as for their overall emergency room experience. The "dissatisfied" cohort was larger than in last year's survey, indicating the continued need for improvements in emergency room care.

Exhibit D – 6 – Satisfaction with Aspects of Emergency Room Care

ER Aspect	*Very Satisfied*	*Somewhat Satisfied*	*Somewhat Dissatisfied*	*Very Dissatisfied*	*Don't Know*
Seeing doctors who know sickle cell disease	41.4%	34.5%	10.3%	13.8%	--
Getting the right services and treatments	48.3%	31.0%	6.9%	13.8%	--
Being listened to and understood (pain related)	48.3%	27.6%	6.9%	17.2%	--
Getting the right medications	55.2%	20.7%	6.9%	13.8%	3.4%
Overall satisfaction with emergency room care	48.3%	27.6%	13.8%	10.3%	--

Town Hall participants in both 2024 and 2025 emphasized the importance of this issue to their quality of life and pointed to their own experiences when seeking care during a pain crisis:

> *"Can you imagine the pain of something dying inside of you? I want to know why sickle cell patients are viewed as drug users when someone with cancer can go into an ER and get the most aggressive pain treatment. It's frustrating for my son as a patient and for me as a mother. Often a crisis is not treated as a crisis. They order tests but a blood test cannot diagnose a pain crisis." – 2025 Town Hall participant*

> *"Waiting in the ER for almost 12 hours is ridiculous. And hearing comments from nurses, 'Oh you're back again.' If you don't want us back, have services that can prevent the need for us to go to the ER." – 2025 Town Hall Participant*

> *There was a time an ER nurse offered her ice for her pain[34]. At times we feel we are at war with people who are supposed to be helping us. As a mom, I have to push my mental health to the side because I can't even fathom what she is going through." – 2025 Town Hall participant*

> *"I hate being labeled that (a drug seeker). I hear those comments from doctors. It's very hurtful. You're just trying to do the right thing." – 2025 Town Hall participant*

[34] In some circumstances, this intervention can worsen the condition of a sickle cell patient in crisis.

> *"My mom had to fight the doctors to get the care I needed. Several times I was left on the table for hours because 'he's just drug seeking'". – 2024 Town Hall participant*

> *"We have to wait until it (pain) gets extreme to get help. If they trusted us as caregivers who know their (children's) bodies, it would help." – 2024 Town Hall participant*

> *"Even at age 4, 5, 6, 7 he was labeled as drug seeking or I was using him to get drugs." – 2024Town Hall participant (parent of member with sickle cell disease)*

> *"People fought in the legislature for the law to change, but they still really don't honor that. The doctor tells me, 'If you're having a crisis, go to the hospital' and at the ER the wait is ridiculous and they don't know you…it's really disheartening and embarrassing." – 2024 Town Hall participant*

In addition to provider/member education and new treatment venues, Town Hall participants stressed the importance of pain management plans and care management support to improve quality of care, both inside and outside of the emergency room:

> *"Personalized pain protocols help to reduce hospital readmissions. They try to treat everyone the same and everyone is different." – 2025 Town Hall participant*

> *"The best and most suitable option is to provide a health care liaison for every sickle cell patient from time of birth. It provides a smoother patient journey and outcomes...Doctors, nurses, APRNs, NPs don't know enough. We need to change this." – 2025 Town Hall participant*

Transition from Pediatric to Adult Care

Adolescent SoonerCare members transitioning into adulthood face important challenges. Members being treated by pediatricians often must locate a new medical home for their care. This includes patients at Jimmy Everest, which does not treat adults.

The Medicaid program itself is not identical for the two populations. Adults, for example, can have different income standards for eligibility, and benefits can differ. More broadly, adolescents aging into adulthood become responsible for managing their health care, even if assisted by others.

The survey included a short question set for parents/caregivers of adolescent members approaching adulthood (ages 14 – 17). Among the nine respondents whose child fell into this cohort over the most recent survey periods (five in 2024 and four in 2025), two reported that the member's care team had helped them to prepare for the transition to adulthood.

During the two Town Hall meetings, members with sickle cell disease who recently became adults, spoke of the importance of support in making the transition:

> *"The transition program (at Jimmy Everest) was a fun experience – I got to meet a lot of people and meet new people. It's an eye-opening experience to talk to people who know what you're going through." – 2025 Town Hall participant*

> *"The problem I see with people who have sickle cell, as soon as you hit 18 or 21, you have nowhere to go – you go straight to the hospital and are treated like a drug addict going to get high…I feel like what we need growing up or transitioning to adults is for starters we need to know the stuff we have to take for our health care and learning how to talk to the doctors – communicating what we need and being advocates for ourselves." – 2024 Town Hall participant*

Indications of Progress

The 2024 survey and Town Hall both occurred several months after implementation of SoonerSelect. Many SoonerSelect members appeared unaware or uncertain about the delivery system change and its relevance to them. Only two members surveyed in 2024 reported having a care manager.

SoonerSelect members in 2025 have a better understanding of the managed care system. They know their health plans and are more likely to be receiving support from a care manager.

Members experiencing a pain crisis continue to face barriers to care at hospital emergency rooms. However, they are enthusiastic about the possibility of having access to new preventive care options intended to reduce the need for emergency room care. Advocates at the 2025 Town Hall reported progress in making these services more available, as discussed further in the next section.

E. UPDATED FINDINGS & RECOMMENDATIONS

1. Study Findings & Recommendations

In the initial 2022 report, PHPG documented findings across three areas:

- Access to covered services
- Adequacy of emergency room physician training and resources
- Adequacy of supports for members to navigate the health care system

The initial report contained a series of recommendations for strengthening the SoonerCare program in each of these areas. PHPG added in 2024 a recommendation to expand preventive care capacity within the framework of a day center model[35].

SCD Task Force and Work Groups

The OHCA began implementation of several of the recommendations in 2023 and 2024 but paused others while it implemented the SoonerSelect program. The OHCA believed it would be more effective to have the SoonerSelect CEs in place when developing a comprehensive strategy for improving care (As noted earlier, the OHCA inquired about experience caring for members with SCD during the SoonerSelect procurement and evaluated responses as part of its process for choosing contractors.)

In 2025, the OHCA, in partnership with the SoonerSelect CEs, Supporters of Families with Sickle Cell Disease and major providers, formed a Task Force to develop a broad-based care improvement strategy for members with SCD. The Task Force created three smaller work groups to implement PHPG's recommendations: Provider-Focused Work Group, Member-Focused Work Group and Systems Change Work Group (i.e., delivery system, not information system).

The Work Groups are coordinating their activities for initiatives that cross boundaries. For example, the Provider-Focused Work Group is designing a new pain management action plan (see below) and the Member-Focused Work Group is taking the lead on developing an outreach strategy to educate members about use of the plan.

The Work Groups met in 2025 to develop plans for presentation to the larger Task Force. Progress to date is summarized below.

[35] This would not necessarily mean constructing a new physical site but rather using existing space at OU or other sites to offer services, such as infusion, that are not readily available to all members, particularly adults.

Provider-Focused Work Group

The Provider-Focused Work Group includes representatives from Oklahoma Complete Health, whose parent company (Centene) has developed an online SCD training module for primary care providers[36]. The training module is open to all doctors in the State.

The module offers a foundational overview of SCD management, explores navigating sickle cell disease in clinical practice, including its epidemiology, pathophysiology, diagnosis, and common complications. Clinicians will evaluate current and emerging therapies and evidence-based strategies to improve management and prevention of SCD-related complications. Providers who complete the training will earn continuing education credits.

The OHCA is communicating to providers about the training opportunity through multiple channels, such as electronic global messages and the provider newsletter. The OHCA's provider education team also is available to conduct targeted outreach to providers who treat members with SCD, as identified through paid claims data. The OHCA's HAN and SoonerCare HMP partners also will assist with outreach to their respective affiliated providers.

The Provider-Focused Work Group also has begun work on developing an individualized action plan template for adults, modeled on an existing template that OU Jimmy Everest uses for children. The action plan will be completed by the member's physician (with his/her participation). It will address medication needs and include instructions for providers and emergency rooms to follow in managing the crisis. The goal is for members to carry the action plans with them but also ultimately to make them available to providers through the Health Information Exchange.

Member-Focused Work Group

The Member-Focused Work Group has assumed responsibility for promoting the adult action plan once it is finalized. As with provider education, this will occur through multiple channels and in partnership with providers and Supporters of Families with Sickle Cell Disease.

The Work Group also has begun to coordinate creation of interdisciplinary care teams for members with SCD. Planning meetings are underway with the two leading centers of care (OU Jimmy Everest and Saint Francis) to support SoonerCare Choice/Traditional members and are to expand to include the SoonerSelect CE care management teams. The CEs will be responsible for SoonerSelect members while the OHCA will work with its HAN and SoonerCare HMP partners to address care management for other SoonerCare beneficiaries.

[36] See: https://www.centeneinstitute.com/activity/68cd64e66cf79168145a7155/overview.

The Work Group also has addressed the need for pediatric-to-adult transition of care planning. The OHCA CCM and all three SoonerSelect CEs have established care management outreach plans to affected members. The OHCA conducts outreach to all members with sickle cell disease aged 17 to 21, regardless of cost or utilization, with a targeted focus on transitional care needs. OU Jimmy Everest and Saint Francis also have formal transition-of-care protocols that are implemented at each visit beginning at age 12.

Systems Change Work Group

The Systems Change Work Group is taking the lead in developing preventive care capacity under the day center model. The Work Group is considering a pilot in Oklahoma City with potential expansion to Tulsa. Pilot development activities include consulting with national experts, exploring partnerships with infusion centers and examining funding options.

Depending on the ultimate design of the day center capacity, one potential funding opportunity is the federally supported Health Home model. CMS authorizes several types of Health Homes, including for treatment of members with SCD. The intent of the Health Home model is to offer holistic care in a single setting. The OHCA previously used the Health Home platform for behavioral health care; the State's Certified Community Behavioral Health Clinics (CCBHCs) are an outgrowth of this initiative.

Medicaid agencies are eligible to claim enhanced federal matching dollars for Health Home services, although the enhanced funding is for a limited period. To be effective, a Health Home model also would have to be integrated with the SoonerSelect program and not operate as a dual system of care.

Supporters of Families with SCD

As discussed earlier, Supporters of Families with Sickle Cell Disease contracts with the OHCA to provide a variety of services to members with SCD. The contract originally covered all SoonerCare beneficiaries but now is restricted to those not enrolled in SoonerSelect.

The organization has reached out to all three CEs to explore contracting opportunities and has been in active discussions with one of three (Oklahoma Complete Health). The objective in contracting is to make available its unique expertise to the CEs as they expand their outreach and care management activities for members with SCD.

The OHCA cannot require contracts between CEs and private organizations. However, the SoonerSelect program mandates that CEs undertake Performance Improvement Projects (PIPs) to enhance quality of care for priority populations. The PIP framework could be an

appropriate way to facilitate execution of a contract with at least one CE and to hold both parties accountable for meeting performance expectations.

Status of PHPG Recommendations

Exhibit E-1 starting on the following page summarizes PHPG's previous recommendations and progress toward their implementation. Some of the information repeats the previous discussion of Work Group activities but is included in presenting a complete status report.

Overall, the OHCA and its partners have made advances in the past year, with much of it focused on planning for 2026. The coming year holds the promise of significant progress as the recently developed plans are implemented.

Exhibit E – 1 – Initial Study Findings/Recommendations & Updated Information

Initial Findings (Areas for Improvement)	Initial Recommendations	2025 Update
Access to Care		
1. PCMH providers are not uniformly knowledgeable about Sickle Cell Disease.	1. The OHCA, in conjunction with SoonerSelect CEs, major providers and Supporters of Families with SCD, should conduct a coordinated educational campaign targeting PCMH providers in counties with SCD members. PCMH providers could be offered continuing education credits for participating.	1. The Provider-Focused Work Group is implementing an educational campaign for PCMH providers, including through a Centene training module. Completion of the course will earn a provider 0.5 continuing education credits.
2. Specialist providers, including at major provider sites such as Jimmy Everest, must channel referrals through PCMH providers. (See PHPG's original report for more detail on this topic.)	2. The OHCA and SoonerSelect CEs should have a process for allowing qualified specialists to make referrals, while keeping PCMH providers informed, either directly or through the HIE.	2. The OHCA is exploring the feasibility of a potential pilot program in which qualified specialists would be permitted to make referrals without prior authorization, on the condition that PCMH providers be kept informed. The SoonerSelect CEs already have the flexibility to implement similar policies.
3. Members needing preventive care to avert a crisis often must seek treatment in an ER or inpatient setting.	3. The SCD Task Force should explore opportunities to expand preventive care capacity under a day center model.	3. The Provider-Focused Work Group is exploring the feasibility of implementing a pilot program in Oklahoma City in 2026, with possible expansion to Tulsa.

Initial Findings (Areas for Improvement)	Initial Recommendations	2025 Update
Emergency Room Provider Training and Resources		
4. Many ER providers see patients in crisis infrequently and may not be equipped to treat pain promptly or aggressively.	4. The OHCA, in collaboration with major providers and Supporters of Families with Sickle Cell Disease, should undertake an educational campaign to increase knowledge of evidence-based protocols for treatment.	4. In conjunction with developing an adult pain management action plan (see below), the Provider-Focused Work Group is developing algorithmic guidance for ER providers treating adults, based on an existing algorithm for children developed by OU. The OHCA is developing a statewide education campaign and a unified education packet to support provider education. This effort will be delivered through multiple channels, including HAN provider relationships, HMP practice facilitation, OHCA provider education, and through all communication and social media platforms and care management activities. The OHCA has invited the hospital association to participate although it has not responded to date.
5. Only a portion of members with SCD today have a pain management action plan.	5. The OHCA, SoonerSelect CEs and advocacy community should collaborate on outreach to members with SCD and hematology community to facilitate creation of plans. Emergency room	5. The Provider-Focused Work Group is developing a pain- and fever-management action plan, using the existing OU plan for children as a template. The Member-Focused Work Group will reach out to members and

Initial Findings (Areas for Improvement)	Initial Recommendations	2025 Update
	providers also can be educated on their efficacy and importance.	families with SCD to encourage them to develop an individualized plan with their regular doctor.
Supports of Members with SCD to Navigate the Health Care System		
6. Only a portion of members with SCD today are assessed to identify the potential need for care management and only a small portion appear to have a comprehensive action or care plan that addresses both clinical and social service needs (based on member self-reporting).	6. The OHCA should collaborate with the CEs, HMP vendor and HANs to contact all non-care managed members for the purpose of performing an assessment and developing a member-centered care plan, as appropriate. Members with very complex conditions (e.g., members with other chronic conditions due to SCD (e.g., kidney disease) or members with frequent inpatient hospital admissions) who are not yet engaged should be given top priority.	6. The OHCA has developed a monthly reporting tool for tracking CE care management activity. For members not enrolled in SoonerSelect, the OHCA identifies all new members with SCD on a quarterly basis. The OHCA has established ongoing care coordination with the two leading care centers (OU Jimmy Everest and Saint Francis) to support both program and individual member needs.
7. Members enrolled in care management should have access to an interdisciplinary care team, as appropriate.	7. The OHCA should strive to make available interdisciplinary care management, where appropriate, by coordinating with the Jimmy Everest Center, MCEs, HMP and HANs on behalf of ABD beneficiaries.	7. The steps described above for recommendation 6 also apply to this recommendation.
8. Interdisciplinary care teams are well-suited to facilitating a member's transition from pediatric to adult care.	8. The OHCA should ensure that SoonerSelect and other care management systems target adolescents and assist in the transition to adult coverage and care.	8. The OHCA CCM and all three SoonerSelect CEs have established care management outreach plans to affected members. The OHCA conducts outreach to all members with sickle cell disease aged 17 to 21, regardless of cost or utilization, with a targeted focus

Initial Findings (Areas for Improvement)	Initial Recommendations	2025 Update
		on transitional care needs. OU Jimmy Everest and Saint Francis also have formal transition-of-care protocols that are implemented at each visit beginning at age 12.
9. Mobile app technology can offer an additional means of supporting members.	9. The OHCA should explore use of a mobile app, either directly or through its contractors.	9. The OHCA has explored the feasibility of new member-facing technology as part of developing its new member portal.

2. Next Steps

The OHCA convened a meeting group in the fall of 2024 that subsequently became the SCD Task Force. The Task Force, through its three Work Groups, began planning in earnest in the summer and fall of 2025.

The plans already are being implemented, with significant progress expected in 2026. As work continues, PHPG will monitor and evaluate its impact in the next annual report.

Members and advocates continue to identify provider capacity issues and lack of training on SCD care, particularly during pain crises, as significant barriers to care. If the Work Group initiatives have a positive effect in addressing these barriers, the potential exists for improving the quality-of-life of all Oklahomans with Sickle Cell Disease or Trait.