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 2024

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 an 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 and the State's two centers-of-excellence (Jimmy Everest Center at Oklahoma University and Saint Francis Hospital) in preparation of the original report.

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COMMONLY-USED ABBREVIATIONS & ACRONYMS

ABD	Aged, Blind, Disabled
CCU	Chronic Care Unit
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.

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 persons. The next most populated counties are Cleveland, Comanche and Muskogee, each with between 10 and 30 persons. There are 34 counties with at least one, but fewer than 10 members with SCD; 38 counties have no members with SCD.

Most members with SCD are enrolled in SoonerCare Choice, the OHCA's primary care case management model. In April 2024, the majority of SoonerCare Choice members will be enrolled into Managed Care Entities (MCEs) under the OHCA's new SoonerSelect model.

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 around 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. This report presents the first annual update to the initial 2022 study. More specifically, it:

- Provides current (SFY 2023) information on the characteristics of the population with SCD (demographics and service use) and advances in treatment of the disease
- Discusses barriers to care for persons with SCD, existing care management opportunities in the SoonerCare program and the upcoming transition to SoonerSelect
- Summarizes initial report findings and documenting the steps taken to-date by the OHCA and its partners to act on recommendations related to improving quality and overcoming barriers-to-care

Characteristics and Service Use among SoonerCare Members with SCD

Approximately 42 percent of members with SCD in SFY 2023 were under the age of 20; this included 30 older adolescents ages 17 to 19 approaching the transition from child to adult coverage. The number of adults ages 20 to 35 increased from 154 in SFY 2022 to 166 in SFY 2023, possibly due in part to the expansion of Medicaid to higher income adults, including those without children.

Paid claims for SoonerCare members with SCD totaled nearly $15.0 million in SFY 2023, up from $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 and in part to growth in expenditures per member. The average annual expenditure per member in SFY 2023 was approximately $29,700, up from $26,900 in SFY 2022 and $25,200 in SFY 2021.

Approximately 300 members with SCD had at least inpatient stay in 2023. Nearly all of the members with inpatient stays were hospitalized at least once for treatment of an SCD-related completion, 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 2023, 321 out of 498 members with SCD, or 64.5 percent, had at least one emergency room visit, down slightly from 67.1 percent in SFY 2022. The subset of ER utilizers sought care an average of 7.9 times each.

The emergency rooms at OU Health Sciences Center and Saint Francis have evidence-based protocols for treatment of patients in crisis and providers are familiar with how to treat the condition. (These hospitals serve as "centers-of-excellence" for treatment of SCD.) However, as PHPG documented in the initial study, the majority of emergency room physicians see only one or two cases per year.

ER physicians with infrequent contact still were responsible 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.

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.

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.

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. Members 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 Unit and contracts with several "Health Access Networks" to provide care management to members with SCD who are patients within their provider networks.

SoonerSelect will expand access to interdisciplinary care management. MCEs will be 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 will be used to develop a comprehensive, interdisciplinary care plan, to be overseen by a designated care manager.

Update to Initial Report Findings & Recommendations

Findings

As documented in the initial (January 2023) report, 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.

Actions Taken in Response to Recommendations

The initial study contained a series of recommendations for improving access and quality of care for members with SCD. The OHCA provided information to PHPG in December 2023 on the status of initial study recommendations. Action has been taken in five areas, as summarized below.

Recommendation: *The OHCA, in conjunction with SoonerSelect MCEs, centers-of-excellence 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.*

Activity: The OHCA assisted Supporters of Families with Sickle Cell Disease in promoting an SCD Awareness Month social media campaign. The effort, which occurred in September, targeted all audiences, including PCMH providers. More information about the campaign, and other activities sponsored by the organization, can be viewed on its website, at Sickle Cell Oklahoma – Supporters of Families with Sickle Cell Disease.

Recommendation: *The OHCA should collaborate with the HMP vendor and HANs to contact all non-care managed ABD 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.*

Activity: The OHCA identifies all members with a diagnosis of SCD on a quarterly basis and currently targets those meeting expenditure/utilization thresholds for care management. The transition of non-ABD members to SoonerSelect in 2024 will expand contact and assessments to all members with SCD. SoonerSelect MCEs will be required contractually to assess all members at time of enrollment (SCD and other). The OHCA intends to reach-out to all members with SCD who remain in SoonerCare Choice, i.e., those whose eligibility is based on Aged, Blind or Disabled status.

Recommendation: *The OHCA also should ensure that current and future care management systems emphasize the importance to members of having a comprehensive*

care/action plan that addresses the member's complete care needs, including future care needs for members transitioning from pediatric to adult coverage.

Activity: The OHCA has partnered with the HANs to initiate a transition-of-care outreach campaign. The OHCA and HANs are targeting members between the ages of 17 and 21 and inviting them to enroll in a short-term care management program to assist with transitioning from pediatric to adult coverage. The initiative began in September and assisted 73 members in its first three months.

Recommendation: *The OHCA should strive to make available interdisciplinary care management, where appropriate, by coordinating with the Jimmy Everest Center, SoonerCare HMP and SoonerCare HANs on behalf of ABD beneficiaries. (All SoonerSelect enrollees will have access to interdisciplinary care teams.)*

Activity: The OHCA has established a collaborative relationship with both Oklahoma centers-of-excellence, to enhance ongoing coordination of care and access to the IDT model. The OHCA and centers held meetings in September and November and intend to continue meeting quarterly.

Recommendation: *The OHCA should explore use of a mobile app, either directly or through its contractors.*

Activity: The OHCA has established a workgroup to explore options for offering a mobile app. The OHCA also has a new care management platform that includes a member-facing portal. The OHCA is preparing to pilot test member access to the portal, with the goal of eventually opening it to all members receiving care management.

Conclusion

The OHCA and its partners have made progress in implementing a majority of the recommendations contained in the initial report. The greatest opportunity for additional progress exists with respect to educating PCMH and emergency room providers on appropriate care for members with SCD, particularly when a patient is experiencing a pain crisis.

The implementation of SoonerSelect offers an ideal opportunity for a coordinated education campaign. The three MCEs will have the great majority of SoonerCare providers in their networks, including those who continue to treat ABD members through SoonerCare Choice.

PHPG will provide an updated progress report in January 2025, along with qualitative and quantitative findings. These will include member impressions of access to, and management of care under the new system, as well as changes in utilization and expenditure patterns.

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 broader SoonerCare Section 1115 Demonstration under which most Medicaid beneficiaries with 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

[1] The upcoming SoonerSelect program operates under a different waiver authority. PHPG also will serve as the independent evaluator of SoonerSelect.

the OHCA to the Legislature in January 2023 and 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.

First (2024) 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."*

This report presents the first annual update to the initial 2022 study. More specifically, it:

- Provides current information on the characteristics of the population with SCD (demographics and service use) and advances in treatment of the disease
- Discusses barriers to care for persons with SCD, existing care management opportunities in the SoonerCare program and the upcoming transition to SoonerSelect
- Summarizes initial report findings and documenting the steps taken to-date by the OHCA and its partners to act on findings and recommendations related to improving quality and overcoming barriers-to-care

PHPG conducted an analysis of state fiscal year (SFY) 2023 paid claims for members with SCD, to capture updated information on demographic characteristics and service use patterns. PHPG also reached-out to OHCA representatives, providers and advocates to inquire about the status of initial report recommendations and actions taken or planned in response.

Section C of the report addresses the first two topic areas outlined above. Section D addresses the third area.

Second (2025) Update

PHPG plans to conduct a comprehensive review of the state-of-care for SoonerCare members with SCD following the April 2024 transition to MCEs. The evaluation scope will include the same data collection methods and lines-of-inquiry as in the original study and report.

Data collection will begin in late summer/early fall, to allow sufficient time for the effects of the transition to be measurable, in terms of access to care and member satisfaction. Findings will be reported to the Legislature in January 2025.

C. CHARACTERISTICS & TREATMENT OF PERSONS WITH SCD

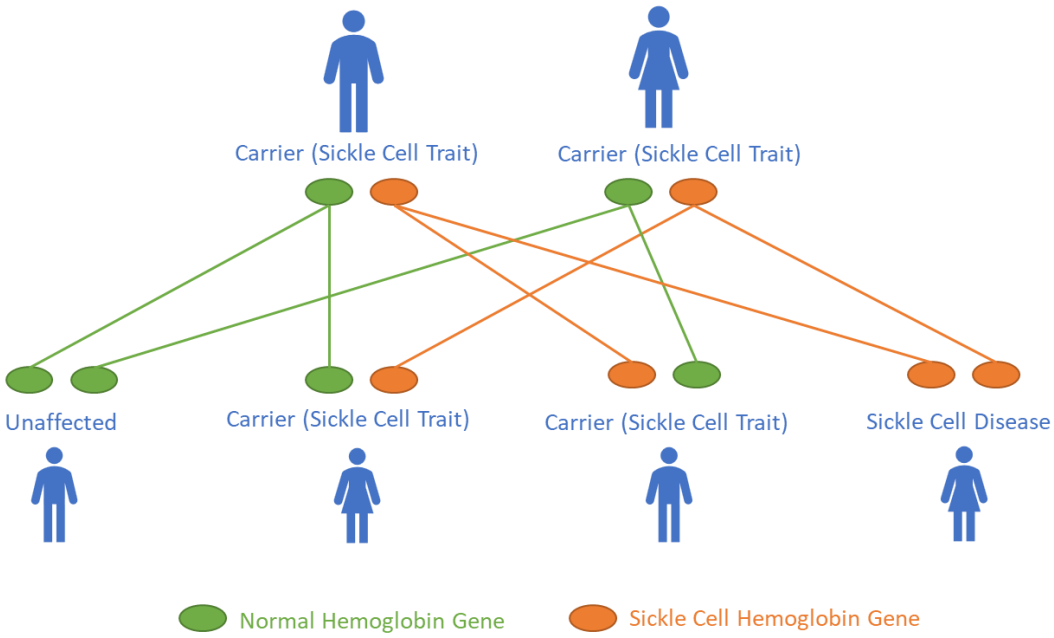
1. *Characteristics of Persons with SCD*

Sickle Cell Disease Types and Prevalence

Sickle cell disease (SCD) 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 the African American community, where it occurs in one of every 365 births[2], 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

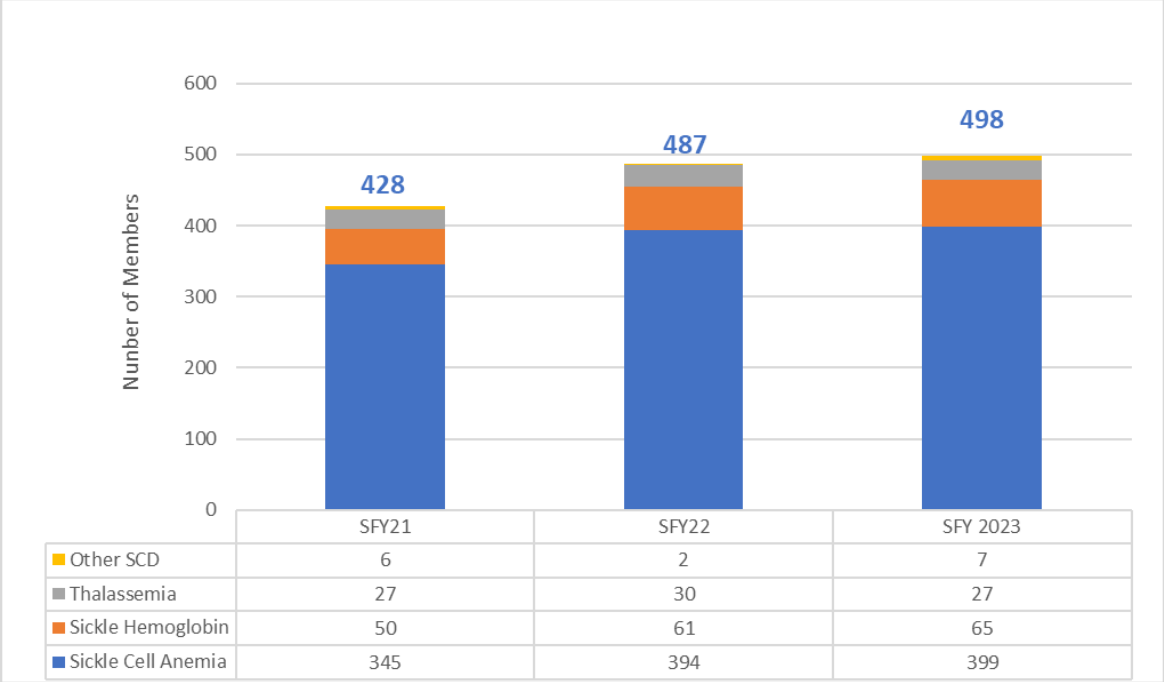


[2] Source: Data & Statistics on Sickle Cell Disease | CDC. SCD occurs in one of every 16,300 births to Hispanic Americans and less frequently among individuals of Asian, Mediterranean and Middle Eastern lineage.

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[3]. 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 three most recent state fiscal years (SFY 2021 – SFY 2023[4]), the SoonerCare program covered between 425 and 500 members with SCD[5] (Exhibit C-2).

Exhibit C-2 – SoonerCare Members with SCD by State Fiscal Year



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

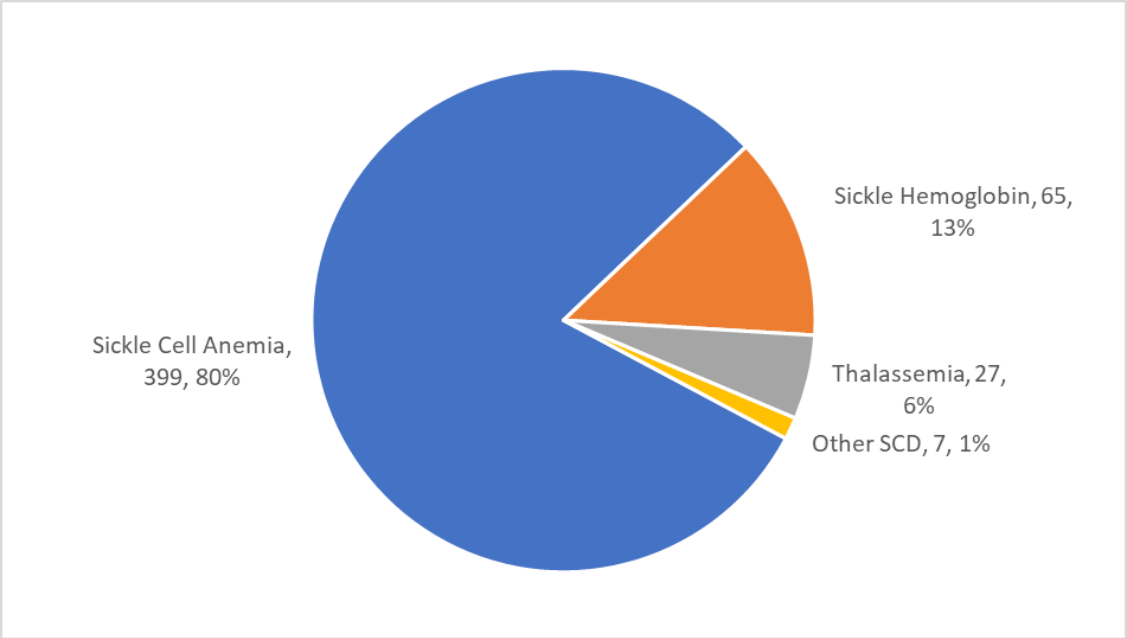
Eighty percent of SoonerCare members with SCD in 2023 were diagnosed with sickle cell anemia, while other SCD conditions occurred with less frequency (Exhibit C-3 on the following page).

[3] Sickle cell disease: MedlinePlus Genetics

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

[5] 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

Exhibit C-3 – SoonerCare Members with SCD by Category (SFY 2023)



Sickle Cell Disease – SoonerCare Member Demographics

PHPG analyzed SFY 2023 eligibility data to profile the demographic characteristics of SoonerCare members with SCD, including places of residence, age ranges, gender and race/ethnicity.

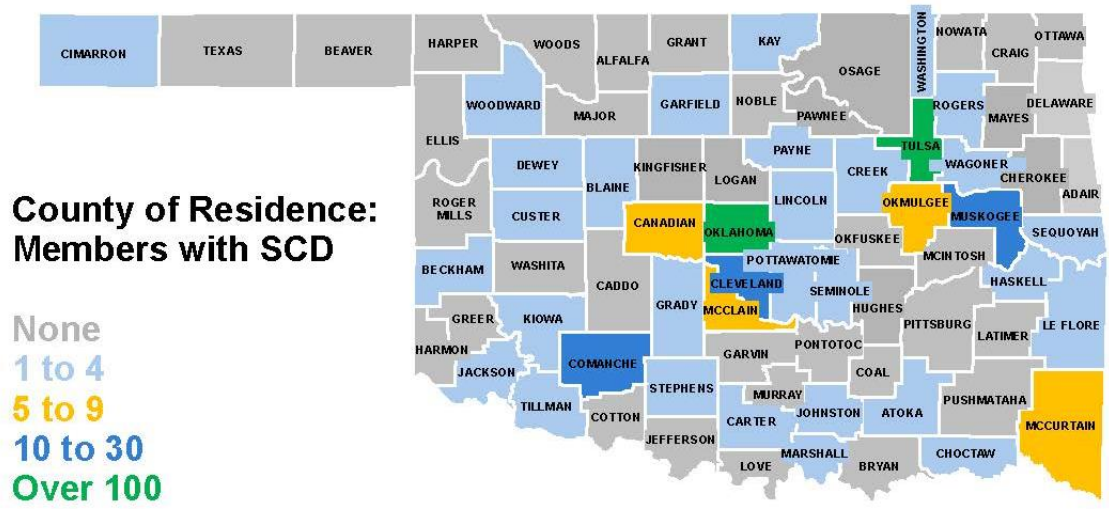
County of Residence

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 on the following page).

The next most populated counties are Cleveland, Comanche and Muskogee, each with between 10 and 30 members. There are 34 counties with at least one, but fewer than 10 members with SCD; 38 counties have no members with SCD[6].

[6] 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. In SFY 2022, there were 41 counties with no members meeting the SCD criteria.

Exhibit C-4 – SoonerCare Members with SCD by County of Residence (SFY 2023)



Oklahoma County contains nearly 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).

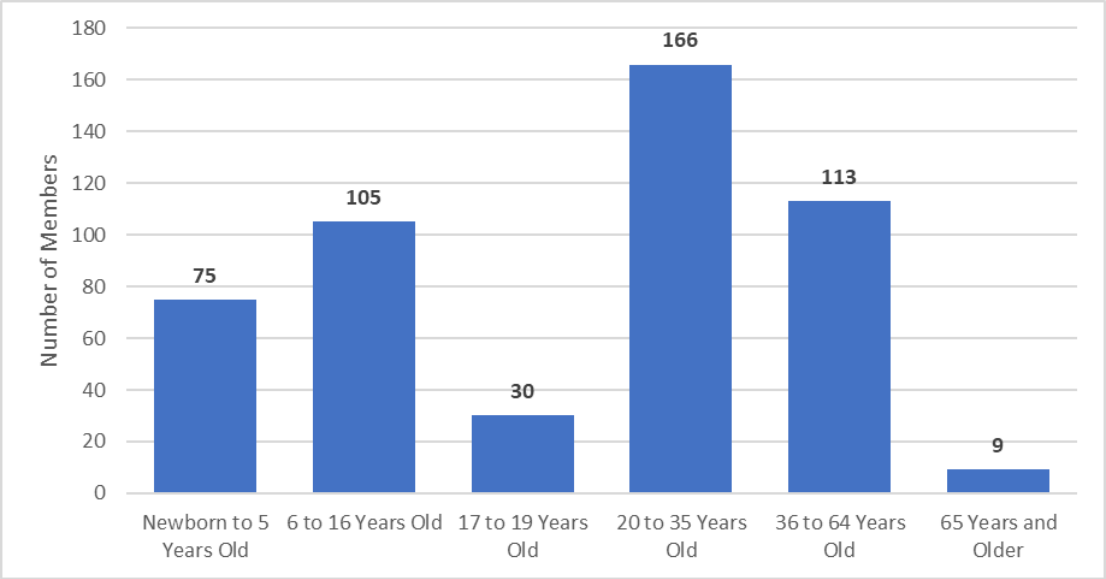
Exhibit C-5 – SoonerCare Members with SCD – Top Five Counties (SFY 2023)

County	Number of Members	Percent of Total	Cumulative Percentage
Oklahoma	229	46.0%	46.0%
Tulsa	135	27.1%	73.1%
Cleveland	22	4.4%	77.5%
Comanche	20	4.0%	81.5%
Muskogee	18	3.6%	85.1%
Other Counties/Out of State	76	14.9%	100.0%
Total	**498**	**100.0%**	**100.0%**

Age Ranges

Approximately 42 percent of members with SCD in SFY 2023 were under the age of 20; this included 30 older adolescents ages 17 to 19 approaching the transition from child to adult coverage. The number of adults ages 20 to 35 increased from 154 in SFY 2022 to 166 in SFY 2023, possibly due in part to the expansion of Medicaid to higher income adults, including those without children (Exhibit C-6 on the following page).

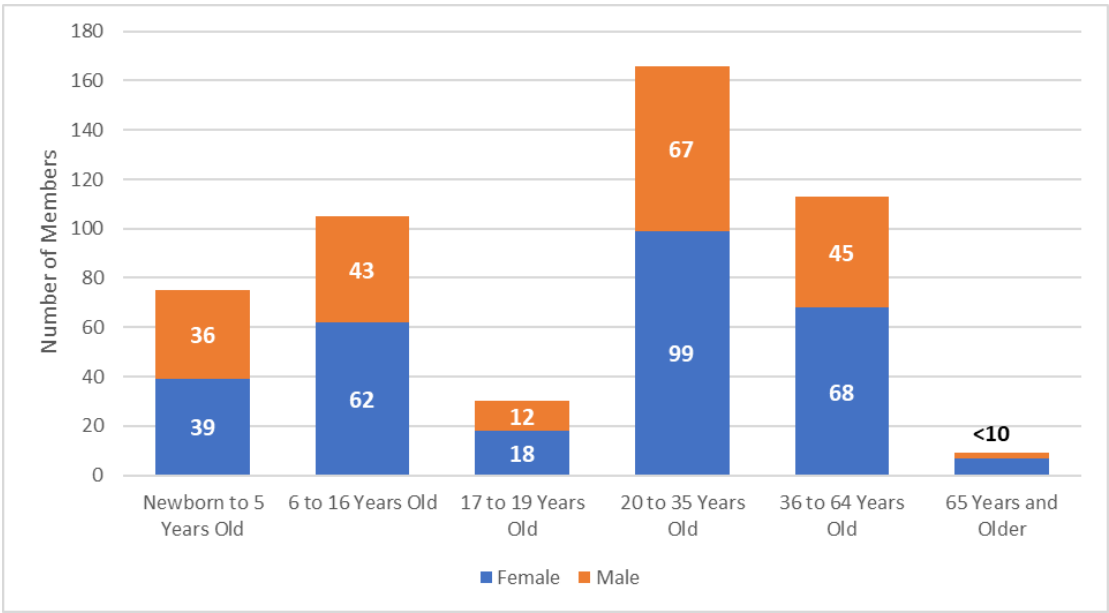
Exhibit C-6 – SoonerCare Members with SCD by Age Range (SFY 2023)



Age and Gender

Females in SFY 2023 outnumbered males by a significant amount in all age cohorts except newborns to five years old (Exhibit C-7).

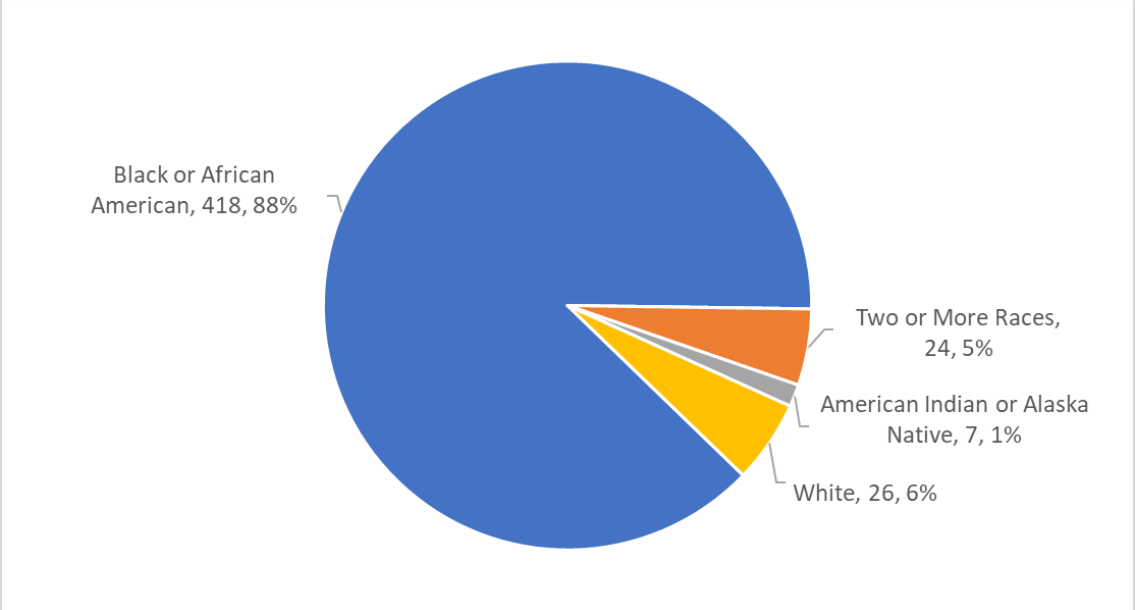
Exhibit C-7 – SoonerCare Members with SCD by Age Range and Gender (SFY 2023)



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)[7]



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

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

2. Treatment of Persons with SCD

Sickle Cell Disease Complications and Treatments

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

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

The transfusions themselves can cause side effects such as iron overload, which pose the risk of damage to the heart, liver, kidneys and other organs. Blood transfusions typically are accompanied by iron chelation therapy to reduce excess iron in the body[8].

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

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.

Voxelotor – this medication helps to restore red blood cells to their normal shape and can be prescribed starting at age four.

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. One recently-developed medication – Adakveo – can reduce the frequency of pain crises in older adolescents and adults; another – Oxbryta – can be used to lower the risk of anemia in adolescents and adults. Medicaid covers all FDA-approved treatments, although some medications require prior approval on a case-by-case basis.

[8] This is not an exhaustive listing of SCD-related complications, which can be damaging to many body systems.

Persons with SCD also 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.

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*."

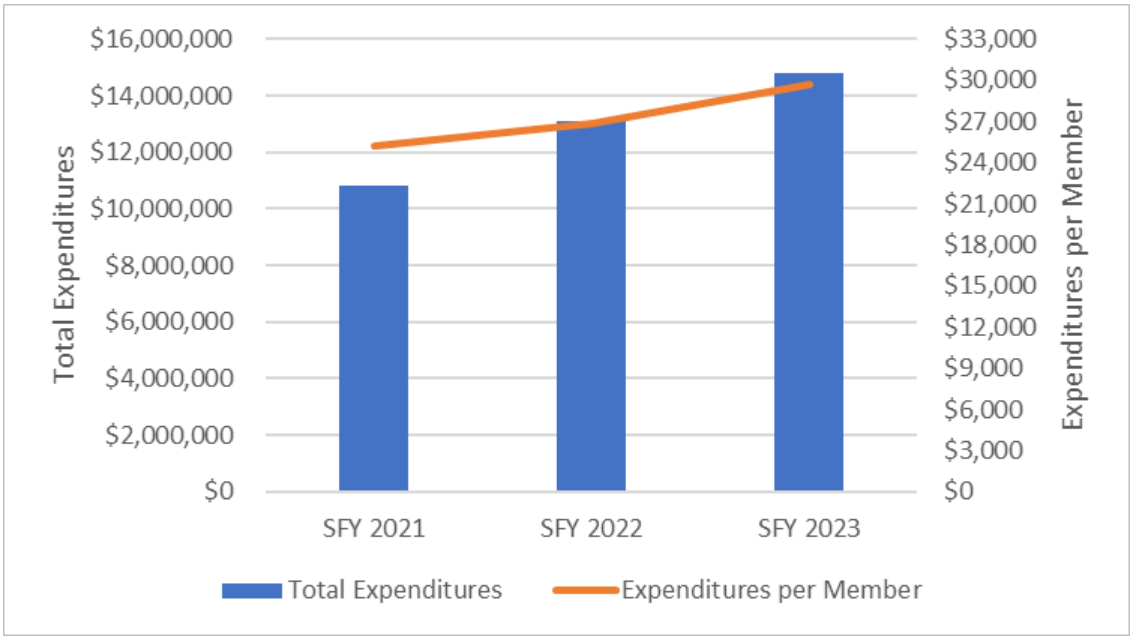
SoonerCare Paid Claims Analysis

Expenditures

Paid claims for SoonerCare members with SCD totaled approximately $15.0 million in SFY 2023, up from $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 and in part to growth in expenditures per member. The average annual expenditure per member in SFY 2023 was approximately $29,700, up from $26,900 in SFY 2022 and $25,200 in SFY 2021. (Exhibit C-9 on the following page). (The average expenditure per SoonerCare member program wide in SFY 2022 was $4,410[9].)

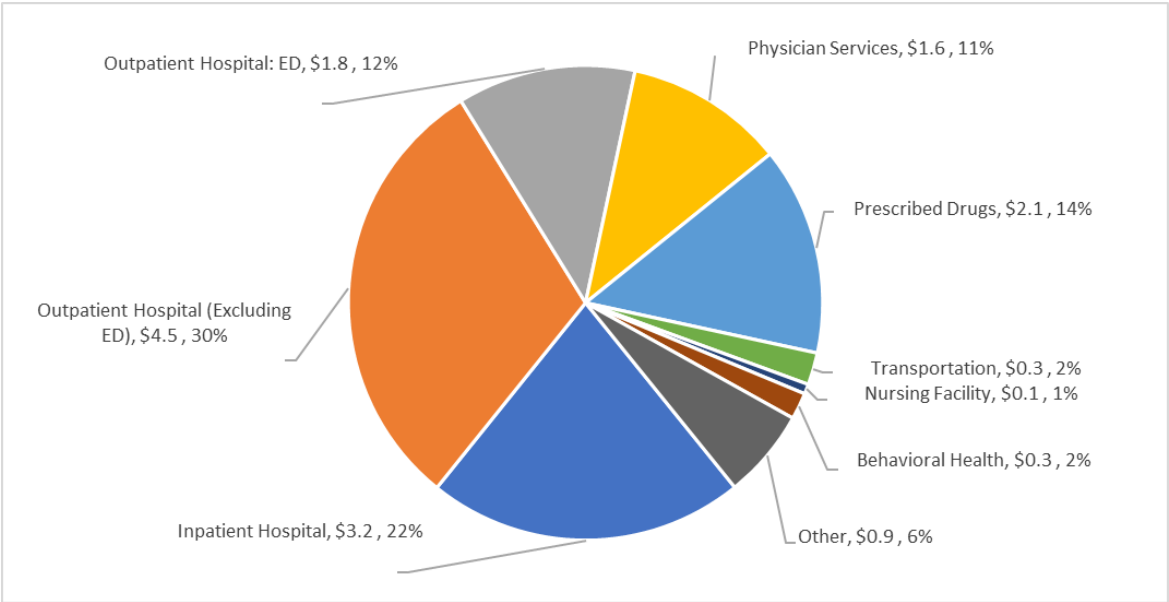
[9] Figure for 2023 not available. Source for 2022 figure is OHCA SFY 2022 Annual Report Appendix, page 22

Exhibit C-9 – Expenditure Trend – SFY 2021 to SFY 2023



The largest service category, in terms of paid claims, was outpatient hospital, excluding emergency room visits (Exhibit C-10).

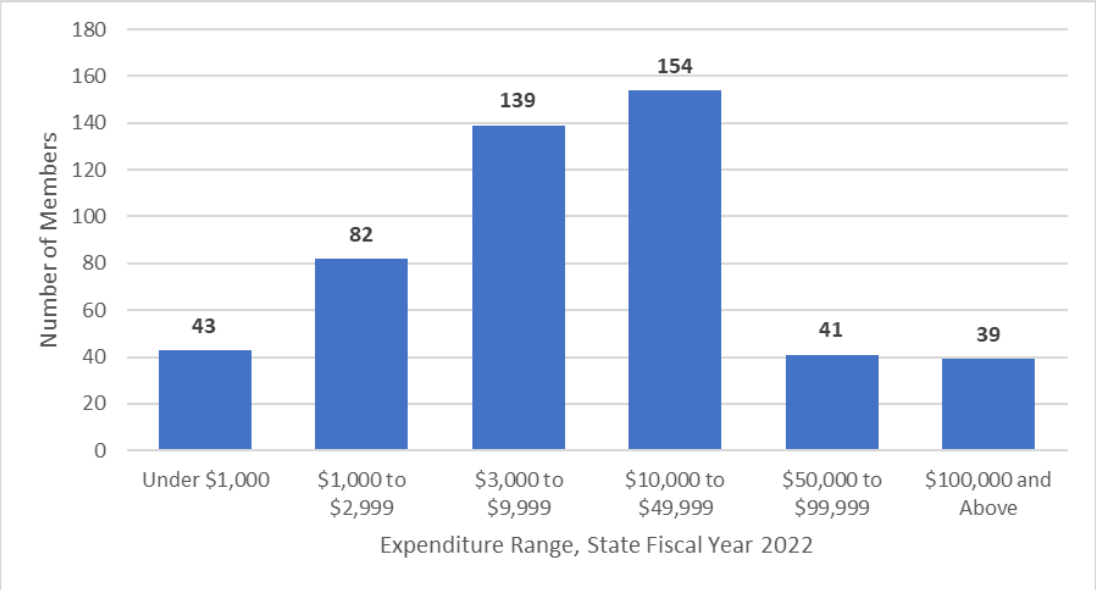
Exhibit C-10 – Expenditures by Service Category (SFY 2023)



Although the average expenditure per member in 2023 was over $29,000, there was a wide range between low- and high-cost members. The top eight percent of members averaged over $186,000 each and accounted for nearly 50 percent of total expenditures.

Conversely, the bottom 25 percent of members accounted for less than two percent of total expenditures (Exhibit C-11).

Exhibit C-11 – Expenditures per Member by Expenditure Range (SFY 2023)



Expenditure Range	Number of Members	Percent of Members	Average Per Member	Percent of Expenditures
Under $1,000	43	8.6%	$471	0.1%
$1,000 to $2,999	82	16.5%	$1,856	1.0%
$3,000 to $9,999	139	27.9%	$5,957	5.6%
$10,000 to $49,999	154	30.9%	$23,813	24.8%
$50,000 to $99,999	41	8.2%	$70,013	19.4%
$100,000 and above	39	7.8%	$186,383	49.1%
Total	**498**	**100.0%**	**$29,733**	**100.0%**

Physician Services

The majority of members with SCD saw a SoonerCare Choice PCMH provider at least once in SFY 2023. Members seeing the two most common provider types, Family Practitioners and Internists, averaged approximately six visits per year (Exhibit C-12).

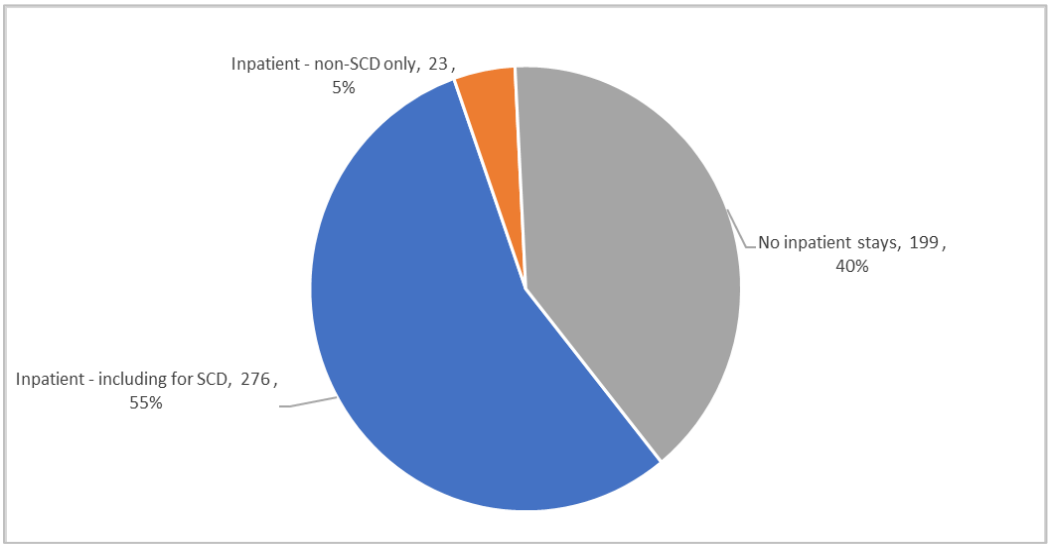
Exhibit C-12 – PCMH Provider Type Activity (SFY 2023)[10]

Primary Care Provider Type	Number of Members	Number of Visits	Average Per Member	Percent of Members
Family Practitioner	197	939	4.8	39.6%
General Pediatrician	189	966	5.1	38.0%
Internist	141	1,040	7.4	28.3%
General Practitioner	32	98	3.1	6.4%

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.

Sixty percent of members with SCD had at least inpatient stay in 2023. Nearly all of the members with inpatient stays were hospitalized at least once for treatment of an SCD-related completion, such as an acute pain crisis (Exhibit C-13).

Exhibit C-13 – Inpatient Hospital Stays – 1 or More (SFY 2023)



[10] 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.

Emergency Departments

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, 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 Health Management Program 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)."*[11]

This 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.

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 2023, 321 out of 498 members with SCD, or 64.5 percent, had at least one emergency room visit, down slightly from 67.1 percent in SFY 2022. The total population (498 members) sought care in the emergency room an average of 5.1 times each; the subset with one or more visits sought care an average of 7.9 times each. The top 15

[11] Section 2.K of the Act.

members (those with over 30 visits) accounted for nearly half of all emergency room activity (Exhibit C-14).

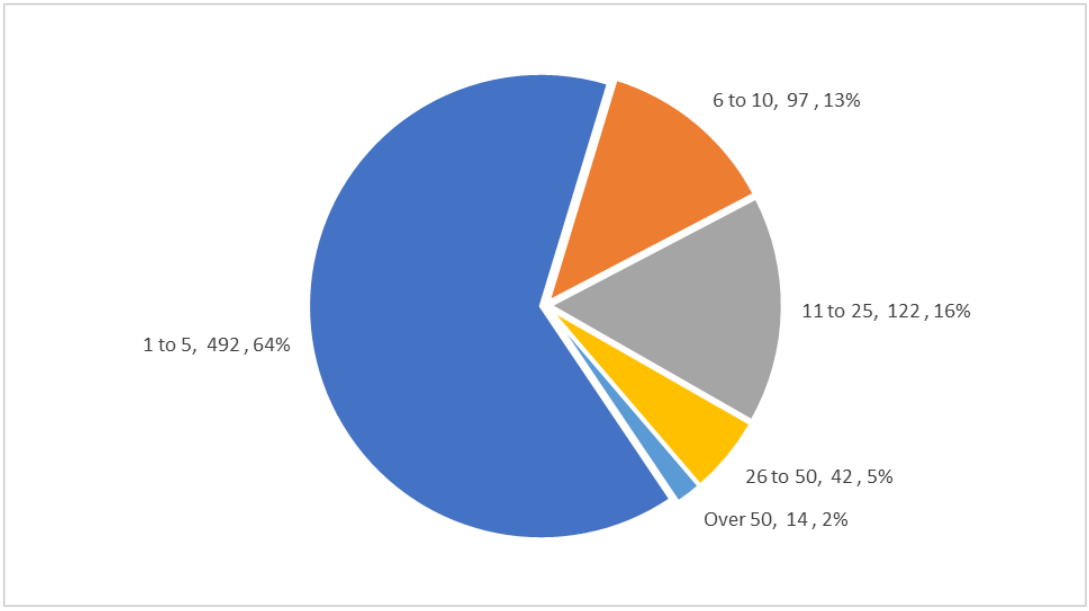
Exhibit C-14 – Emergency Room Visit Activity (SFY 2023)

Number of Visits	Number of Members	Number of Visits	Average Per Member	Percent of Visits
1 Visit	117	117	1.0	4.6%
2 – 3 Visits	114	276	2.4	10.9%
4 – 8 Visits	78	411	5.3	16.3%
9 – 15 Visits	28	323	11.5	12.8%
16 – 30 Visits	11	236	21.5	9.4%
31 – 50 Visits	7	286	40.9	11.3%
Over 50 Visits	8	872	109.0	34.6%
Total	**321**	**2,521**	**7.9**	**100.0%**

The emergency rooms at OU Health Sciences Center and Saint Francis have evidence-based protocols for treatment of patients in crisis and providers are familiar with how to treat the condition. (These hospitals serve as "centers-of-excellence" for treatment of SCD, as discussed in the next section.) However, as PHPG documented in the initial study, the majority of emergency room physicians see only one or two cases per year (Exhibit C-15 on the following page).

ER physicians with infrequent contact still were responsible 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, as discussed later in the report.

Exhibit C-15 – Emergency Room Physician Activity (SFY 2020 – SFY 2022)



Number of Encounters	Number of Physicians	Percent of Physicians	Total Encounters	Average Per Physician
1 – 5 Encounters	492	64.1%	961	2.0
6 – 10 Encounters	97	12.6%	755	7.8
11 – 25 Encounters	122	15.9%	2,001	16.4
26 – 50 Encounters	42	5.5%	1,498	35.7
Over 50 Encounters	14	1.8%	1,295	92.5
Total	**767**	**100.0%**	**6,510**	**8.5**

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.

Oklahoma has two recognized centers-of-excellence for treatment of persons with SCD, both of which serve 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, 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 providers 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 monthly to review emerging trends and best practices. The consortium receives funding to support its activities from the federal Health Resources and Services Administration (HRSA). OU is part of the HRSA SCD Southwest Region.

The Saint Francis program, while smaller, serves 90 patients at any point in time. The program is located within the Hematology/Oncology department and includes five 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[12]:

- 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 Unit 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;
- 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.

[12] 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.

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 health care system without support can lead to fragmented care or gaps in care, as well as patient discouragement.

As outlined in the initial report, one recognized best practice for managing complex care needs is through establishment of a member-centered interdisciplinary care team[13]. 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.

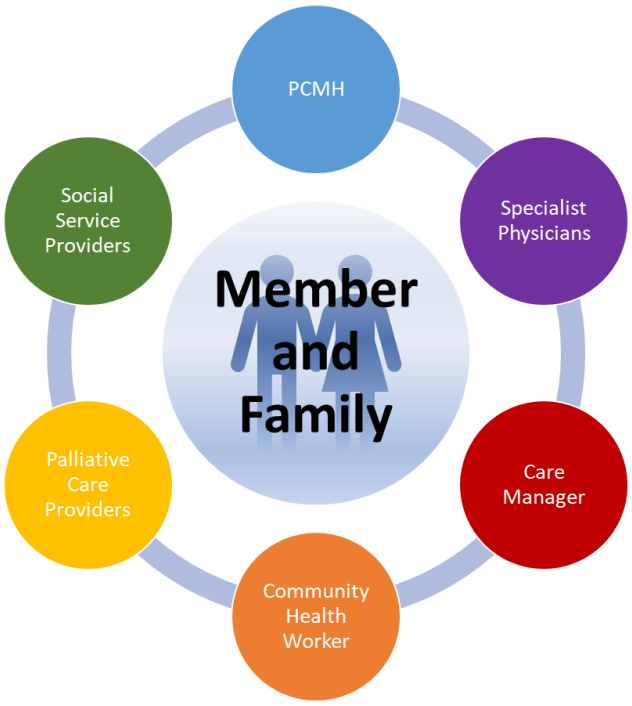
Individuals enrolled with an interdisciplinary care team typically receive a comprehensive assessment, followed by creation of a care plan that addresses both clinical and non-clinical (social) needs. Preventive and therapeutic services are addressed, with preventive services for members with SCD encompassing 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[14].

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 on the following page).

[13] 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

[14] 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)

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 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)[15].*

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.

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

SoonerCare Care Management – Historical

The majority of Medicaid members in Oklahoma have been enrolled since 2005 in SoonerCare Choice, the OHCA's primary care case management model. The program is voluntary and open to most members, the major exceptions being those dually-eligible for Medicare and Medicaid and those receiving long term care services.

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.

The OHCA also has had internal programs and contracts with outside organizations to provide enhanced care management to members with complex conditions such as SCD. These include: the OHCA Chronic Care Unit (CCU), SoonerCare Health Management Program (HMP) and SoonerCare Health Access Networks (HANs) (Exhibit C-17).

Exhibit C-17 – SoonerCare Care Management Models (Current and Planned)

The SoonerCare CCU is located within the OHCA and is staffed by nurses who provide telephonic care management to enrolled members (enrollment is voluntary). The CCU 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 criteria for enrollment are: $50,000 or more in paid claims during the prior 12 months plus five or more emergency room visits. In SFY 2023, the CCU provided

care management to 63 members with SCD, 41 of whom were newly-enrolled during the year.

CCU 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.

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 three HANs: University of Oklahoma Sooner HAN; Partnership for Healthy Central Communities HAN; and Oklahoma State University HAN. The HANs' combined enrollment exceeds 300,000, of which approximately 4,000 receive care management over the course of a year.

The HANs historically have provided care management to a small number of members with SCD, identified through data analytics or physician referral. In SFY 2023, the HANs provided care management to 50 members with SCD.

A small number of members with SCD are eligible for long term care and enrolled in one of the OHCA's home- and community-based "waiver" programs[16] or receive care in an institutional setting. These members receive care management as a component of their long term care eligibility.

[16] 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.

SoonerCare Care Management – Transition to SoonerSelect

In November 2022, the OHCA released its SoonerSelect Request for Proposals (RFP) to contract with risk-based managed care entities (MCEs) to enroll and serve the SoonerCare Choice population, excluding persons eligible due to ABD status or receiving long term care services. The MCE portion of SoonerSelect program is scheduled to go-live in April 2024[17].

The SoonerSelect MCEs will be responsible for assessing all new members and identifying those who would benefit from care management and assistance with clinical and health-related social needs. The SoonerSelect RFP identified SCD as a priority condition by crafting a case study of an adult member with SCD who is experiencing a pain crisis and asking RFP respondents to describe how they would help the member.

In June 2023, the OHCA awarded contracts to three statewide MCEs: Aetna Better Health of Oklahoma, Humana Healthy Horizons of Oklahoma and Oklahoma Complete Health, a subsidiary of Centene Corporation. The OHCA also selected Oklahoma Complete Health to operate a children's specialty program for children in Foster Care, Former Foster Care Children (FFCC) up to 25 years of age, Juvenile Justice (JJ) Involved children, and children receiving Adoption Assistance (AA).

The OHCA has used the period from contract award to go-live to conduct extensive readiness reviews of the contracted MCEs. The OHCA also has launched an outreach and education campaign to inform SoonerSelect-eligible beneficiaries of the upcoming transition and assist in selection of an MCE.

SoonerCare Choice members with SCD who are not ABD will transition to SoonerSelect in April 2024. Members who are ABD but not eligible for Medicare will remain in SoonerCare Choice. Members who are long term care recipients or otherwise dually-eligible for Medicaid and Medicare will remain in a traditional fee-for-service program known as SoonerCare Traditional[18]. Exhibit C-18 presents the expected distribution by program for the population enrolled in SFY 2023.

Exhibit C-18 – SoonerCare Program Eligibility (Projected April 2024)

SCD Population	SoonerSelect	SoonerCare Choice	SoonerCare Traditional
Number of Members	304	113	81
Percent of Total	61.0%	22.7%	16.3%

[17] A related dental managed care program has an earlier start date.
[18] Although outside of managed care, SoonerCare Traditional members receiving long term care services also receive ongoing care management. Many dual eligibles receive care management through their Medicare coverage, if enrolled with a Medicare health plan.

Sickle Cell Disease – Barriers to Care

As documented in the initial (January 2023) report, 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.

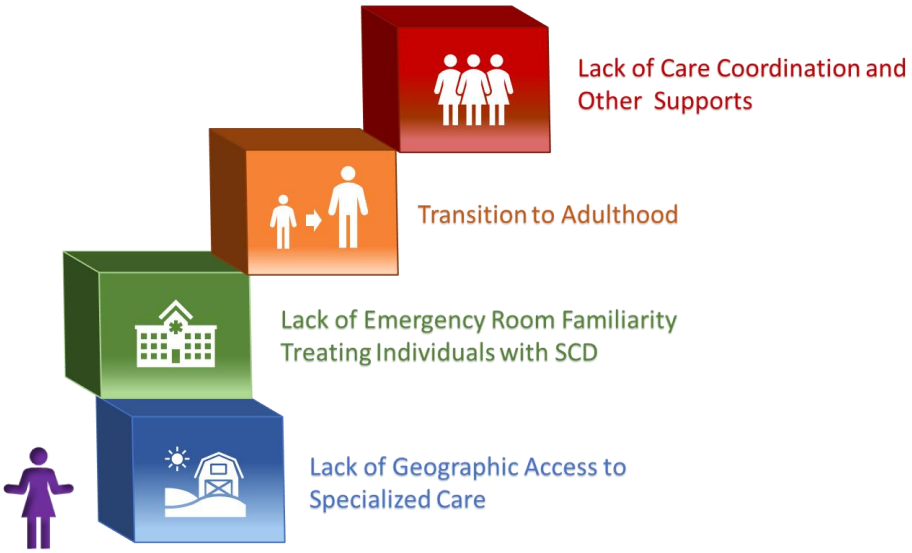
Emergency room providers unfamiliar with SCD may be reluctant to take aggressive steps to manage the pain of patients in crisis. This can prolong the episode and the patient's level of distress.

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.

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



The initial report included findings and recommendations intended to address barriers to care. The status of the recommendations is discussed in the next section.

D. UPDATE TO INITIAL STUDY FINDINGS & RECOMMENDATIONS

1. Initial Study Findings

In the initial study, 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 study employed a combination of qualitative and quantitative methods that included member and provider interviews, a town hall meeting with patients and family members, literature review and analysis of paid claims data. The initial report concluded with recommendations for strengthening the SoonerCare program with respect to serving members with SCD and their families.

The findings and recommendations are summarized below. (See the initial report for a more detailed discussion.)

Access to Covered Services – Summary of Findings

PHPG's review of the SoonerCare program's performance with respect to offering access to covered services found:

- SoonerCare provides coverage to the same extent as commercial insurance and other state Medicaid programs for children. The program does impose some service limits for adults age 21 and older but neither providers nor members with SCD identified any of these limits as posing a barrier to care.
- Members generally are satisfied with their care but some expressed dissatisfaction with the knowledge of SCD among PCMH providers. This concern was voiced both by survey respondents and Town Hall participants. It also was reflected in the desire of provider survey respondents to learn more about treatments for SCD.
- The need for PCMH authorization of all specialist visits was identified as a barrier to timely care by the two SCD centers-of-excellence.

The majority of members with SCD will be enrolled into SoonerSelect MCEs in April 2024. The OHCA already has highlighted the importance of SCD within SoonerSelect by highlighting it within the RFP.

The transition provides an opportunity for educating PCMH providers about evidence-based best practices for care of members with SCD. The OHCA, in conjunction with SoonerSelect MCEs, the two centers-of-excellence and Supporters of Families with SCD, could conduct a coordinated educational campaign targeting PCMH providers in counties with SCD members. The OHCA could explore the potential for offering continuing education credits to participants.

It is common in managed care systems for processes to be put in place to facilitate specialist-to-specialist referrals. For example, specialists that have a proven record of making appropriate referrals are often exempted from the requirement to send patients back to their PCMH to obtain the formal referral authorization. PCMH providers can be kept informed through notification requirements. (The implementation of the HIE also will facilitate information sharing between PCMH providers and specialists in different health care systems.)

The OHCA can encourage SoonerSelect MCEs to put such a policy in place for members with SCD, if a broader policy is not already in effect. The OHCA also could explore modifying its internal policies for the population that will not be enrolled into SoonerSelect.

Emergency Room Care – Summary of Findings

PHPG's review of the SoonerCare program's performance with respect to emergency room services found:

- Members with SCD are high utilizers of the emergency room because of the need for pain crisis treatment in a hospital setting.
- There are no statutory or Medicaid policy barriers preventing emergency room providers from treating patients in crisis aggressively, in terms of pain management.
- Emergency room providers at the Oklahoma centers-of-excellence rely on evidence-based protocols for treatment of patients in crisis and are familiar with the needs of members with SCD.
- Many providers in the State see patients in crisis infrequently and may not be equipped to treat pain promptly or aggressively enough, which can result in a lengthier and more severe crisis episode.
- Members with SCD express frustration and, in some cases, avoid seeking medically necessary care in the emergency room, out of fear of being labeled a drug seeker.

Evidence-based protocols for treatment of patients in crisis are readily available by emergency medical providers (see Appendix 6 in the initial report for two sample protocols). These protocols emphasize the importance of early pain assessment and intervention.

In the initial report, PHPG recommended that the OHCA, in collaboration with centers-of-excellence and Supporters of Families with Sickle Cell Disease, undertake an educational campaign similar to the one discussed for PCMH providers in the previous section. The target of the campaign could include both emergency room physician groups and hospitals in counties where members with SCD reside.

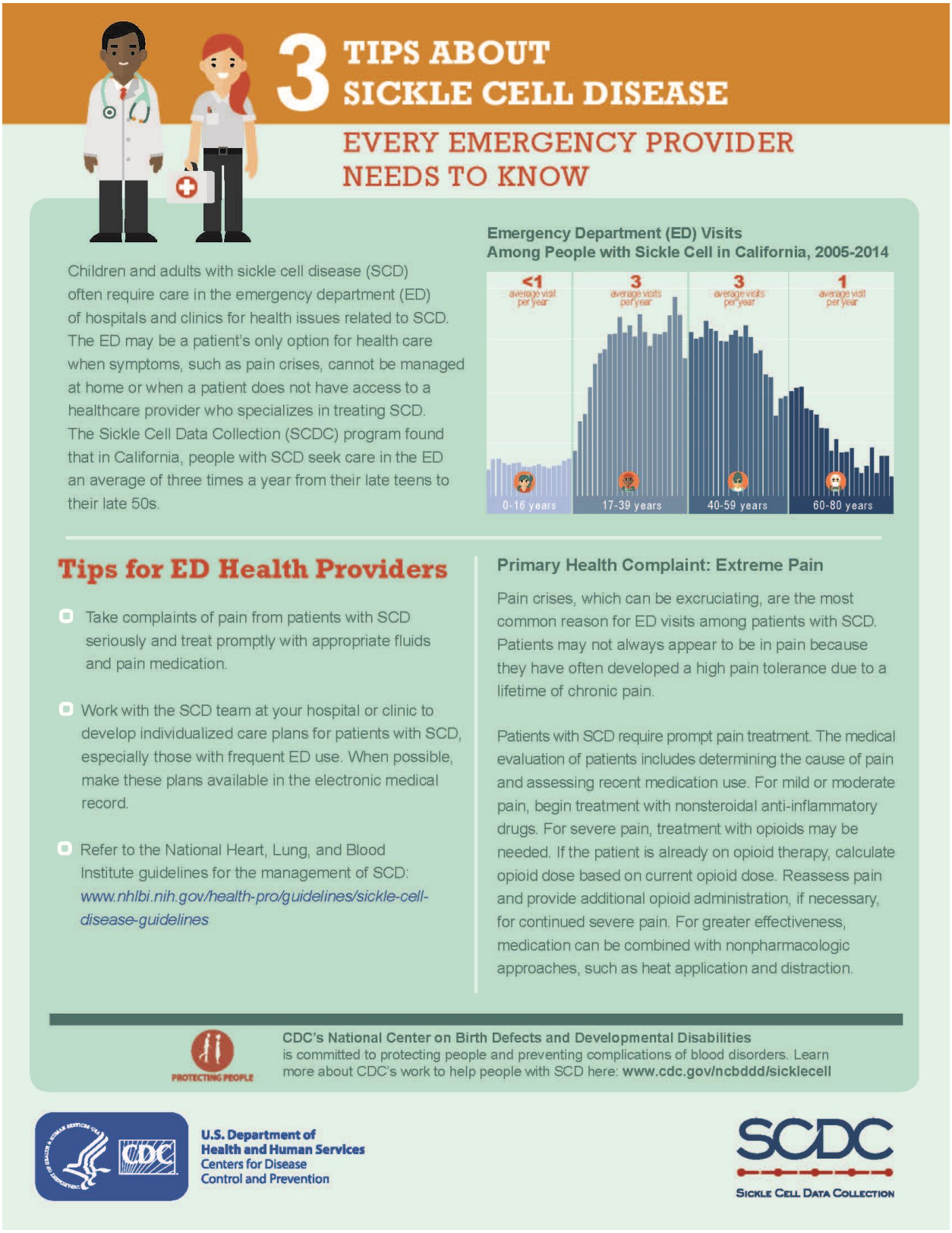
The educational campaign need not be limited to emergency room physicians but also should include other staff (e.g., front desk personnel and triage nurses) who interact with patients. The information for these staff can be at a higher level, while imparting essential information, as demonstrated by the CDC flyer on the following page (Exhibit D-1).

A best practice described in literature and recommended by Supporters of Families with Sickle Cell Disease is creation of a pain management action plan. The plan is a written description from the patient's Hematologist that outlines his or her condition, needs and recommended course-of-care when in crisis[19]. Patients with an action plan have a better (though not certain) chance of receiving timely care when they arrive in an unfamiliar emergency room. The action plans also could be uploaded to the State HIE for ready access from any hospital.

PHPG recommended that the OHCA, SoonerSelect MCEs and advocacy community collaborate on outreach to members with SCD and Hematology community to facilitate creation of plans. Emergency room providers also could be educated on their efficacy and importance.

[19] The majority of survey respondents reported having a pain management plan but PHPG did not frame the question specifically to ask about an action plan with Hematologist-recommended steps in the event of a crisis for review by an emergency room physician.

Exhibit D-1 – CDC Educational Materials



Access to Supports – Summary of Findings

PHPG's review of the SoonerCare program's performance with regard to member supports found:

- Members with complex/chronic conditions can benefit from access to an interdisciplinary care team that addresses both clinical and social needs.
- Mobile app technology can offer an additional tool for monitoring a member's health status and adherence to preventive care guidelines.
- The SoonerCare program currently offers care management to some members with SCD, although the majority do not have an assigned care manager or interdisciplinary care team.
- All members with special needs who are enrolled in SoonerSelect will have access to a care manager and care team.

The majority of SoonerCare Choice members with SCD will transition to SoonerSelect in April 2024. The residual population will include non-Medicare eligible ABD beneficiaries, some of whom already receive care management through the CCU, HMP or a HAN.

The OHCA has the opportunity to ensure all members with SCD have access to care management (ideally through an interdisciplinary care team), including assistance with transition to adult coverage, by targeting ABD beneficiaries not currently assigned a care manager.

In the initial report, PHPG recommended that the OHCA collaborate with the HMP vendor and HANs to contact all non-care managed ABD members for the purpose of performing an assessment and developing a care plan, as appropriate. Special emphasis should be placed on reaching and engaging members with very complex needs (e.g., members with other chronic conditions related to their SCD and members with frequent inpatient hospital admissions) who do not yet have a care manager.

The OHCA also should ensure that current and future care management systems emphasize the importance to members of having an action plan that addresses pain management and other priorities. The team, through the member's care manager, should be available to consult on an urgent basis with emergency room physicians when a member in crisis presents for care.

The OHCA should explore the use of mobile app technology as an additional care management tool. Such an app could be operated directly by the OHCA or through the SoonerSelect MCEs, the SoonerCare HMP vendor and SoonerCare HANs.

2. Initial Study Recommendations (Summary)

Exhibit D-2 below summarizes initial study findings and recommendations. All of the recommendations were intended to be actionable in 12 to 18 months (January 2023 to June 2024).

Exhibit D-2 – Initial Study Findings and Recommendations

Findings (Areas for Improvement)	Recommendations
Access to Care	
1. PCMH providers are not uniformly knowledgeable about Sickle Cell Disease.	1. The OHCA, in conjunction with SoonerSelect MCEs, centers-of-excellence 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.
2. Specialist providers, including at centers-of-excellence, 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.
Emergency Room Provider Training and Resources	
3. Many ER providers see patients in crisis infrequently and may not be equipped to treat pain promptly or aggressively.	3. The OHCA, in collaboration with centers-of-excellence and Supporters of Families with Sickle Cell Disease, should undertake an educational campaign to increase knowledge of evidence-based protocols for treatment.
4. Only a portion of members with SCD today have a pain management action plan.	4. 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.
Supports of Members with SCD to Navigate the Health Care System	
5. Only a portion of members with SCD today are assessed to identify the potential need for care management.	5. The OHCA should collaborate with the HMP vendor and HANs to contact all non-care managed ABD members for the purpose of performing an assessment and developing a member-centered care plan, as appropriate.

Findings (Areas for Improvement)	Recommendations
	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. (All SoonerSelect members will be assessed at time of enrollment.)
6. Only a portion of members with SCD today have a comprehensive action or care plan that addresses both clinical and social service needs.	6. The OHCA also should ensure that current and future care management systems emphasize the importance to members of having a comprehensive care/action plan that addresses the member's complete care needs, including future care needs for members transitioning from pediatric to adult coverage.
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, SoonerCare HMP and SoonerCare HANs on behalf of ABD beneficiaries. (All SoonerSelect enrollees will have access to interdisciplinary care teams.)
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.
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.

3. OHCA Actions in Response to Recommendations

The OHCA provided information to PHPG in December 2023 on the status of initial study recommendations. Action has been taken in five areas, as summarized below.

Access to Care (Recommendations 1 - 2)

Recommendation 1: *The OHCA, in conjunction with SoonerSelect MCEs, centers-of-excellence 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.*

Activity: The OHCA assisted Supporters of Families with Sickle Cell Disease in promoting an SCD Awareness Month social media campaign. The effort, which occurred in September, targeted all audiences, including PCMH providers. More information about the campaign, and other activities sponsored by the organization, can be viewed on its website, at Sickle Cell Oklahoma – Supporters of Families with Sickle Cell Disease.

(No specific activities occurred with respect to the second recommendation or the two ER-related recommendations.)

Navigating the Health Care System (Recommendations 5 – 9)

Recommendation 5: *The OHCA should collaborate with the HMP vendor and HANs to contact all non-care managed ABD 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.*

Activity: The OHCA identifies all members with a diagnosis of SCD on a quarterly basis and currently targets those meeting expenditure/utilization thresholds for care management (as discussed earlier in the report). The transition of non-ABD members to SoonerSelect in 2024 will expand contact and assessments to all members with SCD. SoonerSelect MCEs will be required contractually to assess all members at time of enrollment (SCD and other). The OHCA intends to reach-out to all members with SCD who remain in SoonerCare Choice, i.e., those whose eligibility is based on Aged, Blind or Disabled status.

Recommendation 6: *The OHCA also should ensure that current and future care management systems emphasize the importance to members of having a comprehensive care/action plan that addresses the member's complete care needs, including future care needs for members transitioning from pediatric to adult coverage. (Recommendation 8 also addresses this topic.)*

Activity: The OHCA has partnered with the HANs to initiate a transition-of-care outreach campaign. The OHCA and HANs are targeting members between the ages of 17 and 21 and inviting them to enroll in a short-term care management program to assist with transitioning from pediatric to adult coverage. The initiative began in September and assisted 73 members in its first three months.

Recommendation 7: *The OHCA should strive to make available interdisciplinary care management, where appropriate, by coordinating with the Jimmy Everest Center, SoonerCare HMP and SoonerCare HANs on behalf of ABD beneficiaries. (All SoonerSelect enrollees will have access to interdisciplinary care teams.)*

Activity: The OHCA has established a collaborative relationship with both Oklahoma centers-of-excellence, to enhance ongoing coordination of care and access to the IDT model. The OHCA and centers held meetings in September and November and intend to continue meeting quarterly.

Recommendation 9: *The OHCA should explore use of a mobile app, either directly or through its contractors.*

Activity: The OHCA has established a workgroup to explore options for offering a mobile app. The OHCA also has a new care management platform that includes a member-facing portal. The OHCA is preparing to pilot test member access to the portal, with the goal of eventually opening it to all members receiving care management.

Conclusion

The OHCA and its partners have made progress in implementing a majority of the recommendations contained in the initial report. The greatest opportunity for additional progress exists with respect to educating PCMH and emergency room providers.

The implementation of SoonerSelect offers an ideal opportunity for a coordinated education campaign. The three MCEs will have the great majority of SoonerCare providers in their networks, including those who continue to treat ABD members through SoonerCare Choice.

PHPG will provide an updated progress report in January 2025, along with qualitative and quantitative findings. These will include member impressions of access to, and management of care under the new system, as well as changes in utilization and expenditure patterns.