OKLAHOMA
Health Care Authority

Independent Evaluation of Sickle Cell Disease Management within the SoonerCare Population – *2024 Update*

LEGISLATIVE REPORT IN COMPLIANCE WITH SB 1467

Prepared by the Pacific Health Policy Group for:

State of Oklahoma
Oklahoma Health Care Authority

JANUARY 2025

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 second 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 cooperation of 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
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 persons 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 37 counties with at least one, but fewer than 10 members with SCD; 34 counties have no members with SCD.

Prior to 2024, the majority of Medicaid members in Oklahoma were enrolled in SoonerCare Choice, the OHCA's primary care case management model. In April 2024, most non-disabled members were enrolled into SoonerSelect, the State's new Medicaid managed care program. The SoonerSelect private managed care entities (MCEs) serve over 40 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. 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, persons 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 similarly were selected to obtain the data necessary to inform findings and recommendations across the areas defined in SB 1467. They included: interviews with members (through a structured survey), 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 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.

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. The first annual update was submitted in January 2024 and documented early steps being taken to implement a portion of PHPG's recommendations.

The implementation of SoonerSelect in April 2024 has introduced significant changes to the Medicaid program and also has provided new opportunities for improving the care and quality-of-life of members with SCD. PHPG expanded the scope of the second update to include a new round of member surveys and other research activities, to understand the impact of the transition and how best to move forward with the schedule of recommendations outlined in the initial report.

More specifically, this report:

- Provides current (SFY 2024) information on the characteristics of the population with SCD (demographics and service use) and advances in treatment of the disease.
- Discusses continuing barriers to care for persons with SCD, notwithstanding positive steps taken by the OHCA and its partners since issuance of the initial report.
- Provides updated recommendations, organized around the new delivery system, and a proposed schedule for implementation.

Characteristics and Service Use among SoonerCare Members with SCD

PHPG identified 473 members with SCD in SFY 2024, based on paid medical claims. Approximately 42 percent of the members were under the age of 20; this included 31 older adolescents ages 17 to 19 approaching the transition from child to adult coverage. The number of adults ages 20 to 64 decreased slightly, from 279 in SFY 2023 to 263 in SFY 2024, possibly due to the expiration of the COVID-19 Public Health Emergency (under which procedural disenrollments from Medicaid were suspended).

Paid claims for SoonerCare members with SCD totaled an estimated $16.5 million in SFY 2024, up from $14.6 million in SFY 2023, $13.1 million in SFY 2022 and $10.8 million in

SFY 2021. The increase was due in part to growth in members with SCD (2021 – 2023) and in part to growth in expenditures per member.

Approximately 275 members with SCD had at least one inpatient stay in 2024. Nearly all of these members were hospitalized for treatment of an SCD-related complication, such as an acute pain crisis.

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.

In SFY 2024, 350 out of the 473 members with SCD, or 74 percent, had at least one emergency room visit, up from 65 percent in SFY 2023. The total population with SCD sought care in the emergency room an average of about six times each; the subset with one or more visits sought care an average of 7.5 times each. Both figures were higher than in SFY 2023.

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 the previous studies, the majority of emergency room physicians see only one or two cases per year.

ER physicians with infrequent contact still 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 also 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 persons 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.

SoonerCare Delivery System and Care Management

Individuals with complex/chronic disease 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 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 for 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 the 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."*

Another best practice is use of mobile app technology as a means of monitoring a member's health status and adherence to preventive care guidelines. Recent research

indicates the technology can be effective in reducing acute care utilization among persons with SCD.

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

The OHCA provides care management to the costliest members with SCD through its Chronic Care Management unit and 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 MCEs 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.

Despite these multiple pathways, almost none of the members with SCD who PHPG surveyed or who participated in the Town Hall reported being in care management. This represents a major opportunity for improvement in care delivery.

Findings & Recommendations

Findings

As documented in previous reports and through 2024 research activities, 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 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.

Recommendations

The initial study contained a series of recommendations for improving access and quality of care for members with SCD. The OHCA and its partners in 2023 and 2024 took steps to begin implementation of key recommendations. However, there is significant opportunity for continued improvement with respect to access to care and management of the population's medical and social service needs.

The OHCA organized a task force in the fall of 2024 to plan for additional program improvements based on PHPG's recommendations. The task force includes representatives from the OHCA, MCEs and Supporters of Families with Sickle Cell Disease. It will be expanded in the future to include major providers and (potentially) other sources of care management, such as the SoonerCare HMP vendor and Health Access Networks.

The task force is an ideal vehicle for planning and implementation of program improvements in the areas outlined in the report. These action areas are described in detail in the last section of the report and include:

- Providing outreach and education on treatment of SCD to primary care providers in counties where the population is concentrated.
- Ensuring access to specialty care, particularly hematology and oncology.
- Exploring the feasibility of establishing SCD preventive care day centers (free-standing or within existing facilities) in Oklahoma City and Tulsa.
- Providing outreach and education on national guidelines for treatment of SCD crises to physicians and other staff in hospital emergency rooms.
- Using the multiple pathways created by the OHCA to offer care management and interdisciplinary care, as applicable, to all members with SCD.
- Exploring new opportunities to use technology on behalf of members with SCD.

Significant progress can be made in all of these areas over the next 12 to 18 months, building on the previous accomplishments of the OHCA and its partners. Success on behalf of members with SCD also can serve as a template for other SoonerCare populations with complex/chronic health needs who would benefit from such a strategy.

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 similarly 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 (2023) Update

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.

Second (2024) Update

In April 2024, the majority of SoonerCare members, including those with SCD, were transitioned to the SoonerSelect program, under which risk-based managed care entities (MCEs) assumed responsibility for providing health services and care management to their enrollees. There are three statewide MCEs 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.)

In light of this shift, PHPG conducted a comprehensive evaluation similar in scope to the initial 2022 study. Specifically, this 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 surveys conducted with SoonerCare members who transitioned to SoonerSelect, as well as members who remain enrolled in the SoonerCare Choice or SoonerCare Traditional programs.

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

- Presents information from a 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 MCEs 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, MCEs and community-based partners to act on PHPG initial report findings and provides updated recommendations for improving quality and overcoming barriers-to-care.

Sections C and D of the report address PHPG findings. Section E presents recommendations and a proposed implementation schedule.

C. CHARACTERISTICS & TREATMENT OF PERSONS WITH SCD

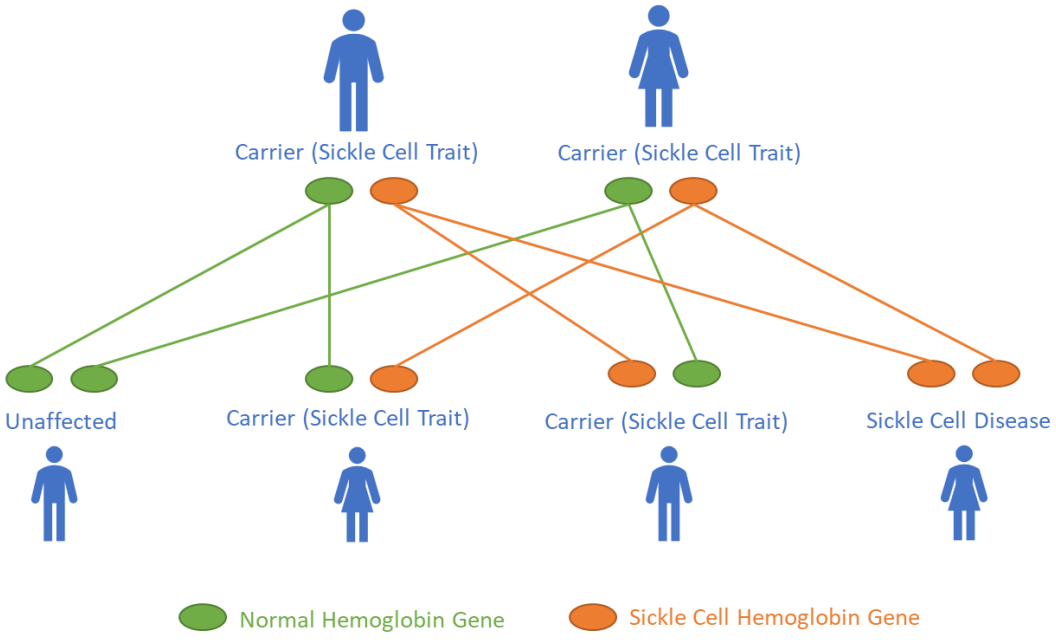
1. Characteristics of Persons with SCD

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

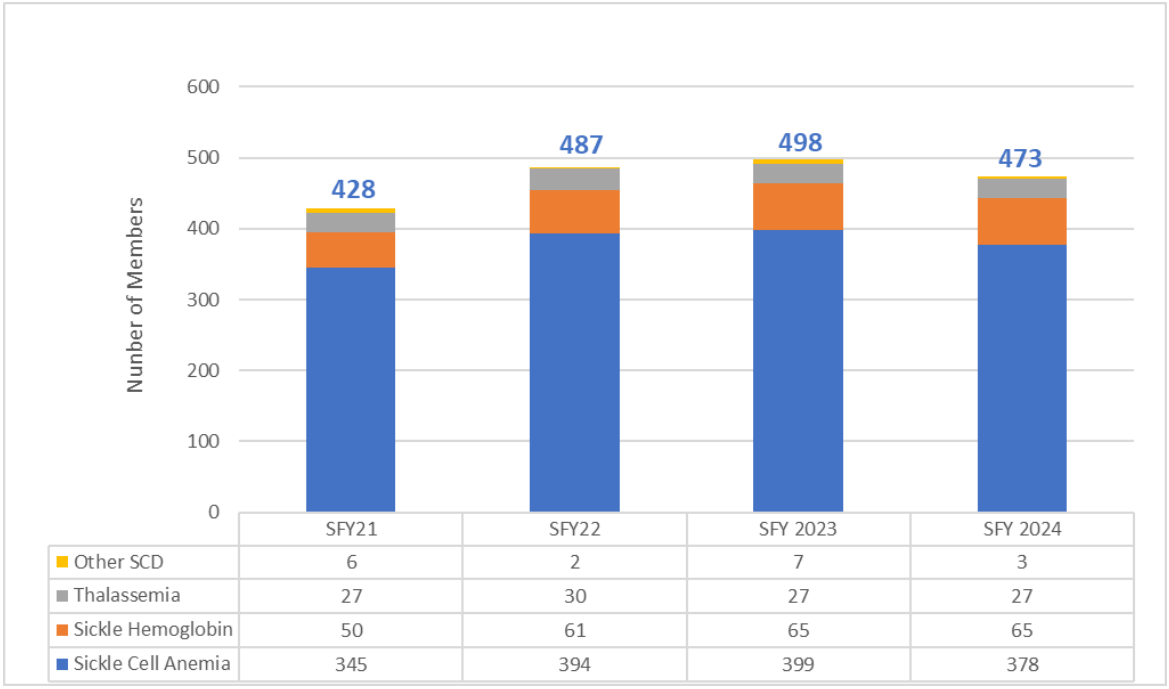


[3] Source: Data & Statistics on Sickle Cell Disease | CDC. SCD occurs in one of every 16,300 births to Hispanic Americans and less frequently among individuals of Asian, Mediterranean and Middle Eastern lineage.

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 persons with SCD receive health care services through their state Medicaid program. During each of the four most recent state fiscal years (SFY 2021 – SFY 2024[5]), the SoonerCare program covered between 425 and 500 members with SCD[6] (Exhibit C – 2). The slight decline from SFY 2023 to SFY 2024 occurred at a time when overall SoonerCare enrollment dropped by 23 percent, as procedural disenrollments – which had been suspended during the COVID-19 public health emergency (PHE) – were resumed.

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



	SFY21	SFY22	SFY 2023	SFY 2024
Other SCD	6	2	7	3
Thalassemia	27	30	27	27
Sickle Hemoglobin	50	61	65	65
Sickle Cell Anemia	345	394	399	378

[4] Sickle cell disease: MedlinePlus Genetics

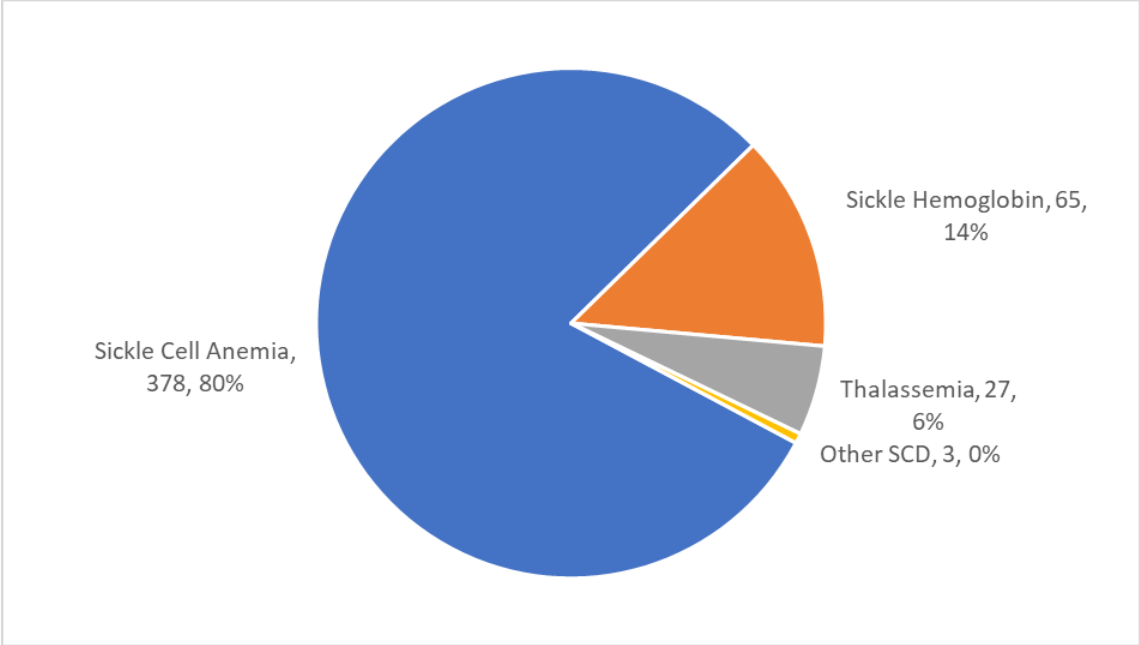
[5] State fiscal years run from July to June.

[6] Precise counts on the total number of Oklahomans with SCT and SCD are not readily available. Supporters of Families with Sickle Cell Disease, a leading community-based organization in the State, estimates there are 40,000 Oklahomans with the sickle cell trait and 1,500 families with one or more members who has been diagnosed with sickle cell anemia or another SCD. See: Sickle Cell Oklahoma – Supporters of Families with Sickle Cell Disease.

[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.

Eighty percent of SoonerCare members with SCD in 2024 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 2024)



In addition to members with SCD, there were 862 SoonerCare members in 2024 with sickle cell trait[8]. 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].

Sickle Cell Disease – SoonerCare Member Demographics

PHPG analyzed SFY 2024 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.

[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.

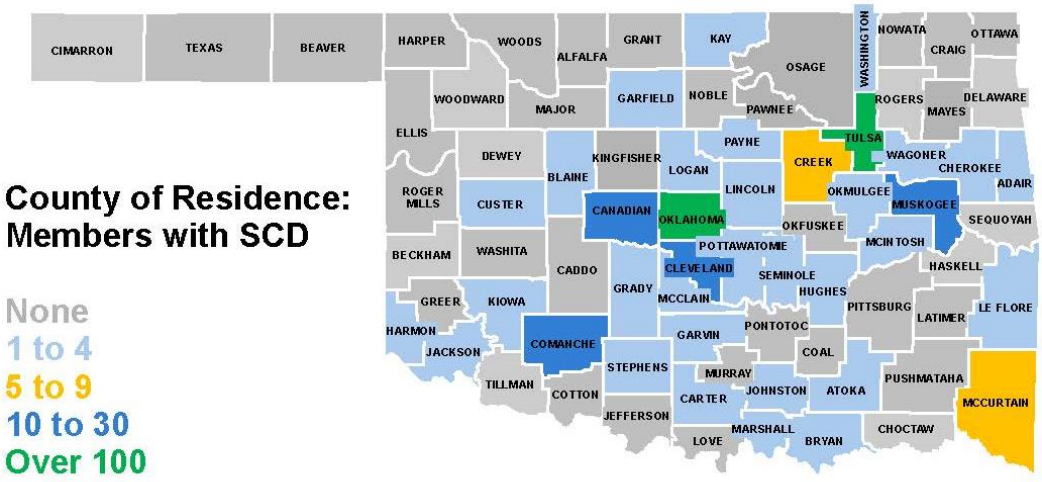
[9] Sickle Cell Trait - Hematology.org

County of Residence

SoonerCare members with SCD are not evenly distributed throughout the State. Most reside in Oklahoma and Tulsa Counties, each of which is home to over 100 members with SCD (Exhibit C – 4).

The next most populated counties are Canadian, Cleveland, Comanche and Muskogee, each with between 10 and 30 members. There are 37 counties with at least one, but fewer than 10 members with SCD; 34 counties have no members with SCD.

Exhibit C – 4 – SoonerCare Members with SCD by County of Residence (SFY 2024)



Oklahoma County contains nearly one-half of SoonerCare members with SCD. The top five counties, as a group, account for over 85 percent of all members with SCD (Exhibit C – 5).

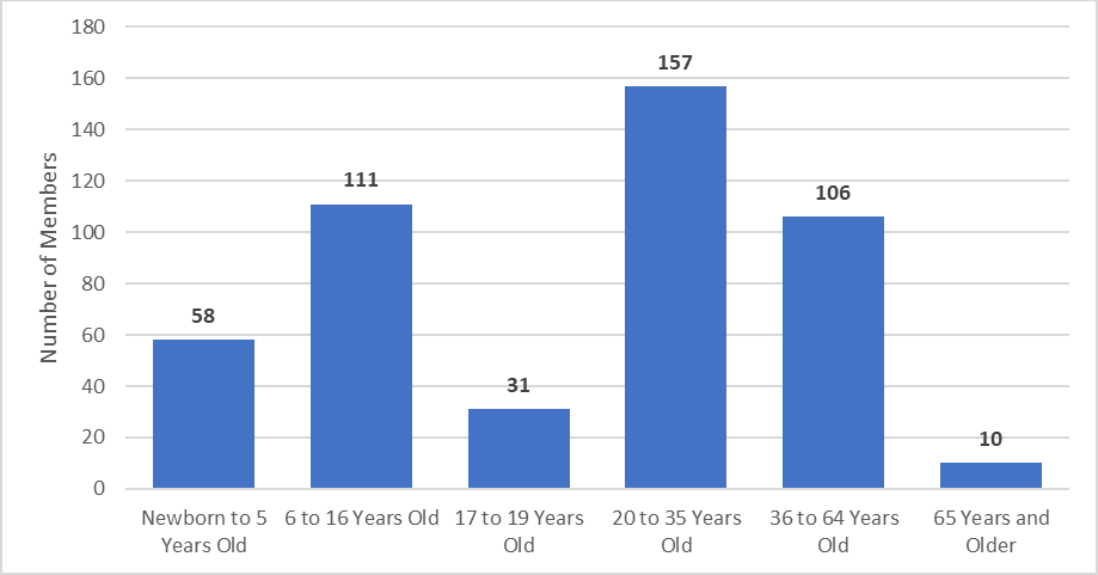
Exhibit C – 5 – SoonerCare Members with SCD – Top Five Counties (SFY 2024)

County	Number of Members	Percent of Total	Cumulative Percentage
Oklahoma	211	44.6%	44.6%
Tulsa	137	29.0%	73.6%
Cleveland	22	4.7%	78.2%
Comanche	19	4.0%	82.2%
Muskogee	13	2.7%	85.0%
Other Counties/Out of State	71	15.0%	100.0%
Total	**473**	**100.0%**	**100.0%**

Age Ranges

Approximately 42 percent of members with SCD in SFY 2024 were under the age of 20; this included 31 older adolescents ages 17 to 19 approaching the critical transition from child to adult coverage. Adults ages 20 to 64 declined slightly from 279 in SFY 2023 to 263 in SFY 2024, possibly due to the expiration of the PHE (Exhibit C – 6).

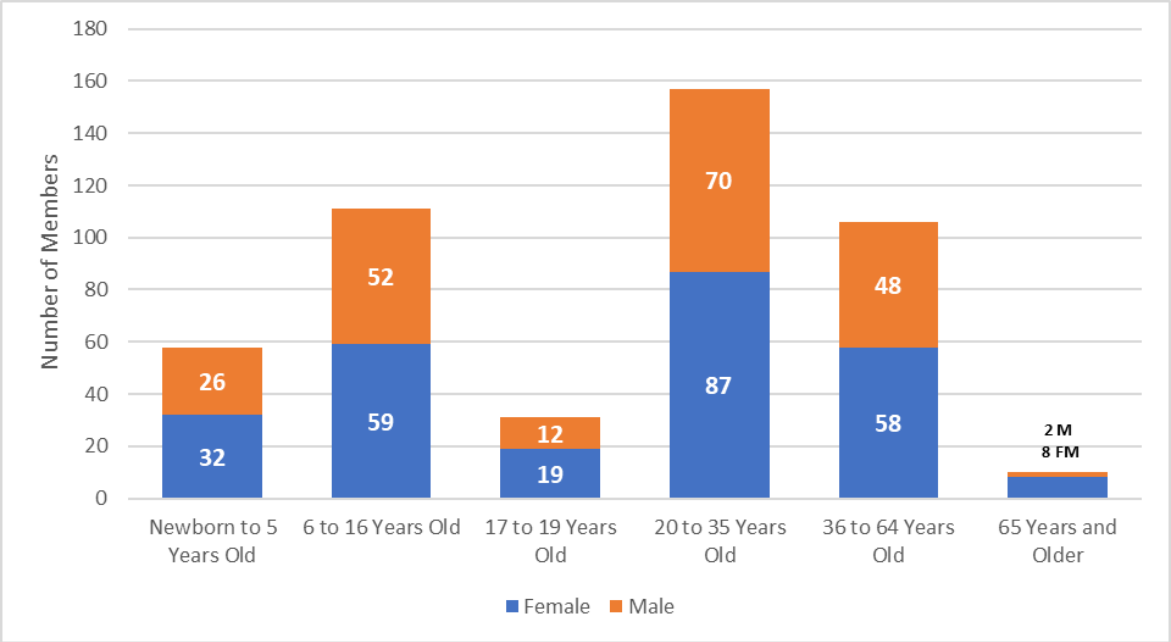
Exhibit C – 6 – SoonerCare Members with SCD by Age Range (SFY 2024)



Age and Gender

Females with SCD accounted for 56 percent of members in SFY 2024 and outnumbered males in all age cohorts (Exhibit C – 7 on the following page).

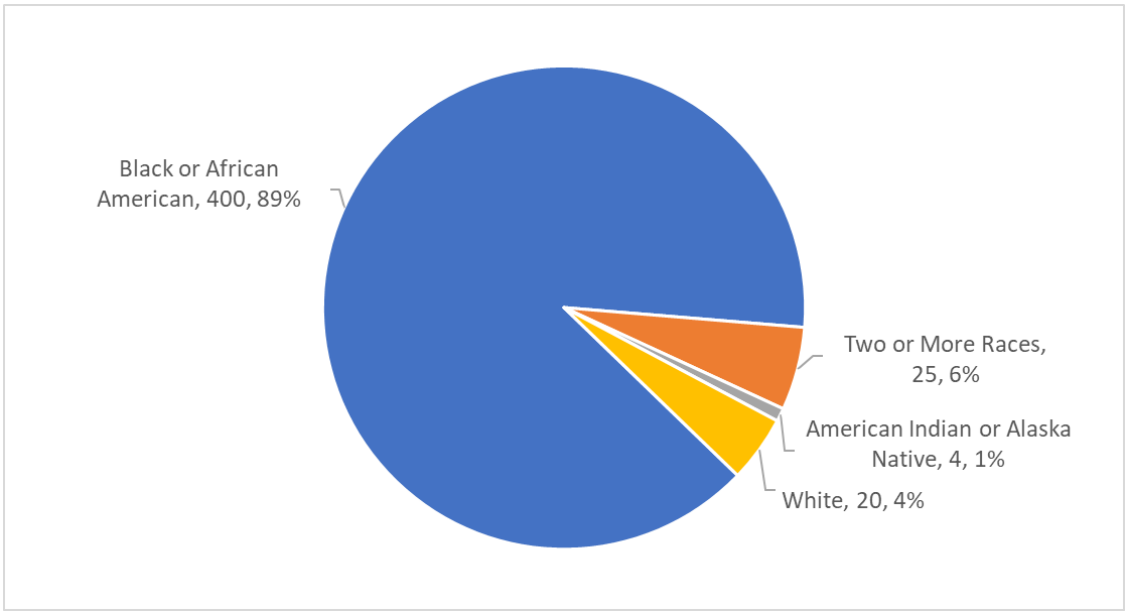
Exhibit C – 7 – SoonerCare Members with SCD by Age Range and Gender (SFY 2024)



Race (Self-Reported)

African Americans comprised nearly 90 percent of members with SCD in SFY 2023, based on self-reported race (Exhibit C – 8).

Exhibit C – 8 – SoonerCare Members with SCD by Race (Self-Reported)[10]



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

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

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].

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.

There also are new medications in clinical trials or awaiting FDA approval. Inclacumab, a P-selectin inhibitor, is currently being assessed in a phase III trial to determine its safety and efficacy in reducing vaso-occlusive crises. Etavopivat, a pyruvate kinase (PK) activator that may inhibit the sickling process, also is in a phase III trial scheduled for completion in 2026.

[11] This is not an exhaustive listing of SCD-related complications, which can be damaging to many body systems.
[12] The list in the 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.

In addition to medications, persons 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.

In December 2023, the US Food and Drug Administration approved gene and gene-editing therapies for persons 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[13].

The introduction of new medications and treatments in recent decades has resulted in reduced mortality rates among younger persons 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 time 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, persons 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 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

Expenditures

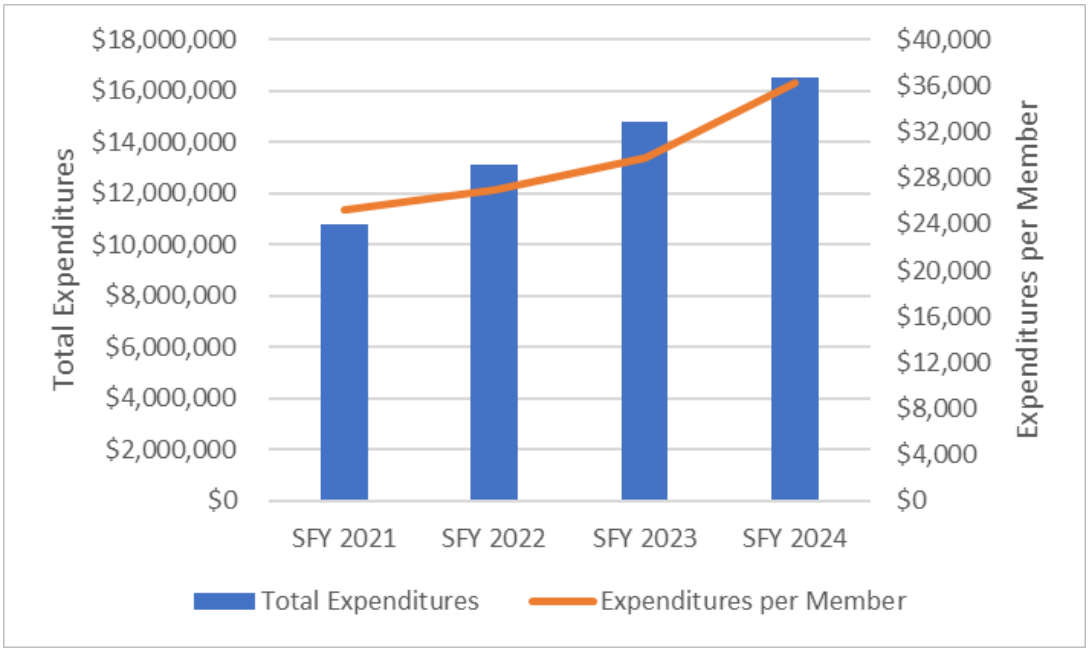
Medical claim costs for SoonerCare members with SCD reached an estimated $16.5 million in SFY 2024[14], up from approximately $14.8 million in SFY 2023, $13.1 million in SFY 2022 and $10.8 million in SFY 2021. The increase was due to a combination of growth in members (2021 – 2023) and increasing per member costs. The average annual

[13] 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)

[14] PHPG had access only to fee-for-service claim costs. To estimate total program costs, including medical costs for members enrolled in SoonerSelect (a capitated program), PHPG calculated the average per member per month cost for members in fee-for-service and used it as a proxy for SoonerSelect monthly costs. The average annual per member cost represents the average monthly cost x 12. (Some members were enrolled for less than 12 months.)

expenditure per member rose from approximately $25,200 in SFY 2021 to $36,000 in SFY 2024 (Exhibit C – 9). (The average expenditure per SoonerCare member program wide in SFY 2023 was $5,681[15].)

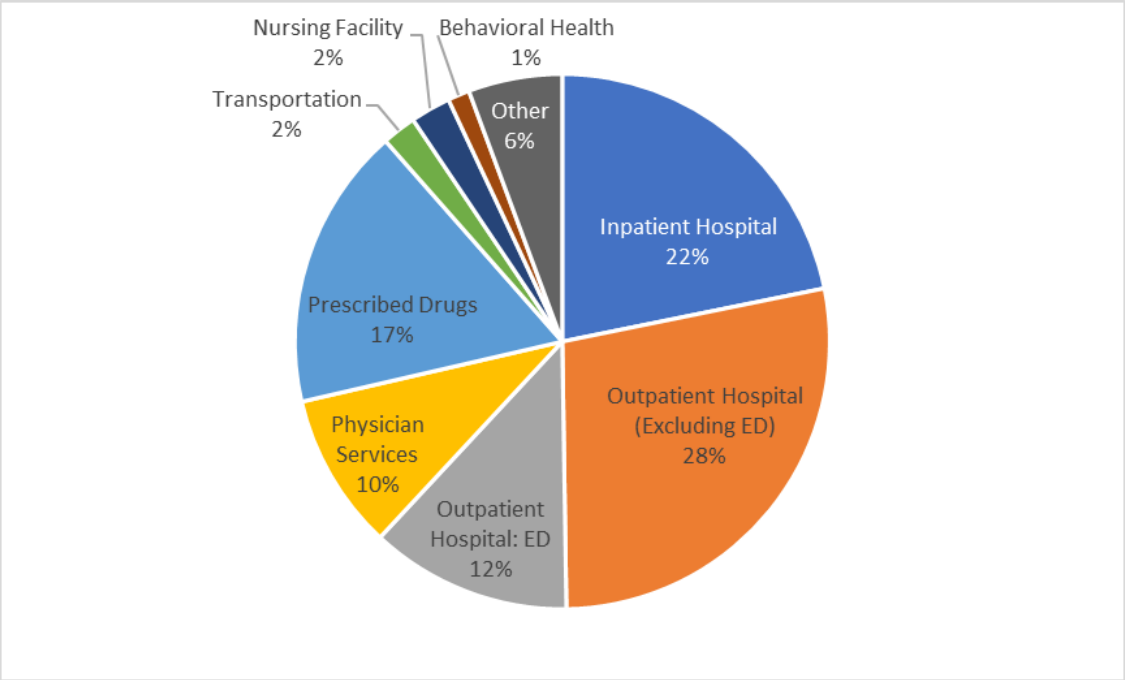
Exhibit C – 9 – Expenditure Trend – SFY 2021 to SFY 2024



The largest service category, in terms of paid claims, was outpatient hospital (non-emergency room), followed by inpatient hospital, prescribed drugs and emergency room visits (Exhibit C – 10 on the following page).

[15] Source: Historic Category of Member Services and Expenditures (oklahoma.gov). Figure for SFY 2024 not yet available.

Exhibit C – 10 – Expenditures by Service Category (SFY 2024)



Although the average expenditure per member in 2024 was over $36,000, there was a wide range between low- and high-cost members. The top eight percent of members averaged more than $214,000 each and accounted for over 50 percent of total expenditures. Conversely, the bottom 25 percent of members accounted for less than two percent of total expenditures (Exhibits C – 11 and C – 12).

Exhibit C – 11 – Expenditures per Member by Expenditure Range (SFY 2024) – Chart

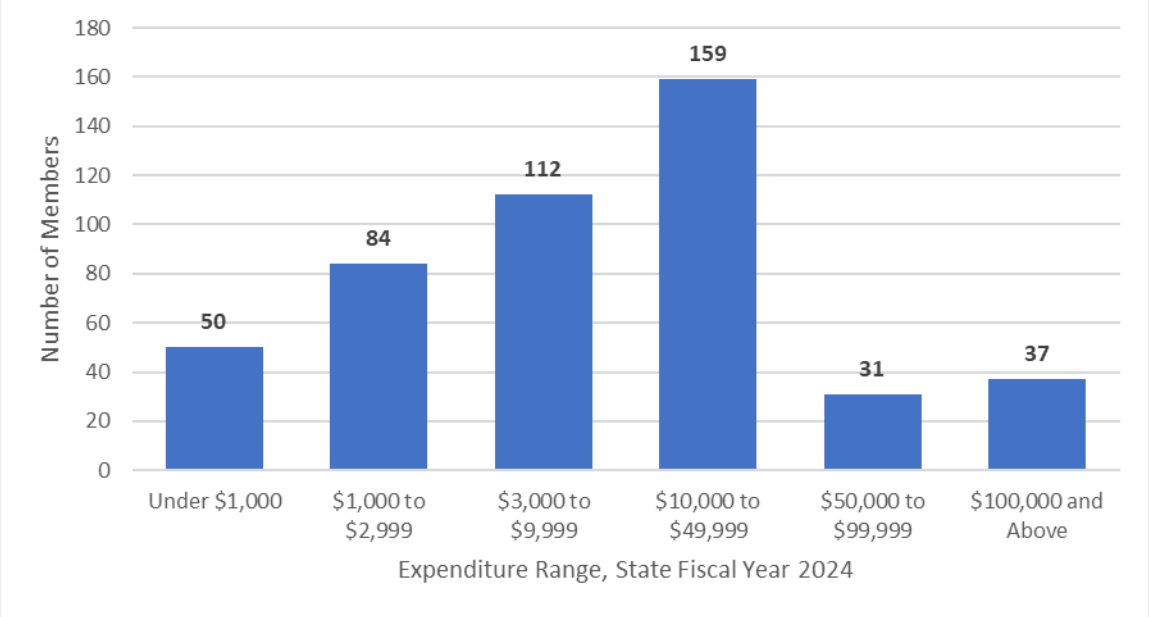


Exhibit C – 12 – Expenditures per Member by Expenditure Range (SFY 2024) - Table[16]

Expenditure Range	Number of Members	Percent of Members	Average Per Member	Percent of Expenditures
Under $1,000	50	10.6%	$456.58	0.2%
$1,000 to $2,999	84	17.8%	$1,856.00	1.1%
$3,000 to $9,999	112	23.7%	$5,786.98	4.4%
$10,000 to $49,999	159	33.6%	$23,174.49	25.2%
$50,000 to $99,999	31	6.6%	$70,169.74	14.9%
$100,000 and above	37	7.8%	$214,292.44	54.2%
Total	**473**	**100.0%**	**$30,900.00**	**100.0%**

*Note: Average tenure is 10.2 months. Annualized Average Cost per Member is **$36,267**.*

Physician Services

The majority of members with SCD saw a SoonerCare Choice PCMH provider at least once in SFY 2024. Members seeing the two most common provider types, Family Practitioners and General Pediatricians, averaged approximately five visits per year (Exhibit C – 13).

Exhibit C – 13 – PCMH Provider Type Activity (SFY 2024)[17,18]

Primary Care Provider Type	Number of Members	Number of Visits	Average Per Member	Percent of Members
Family Practitioner	162	797	4.9	34.3%
General Pediatrician	188	1,007	5.4	39.8%
Internist	146	1,264	8.7	30.9%
General Practitioner	32	101	3.2	6.8%

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 in Lawton and Muskogee.

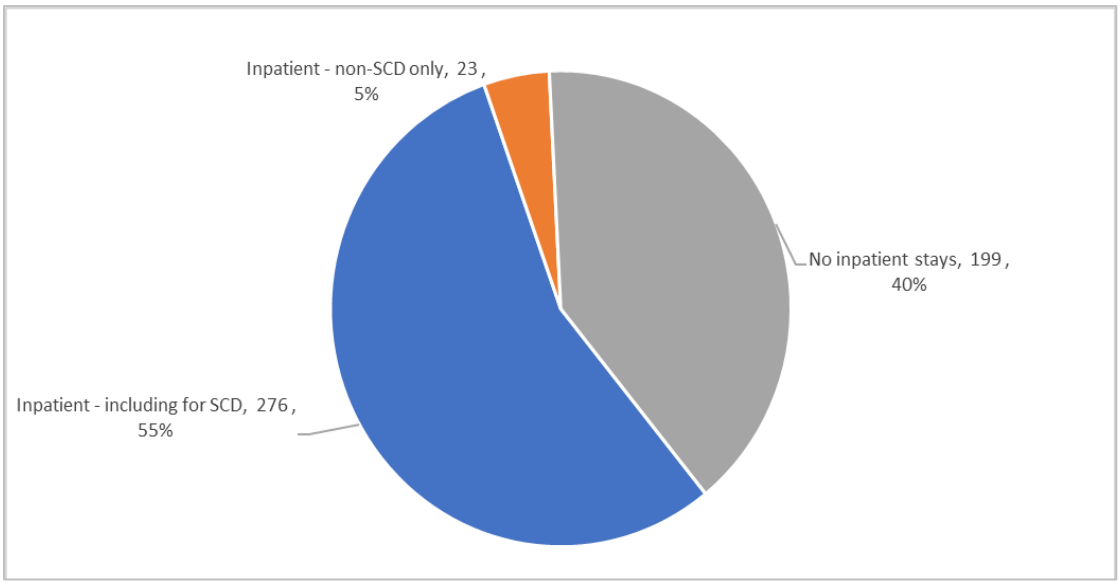
[16] SoonerSelect member costs are based on paid claims only and do not reflect expenditures under managed care. Some members likely are depicted in a lower tier than actual. (Aggregate adjustment made to data in Exhibit C-9 could not be replicated at the member level.)

[17] Member count is not unduplicated. Members who saw multiple physician types are shown within each category in order to provide an accurate total visit count.

[18] SoonerSelect enrollee physician visits in April, May and June 2024 are not reflected in the data. The total visit count therefore slightly understates actual volume. The same qualifier applies to inpatient and ER data presented later in the section.

Sixty percent of members with SCD had at least one inpatient stay in SFY 2024. Nearly all of 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 – 14).

Exhibit C – 14 – Inpatient Hospital Stays – 1 or More (SFY 2024)



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 and also 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 persons 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)."*[19]

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 2024, 350 out of 473 members with SCD, or 74 percent, had at least one emergency room visit, up from 65 percent in SFY 2023. The total population sought care in the emergency room an average of six times each; the subset with one or more visits sought care an average of 7.5 times each. These results were driven in part by the top 19 members (those with over 30 visits), who accounted for over 40 percent of all emergency room activity (Exhibit C – 15).

Exhibit C – 15 – Emergency Room Visit Activity (SFY 2024)

Number of Visits	Number of Members	Number of Visits	Average Per Member	Percent of Visits
1 Visit	91	91	1	3.5%
2 – 3 Visits	107	246	2.3	9.3%
4 – 8 Visits	87	481	5.5	18.3%
9 – 15 Visits	37	396	10.7	15.0%
16 – 30 Visits	9	195	21.7	7.4%
31 – 50 Visits	11	449	40.8	17.0%
Over 50 Visits	8	777	97.1	29.5%
Total	**350**	**2,635**	**7.5**	**100.0%**

[19] Section 2.K of the Act.

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[20]. (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, the majority of 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 persons with SCD, including SoonerCare members. They are the Jimmy Everest Center at Oklahoma University (OU) Children's Hospital in Oklahoma City and 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.

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 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.

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

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.

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.

Supporters of Families with Sickle Cell Disease 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[21]:

- 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;
- Identifying and contacting mothers of babies to five (5) years of age and children ages six (6) to eighteen (18) who are newly diagnosed or currently have sickle cell disease in Oklahoma;
- Assembling and distributing Care Kits that provide educational, parental and/or self-care best practices materials for the children identified as newly diagnosed or currently diagnosed with sickle cell disease. Providing education to parent/child on items included in the Care Kit;
- 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);
- Creating a free-standing website that is full of resources and an interactive source for sickle cell disease individuals, carriers and their families;

[21] Contract scope-of-work condensed from original language for space and readability. See "Sickle Cell Disease Consulting Contract (Purchase Order 8079004242) Section B.5 for complete language.

- 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 patient, families, clinicians; and
- Focusing on compliance critical to medication and treatment plans.

Care Management – Best Practices

Individuals with a complex/chronic disease 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[22]. 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.

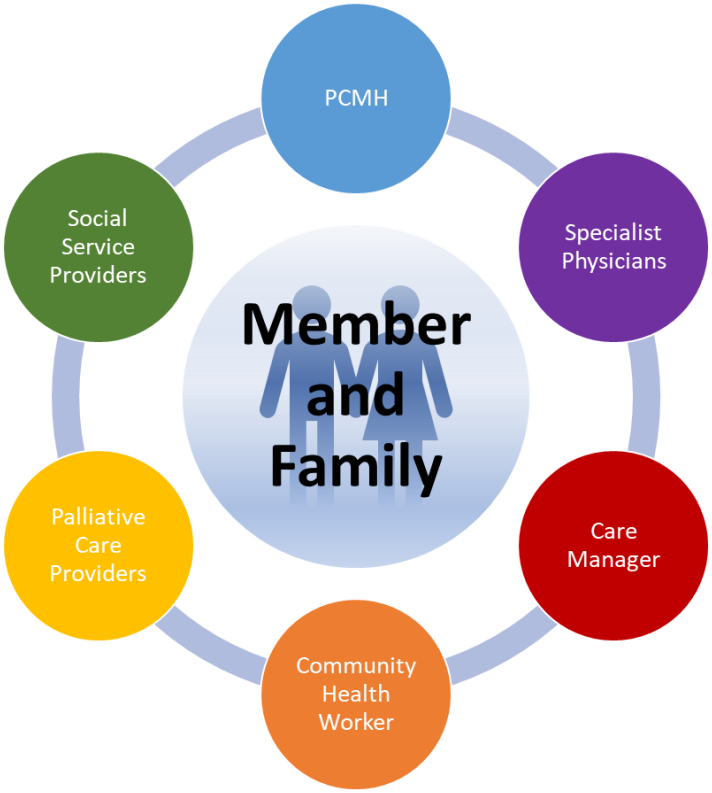
Medicaid beneficiaries often face additional, non-clinical hurdles to accessing care. These factors, referred to either as "health related social needs" (HRSN) or "social determinants of health" (SDOH), can include housing insecurity, food insecurity, difficulty making utility payments and lack of reliable 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.

[22] 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

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 for this task[23].

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 supports also can 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 – 16).

Exhibit C – 16 – 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

[23] For a description of the Community Health Worker 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)

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)[24].*

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.

Care Management in the SoonerCare Program

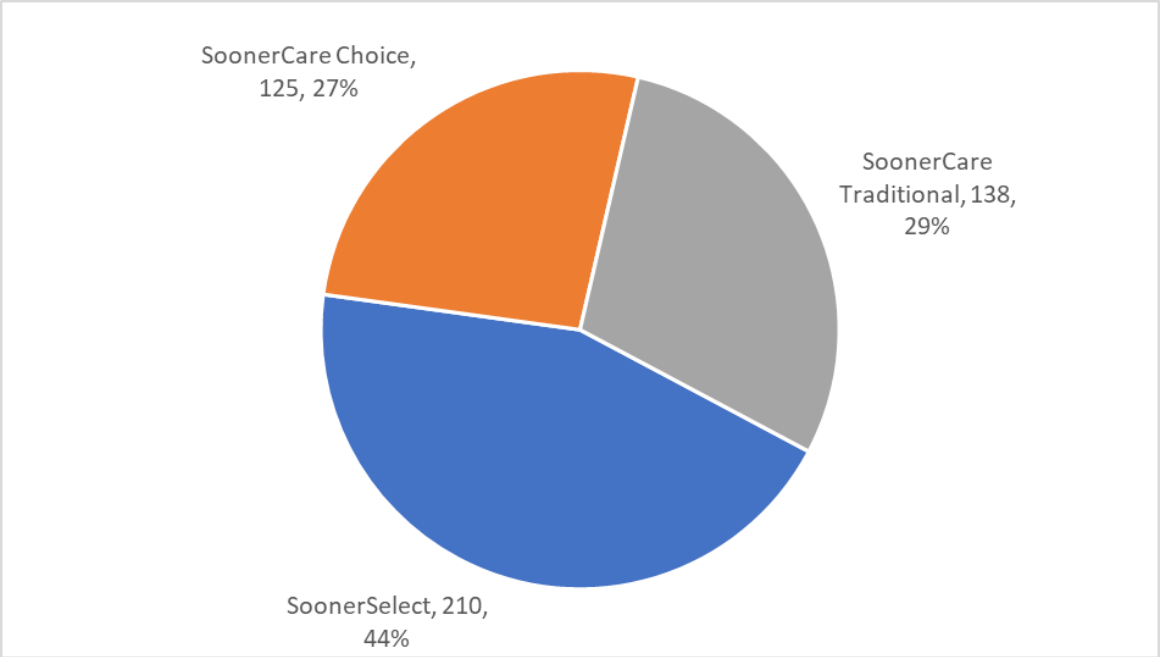
Prior to 2024, the majority of Medicaid members in Oklahoma were enrolled in SoonerCare Choice, the OHCA's primary care case management model. SoonerCare Choice enrollees select a primary care provider to serve as their patient centered medical home, or PCMH. The PCMH is responsible for coordinating the member's care needs, including specialist referrals. Members who require a 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 MCEs serve non-disabled children and adults, including persons eligible as a result of Medicaid expansion. The MCEs are responsible for all Title-XIX medical, behavioral health and social services. Nearly one-half 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 – 17 on the following page).

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

Exhibit C – 17 – SoonerCare Members with SCD by Program



The SoonerSelect MCEs 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 also has 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 2024, the CCM provided care management to 63 members with SCD, consistent with enrollment 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 prior to the member's nineteenth birthday, 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 2024, 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[25]. 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[26].

The HANs historically have provided care management to a small number of members with SCD, identified through data analytics or physician referral. In SFY 2024, there were approximately 200 members with SCD aligned with a HAN-affiliated PCMH provider.

HAN members have reported having difficulty gaining access to a PCMH knowledgeable about their condition, consistent with PHPG's findings for the program as a whole. OU SoonerHAN began work in late 2023 on an evidence-based care management initiative for members with SCD, to address access and other care-related needs.

During the past year, the HAN identified and reached-out to 29 members with SCD to offer care management and other supports. The HAN made contact with 22 members and initiated care management with 16 of the 22 (the other six declined to participate). The HAN is continuing to work with eight of the 16, while the others chose to end their care management or were transferred to another SoonerCare program due to a change in eligibility.

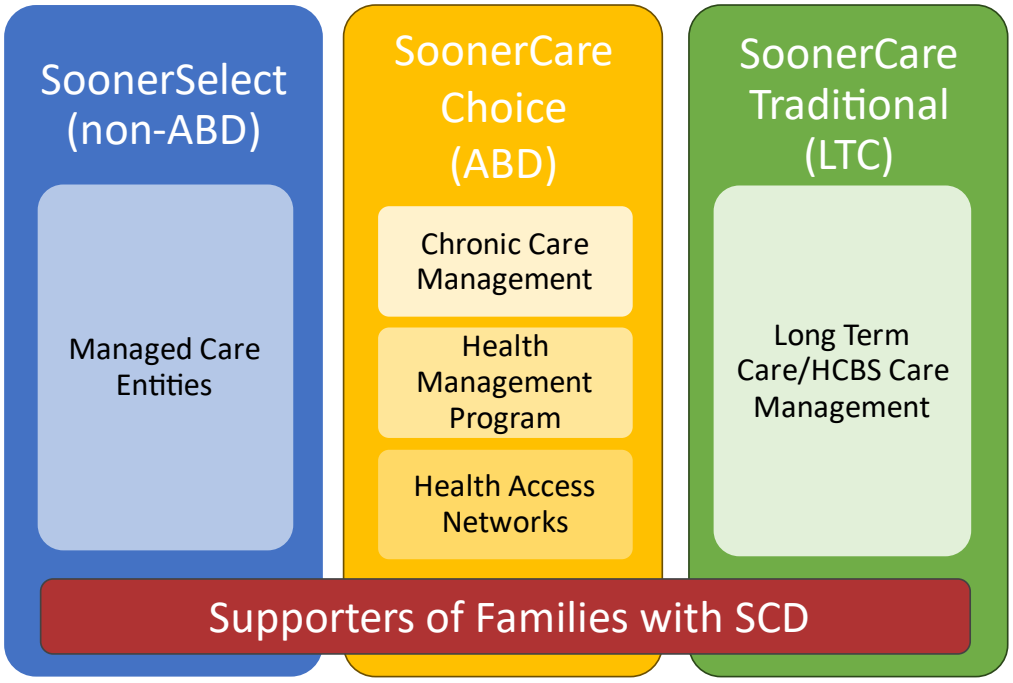
[25] A third HAN, Partnership for Healthy Central Communities, discontinued operations in the Spring of 2024. PHCC was the smallest of the HANs and had too few members after implementation of SoonerSelect to remain viable.
[26] The two HANs also contract with one of the SoonerCare MCEs and continue to serve a portion of the SoonerSelect population through these contracts.

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[27] 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 MCEs.

Exhibit C – 18 summarizes the various care management models and programs available to SoonerCare members with SCD.

Exhibit C – 18 – SoonerCare Care Management Models



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.

[27] 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 ADvantage program for frail elders and adults with physical disabilities.

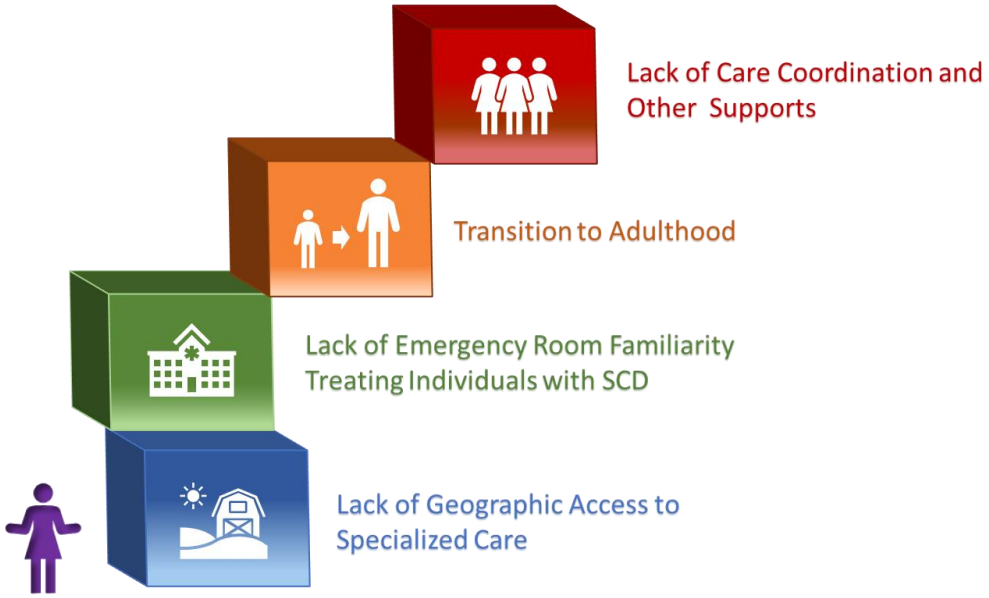
Emergency room providers unfamiliar with SCD may be reluctant to take aggressive steps to manage the pain of patients in crisis. This can prolong the episode and the patient's level of distress.

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[28].

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 – 19).

Exhibit C – 19 – Examples of Health Disparities/Barriers to Care



PHPG explored member perceptions of care through a structured telephone survey conducted in September and October of 2024. Supporters of Families with Sickle Cell Disease held a virtual Town Hall meeting on November 14, to hear about the experiences of members throughout the State. (PHPG staff also attended.) Findings from the survey and Town Hall are presented in the next section.

[28] SoonerSelect MCEs may waive adult benefit limits as a "value-added" benefit.

D. MEMBER PERCEPTIONS OF CARE

1. *Data Collection*

Survey Data Collection

PHPG developed a structured member survey instrument to be administered by telephone. The survey 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 up to six contact attempts over a 30-day period in September/October 2024, 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.)

Fifty-six surveys were completed with adult members or the parents/caregivers of members under age 18. The respondents included 45 persons with sickle cell anemia and 11 with another SCD diagnosis, such as thalassemia.

The results were analyzed for respondents in total and by program of enrollment. Twenty respondents were enrolled in SoonerSelect and the other 36 in SoonerCare Choice or Traditional. Differences between the SoonerSelect and 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 November 14, 2024 and extended invitations to sickle cell families and stakeholders across Oklahoma. Over 50 persons attended the meeting, including patients,

family members, advocates, front line staff (nurses and community health workers) and representatives of the SoonerSelect MCEs. (PHPG attended as an observer.)

The topics covered were similar to 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 comments and data from the member survey.

2. Findings

Regular Source of Care

Forty-three of the 56 survey respondents (81 percent) confirmed that they had a regular primary care provider, either a family physician or pediatrician; 11 (15 percent) identified a hematologist as their regular provider. The remaining two did not have a regular doctor and instead cited the emergency room as their regular venue for care (Exhibit D – 1).

Exhibit D – 1 – Regular Source of Care

Source	*All Respondents*	*SoonerSelect*	*SoonerCare Choice/ Traditional*
Family Practice	52.8%	47.4%	55.9%
Pediatrics	28.3%	47.4%	17.6%
Hematology	15.1%	5.2%	20.6%
Emergency Room	3.8%	--	5.9%
TOTAL	**100.0%**	**100.0%**	**100.0%**

The majority of 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[29] on the following page).

[29] Members who use a hematologist as their regular provider are excluded from the counts in Exhibit D-1.

Overall, 36 of the 56 respondents (64.3 percent) reported having a specialist provider, either as their sole source of regular care or in addition to a primary care provider. (Best practice is to have both provider types, to ensure regular preventive care needs are met.)

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

Specialist	*All Respondents*	*SoonerSelect*	*SoonerCare Choice/ Traditional*
Yes - Hematology	52.1%	73.7%	37.9%
Yes- Oncology	6.3%	--	10.3%
No	42.6%	26.3%	51.8%
TOTAL	**100.0%**	**100.0%**	**100.0%**

Only two survey respondents (one SoonerSelect member 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. It is possible that some respondents with care managers answered "no" to this question because they are unfamiliar with the concept by that name, but it appears the great majority 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.

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 – 3 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. Other services were reported less frequently, with some more prevalent among SoonerSelect members than SoonerCare Choice/Traditional members, and vice-versa.

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".

PHPG inquired about the same tests and services in a 2022 survey of members with sickle cell disease. In most instances, the percent answering "yes" was lower in 2024. However, the sample sizes in both surveys were small and the differences were not statistically significant. Overall, however, room for improvement was documented in 2022 and this continues to be the case.

Exhibit D – 3 – Received Service – Percent answering "Yes"

Service	*All Respondents*	*SoonerSelect*	*SoonerCare Choice/ Traditional*
Daily penicillin[30]	8.9%	20.0%	2.8%
Hydroxyurea	35.7%	20.0%	44.4%
Transcranial Doppler (Head) X-Ray	21.4%	30.0%	16.7%
Blood pressure checked	98.2%	100.0%	97.2%
Retinas examined	57.1%	60.0%	55.6%
Kidneys checked	53.6%	60.0%	50.0%
Lungs checked	75.0%	85.0%	69.4%
Heart checked	80.4%	80.0%	80.6%
Received pneumococcal vaccine	16.1%	15.0%	16.7%
Received blood transfusions	42.9%	15.0%	58.3%
Received chelation therapy	3.6%	5.0%	2.8%
Have a treatment plan for pain control	78.6%	80.0%	77.8%

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 – 4 on the following page. For ease of presentation, only aggregate responses are shown; however, SoonerSelect and SoonerCare Choice/Traditional satisfaction rates were similar on all attributes.

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

Exhibit D – 4 – Satisfaction with Aspects of Care (non-Emergent) and Program[31]

Service/Program	*Very Satisfied*	*Somewhat Satisfied*	*Somewhat Dissatisfied*	*Very Dissatisfied*
Finding doctors who know sickle cell disease	53.6%	37.5%	---	8.9%
Being able to schedule appointments when needed	85.5%	10.9%	---	3.6%
Getting the right services and treatments	76.4%	20.0%	---	3.6%
Getting the right medications	75.9%	20.4%	---	3.7%
Getting extra support & help to manage sickle cell disease	74.1%	20.4%	1.9%	3.7%
Being listened to and understood (non-pain related)	72.2%	22.2%	3.7%	1.9%
Being listened to and understood (pain related)	68.5%	27.8%	1.9%	1.9%
Overall satisfaction with care team	75.9%	22.2%	---	1.9%
Overall satisfaction with program	69.1%	25.5%	1.8%	3.6%

PHPG also inquired about the same aspects of care in 2022. The 2022 respondents were more likely to describe themselves as “very satisfied” rather than “somewhat satisfied”, but the percentages describing themselves as “dissatisfied” were similar across the two time periods.

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 “being listened to and understood” with respect to pain.

[31] A small percentage answered “don’t know/not sure” to the questions and are excluded from the totals.

These findings are supported by the additional comments offered by survey respondents and by the remarks made by Town Hall participants. Many expressed frustrations with the lack of knowledge among physicians about sickle cell disease and its symptoms:

> *"I am still trying to find a doctor who takes SoonerCare and treats sickle cell anemia." – Survey respondent*

> *"I can't find a doctor to take me. I was going to a doctor who was seeing me for sickle cell in Tulsa for eight years. He all of a sudden dropped a bunch of patients and I was one of them. I have been to the emergency room over 40 times this past year because I don't have a doctor." – Survey respondent*

> *"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." – 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." – 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)." – Town Hall participant*

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

Families receiving care at the two leading Oklahoma care sites had more positive comments, reflecting the value of being seen by providers with knowledge of the disease:

> *"His entire team (at Jimmy Everest) is amazing. They treat him like he's a star. I laugh every time we go to any of his doctors because they all come out to see him and give him so much attention. He is non-verbal and has the worst type of sickle cell you can have and he has stolen all their hearts. He gets the best care from his doctors and at the hospital I could ask for. They always get to work as quickly as possible to take care of him. I am very grateful for SoonerCare and his care team. I know how expensive treating this is." – Parent survey respondent*

> *"I had a really good experience at Saint Francis. The doctor said, 'I looked at your chart and the pain on your face – what do you want (for pain relief)?'" – Town Hall participant*

Several members endorsed the idea of having a dedicated location for patients with sickle cell disease to seek routine/preventive services outside of a hospital setting:

> *"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." – Town Hall participant*

> *"I am satisfied with SoonerCare but wish there were more resources for people with sickle cell. I came from Tennessee and they had an entire building just for sickle cell patients." – Survey respondent*[32]

Another Town Hall participant mentioned the "sickle cell sanctuary" day center in Atlanta as a potential model for Oklahoma. The center is interdisciplinary and offers holistic care to patients with the goal of reducing pain crises and the need for emergency room visits and hospitalizations[33].

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 two 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). Thirty-three of the 56 respondents reported visiting the emergency room at least once in the past 12 months for any reason (58.9 percent).

SoonerCare Choice/Traditional members were more likely than their SoonerSelect counterparts to have made a visit (66.7 percent versus 45.0 percent). This may be a reflection of the demographic differences between the two populations, as Choice/Traditional members include ABD and Medicare/Medicaid dual eligibles and are older, on average, than SoonerSelect members.

[32] The member likely was referring to the Diggs Kraus Center or Methodist Hospital center, both located in Memphis. There are approximately 1,400 Tennessee Medicaid members with SCD.
[33] See: Sickle Cell Sanctuary offers new care option for thousands of Georgians | FOX 5 Atlanta. Atlanta is home to over 7,000 persons with sickle cell disease.

Survey respondents averaged slightly over four visits apiece, although the largest segment (10 respondents) stated they visited the emergency room once. The highest reported count by a survey respondent was 42 visits in the past 12 months.

Exhibit D – 5 below presents satisfaction ratings on various aspects of emergency room care. Once again, only aggregate responses are shown; however, SoonerSelect members were more likely than SoonerCare Choice/Traditional members to rate themselves as "very satisfied".

Significant numbers of 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 smaller than in 2022 but still indicative of the need for improvements in care.

Exhibit D – 5 – Satisfaction with Aspects of Emergency Room Care[34]

ER Aspect	*Very Satisfied*	*Somewhat Satisfied*	*Somewhat Dissatisfied*	*Very Dissatisfied*
Seeing doctors who know sickle cell disease	53.1%	28.1%	12.5%	6.3%
Getting the right services and treatments	68.8%	21.9%	6.3%	3.1%
Being listened to and understood (pain related)	56.3%	28.1%	9.4%	6.3%
Getting the right medications	62.5%	21.9%	6.3%	9.4%
Overall satisfaction with emergency room care	59.4%	25.0%	9.4%	6.3%

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

> *(The) emergency room doctors don't listen to me. I tell them I can't take morphine – it makes my pain so much worse, but they give it to me anyway. They also put me in a box like I am a drug seeker." – Survey respondent*

> *"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'". – Town Hall participant*

[34] A small percentage answered "don't know/not sure" to the questions and are excluded from the totals.

"I shouldn't have to feel like I'm at war when I'm trying to get help. I have to keep watch. Things can happen that can be life altering. I had a(n ER) nurse offer my daughter ice for the pain[35]." – 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." – Town Hall participant

"Even at age 4, 5, 6, 7 he was labeled as drug seeking or I was using him to get drugs." – Town 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." – 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 five respondents whose child fell into this cohort, only one reported that the member's care team had helped them to prepare for the transition to adulthood.

During the Town Hall meeting, a member with sickle cell disease who recently became an adult, spoke of the need for support in making the transition:

"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

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

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." – Town Hall participant

Transition from SoonerCare Choice to SoonerSelect

At the conclusion of the Town Hall meeting, participants who had transitioned from SoonerCare Choice to SoonerSelect were asked a series of questions about their experience. Twenty-five persons answered the questions.

Nearly all of the members reported that there was no disruption in care during the transition. Every member was able to retain their existing primary care provider and nearly every member was able to continue seeing all (87 percent) or some (10 percent) of their existing specialist physicians.

Consistent with the structured survey findings shown earlier, none of the Town Hall participants reported having yet been contacted by their health plan to ask about their needs and interest in care management.

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. Work has begun on implementing several of the recommendations but, as a whole, they remain valid[36].

The findings and recommendations are discussed below. Progress made since the initial report in 2022 is noted where applicable.

The section also includes a new recommendation for further study, based on an emerging best practice in other states: the establishment of one or more day centers for preventive sickle cell care.

The final section of the report proposes next steps, in the form of a structure and proposed schedule for timely implementation of the recommendations. The recent changes to the SoonerCare program brought on by the transition to SoonerSelect make this an ideal time for organizing a coordinated effort to make Oklahoma a leader in caring for individuals with SCD and their families.

Access to Covered Services – Summary of Findings

SoonerCare members with SCD are generally appreciative of their care but can find it challenging to locate a primary care provider who is familiar with their condition. This is particularly true of members with an SCD diagnosis other than sickle cell anemia.

Most members receive care at least periodically from a specialist, usually a hematologist or oncologist. In the 2022 study, some members (and primary care providers) expressed frustration with the OHCA's requirement that all specialty care must begin with a referral

[36] The initial report also noted various accomplishments of the legislature and OHCA in the period leading up to the study. In the interest of space, these are not repeated but can be found in the 2022 document.

from the member's primary care provider. The referral issue was not raised specifically in 2024 but remains relevant, particularly for members new to SoonerSelect managed care.

The leading site for members with SCD – Jimmy Everest – offers interdisciplinary care to its patients, which is a best practice. However, Jimmy Everest does not treat adults, who make-up a majority of the SoonerCare SCD population.

Oklahoma also lacks outpatient settings dedicated to offering preventive care to patients prior to a crisis. Individuals who require one or more days of hydration therapy to avert a crisis typically must be treated in the emergency room or as an inpatient, if they can arrange treatment at all.

One best practice that has been implemented in other states, including California, Georgia and Tennessee, is creation of day centers for care of SCD patients. Such a center need not be in a free-standing location, but could be an adjunct to a hospital outpatient setting. Both Oklahoma City and Tulsa likely have a sufficient critical mass of patients to support this concept in some form[37].

The transition of the non-ABD population to SoonerSelect MCEs also presents a significant opportunity for improved access to care. The OHCA, in partnership with the MCEs/MCE provider networks and SCD advocates, can spearhead development of a coordinated strategy to improve access. The OHCA's CCM unit and SoonerCare HMP vendor can similarly be tasked with assisting ABD members with SCD.

Emergency Room Care – Summary of Findings

The quality of emergency room care for members in crisis was one of the paramount issues raised in the 2022 study and it remains a source of dissatisfaction today. Although there are no statutory or Medicaid policy barriers preventing emergency room providers from treating patient pain aggressively, it often does not occur.

The source of the problem continues to be a lack of knowledge among providers concerning best treatment practices. This applies in particular to providers who see patients in sickle cell crisis infrequently.

Once again, the OHCA, in partnership with the MCEs and partner organizations, can facilitate outreach to, and education of, emergency room facilities, physicians, nurses and

[37] Another treatment venue may arise through federal legislation. A bill introduced in Congress in February 2024 would extend the Medicaid Health Home model to sickle cell disease. Health Homes are integrated care settings for individuals with complex needs; most states, including Oklahoma, established behavioral Health Homes when the concept was first introduced. Health Homes are funded at a 90 percent match rate by the federal government during their initial years of operation. Any Health Home initiative would have to be aligned with the OHCA's goal of serving members through managed care, including SoonerSelect MCEs, to avoid fragmentation of care.

other staff. An aggressive outreach and education strategy has the potential to address a major quality-of-life issue for SoonerCare members with SCD. (The benefits of any campaign also would carry over to the commercially-insured population.)

Access to Supports – Summary of Findings

The OHCA has long recognized that members with complex and chronic conditions such as SCD can benefit greatly from holistic, or integrated, care that combines medical, behavioral health and social services under the direction of an interdisciplinary care team and manager. Such care also must be person-centered, such that the member remains the ultimate decision maker for his or her own health.

The OHCA has sought to advance this model of care through various programs, including the SoonerCare CCM, the SoonerCare HMP, SoonerCare HANs and SoonerSelect, as well as through its contract with Supporters of Families with Sickle Cell Disease (for outreach and assistance, when requested). The MCEs, for their part, are required to assess all members for health/social service needs and to offer care management when needed.

Most members with SCD today do not have an interdisciplinary care team or care manager. The coordinated strategy discussed above in the Access to Care section is also the appropriate vehicle for advancing the holistic model and closing this gap in care. This strategy, if deployed successfully for members with SCD, could serve as a template for addressing other complex/chronic conditions that affect children and adults enrolled across all three SoonerCare programs (Select, Choice and Traditional).

In addition to general care management, the care team can serve as a resource to members transitioning from pediatric to adult status. Adolescent members will benefit from assistance in reconstituting their provider support system, understanding changes in their coverage and preparing to take greater responsibility for their treatment plan.

Exhibit E-1, starting on the next page, summarizes the original findings and recommendations for improving access, emergency room care and health care system supports. It also presents updated information based on 2024 evaluation activities.

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

Initial Findings (Areas for Improvement)	Initial Recommendations	2024 Update
Access to Care		
1. PCMH providers are not uniformly knowledgeable about Sickle Cell Disease.	1. The OHCA, in conjunction with SoonerSelect MCEs, 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 OHCA, MCEs and Supporters of Families with SCD held an introductory task force meeting in the fall of 2024. The task force is to be expanded to include major providers. Future sessions should be used to prioritize activities and formulate a schedule for implementation.
2. Specialist providers, including at major provider sites such as Jimmy Everest, must channel referrals through PCMH providers.	2. The OHCA and SoonerSelect MCEs should have a process for allowing qualified specialists to make referrals, while keeping PCMH providers informed, either directly or through the HIE.	2. The specialty referral process can be an action item for the SCD task force.
3. Members needing preventive care to avert a crisis often must seek treatment in an ER or inpatient setting.	3. N/A – New Recommendation	3. The task force can be used to explore the potential for creating day centers in Oklahoma City and Tulsa.
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. The ER education campaign can be an action item for the SCD task force. Work can begin in counties with the greatest number of members with SCD and expand outward over time.

Initial Findings (Areas for Improvement)	Initial Recommendations	2024 Update
5. Only a portion of members with SCD today have a pain management action plan.	5. The OHCA, SoonerSelect MCEs and advocacy community should collaborate on outreach to members with SCD and hematology community to facilitate creation of plans. Emergency room providers also can be educated on their efficacy and importance.	5. The portion of members reporting they have a plan now stands at 80%. The OHCA, through its internal programs and contracts with MCEs and the SoonerCare HMP vendor, should ensure all members are offered the opportunity to develop a plan. (The OHCA's role will be one of oversight.)
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 MCEs, 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, through its managed care oversight function, should ensure that MCEs are meeting their contractual obligation to assess and develop care plans, as appropriate, for all members with SCD. The OHCA identifies all new members with SCD on a quarterly basis. The OHCA can use this information is collaboration with the HMP vendor and HANs to ensure the same assessment and care planning opportunity is extended to all ABD members with SCD. (OU SoonerHAN has begun such an initiative for members aligned with its provider network.)

Initial Findings (Areas for Improvement)	Initial Recommendations	2024 Update
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 same steps described above for recommendation 7 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 same steps described above for recommendation 7 apply to this recommendation
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. This recommendation can be an action item for the task force. (The OHCA and individual MCEs may have discrete solutions based on their member platforms.)

2. Next Steps

The OHCA convened a meeting group in the fall of 2024 to begin planning next improve access and quality of care for members with SCD. Representatives of the three MCEs and Supporters of Families with Sickle Cell Disease participated. This group, with some additions, can serve as the appropriate platform for implementing report recommendations.

Structure

The OHCA already intends to add major providers (e.g., Jimmy Everest) to the group. The meeting group should be converted into a formal task force and further expanded to include representatives from the SoonerCare HMP and HANs.

The inclusion of the SoonerCare HMP vendor would be contingent on the OHCA deciding to use the vendor to serve non-HAN affiliated ABD members with SCD. Although the SoonerCare HMP has a handful of such members today, it could expand outreach and enrollment if requested by the OHCA.

The task force could meet quarterly as initiatives are developed and implemented. The initiatives themselves could be divided between two workgroups – one that focuses on provider education activities and a second that addresses policy-related items.

The first meeting of the reconstituted task force can be used to make workgroup assignments and set priorities for action. The OHCA also can use to make assignments to two smaller work groups, one focused on provider education initiatives and the other on policy and care management-related initiatives.

The initial meeting also can be used to share baseline data on the number of members with SCD that each participant has assessed and enrolled in care management, as well as provider educational contacts. The numbers can be updated at each meeting and used by the OHCA to track contractor performance.

The task force can establish a regular meeting schedule (e.g., quarterly) and begin by prioritizing development and implementation of the discrete recommendations.

Schedule

Exhibit E – 2 below presents a proposed schedule (timeline) for action. As it suggests, major progress should be feasible across all areas in the next 12 to 18 months.

Exhibit E – 2 – Proposed Schedule

Activity	Quarter 1	Quarter 2	Quarter 3	Quarter 4	Quarter 5	Quarter 6
Task Force Meetings	Create workgroups Set baselines	Meeting Update results	Meeting Set baselines	Meeting Set baselines	Meeting Set baselines	Meeting Set baselines
PCMH Education		Develop outreach/education plan	Implement in primary SCD counties		Expand to other counties with SCD members	
Specialty Referrals	Document existing policies/barriers	Make recommendations for uniform policies	Implement policies			
SCD Centers for Preventive Care		Conduct feasibility study		Report study findings; identify next steps		
ER Provider Education		Develop outreach/education plan	Implement in primary SCD counties		Expand to rest-of-state	
Assessments, Care Plans & IDTs	Provide member-level data on SCD population within each entity; share best practices	Conduct outreach and enrollment activities; report on results	Conduct outreach and enrollment activities; report on results	Conduct outreach and enrollment activities; report on results	Conduct outreach and enrollment activities; report on results	Conduct outreach and enrollment activities; report on results
Mobile Apps & Other Technology		Identify best practices; explore opportunities for shared initiatives				