TennCare Sickle Cell Disease Report
January 15, 2024

BACKGROUND OF TENNESSEE PUBLIC CHAPTER NO. 186 of 2021

PC 186 of 2021 establishes that the Division of TennCare conduct an annual review of all medications, forms of treatment, and services for enrollees with a diagnosis of sickle cell disease who are eligible for coverage under the medical assistance program. The first Sickle-Cell Disease report was submitted to the legislature by TennCare on January 15, 2022. The Sickle-Cell Disease report (the report hereafter) will be submitted annually every January 15 to the legislature detailing TennCare's findings and any recommendations to the General Assembly based on those findings. TennCare must also publish the annual report to its website making it accessible to the general public. The purpose of the review is to determine if the available covered medications, treatments, and services are adequate to meet the needs of TennCare enrollees and whether TennCare should seek to add additional medications, treatments, or services. TennCare is required to solicit and consider input from the general public, with specific emphasis on input from persons or groups with knowledge and experience in sickle cell disease treatment.

Since the 2022 report, TennCare and its three Managed Care Organizations (MCOs) have had regular communications with TennCare enrollees and care providers from the Sickle Cell community. Over the past few years, as described in previous TennCare Sickle Cell Disease Reports, TennCare and all three MCOs have continued to have regular meetings with Sickle Cell Providers through forums, onsite and virtual visits, and other avenues of continued feedback and conversation. This report outlines the information required by PC 186 of 2021.

OVERVIEW AND CONTEXT OF SICKLE CELL DISEASE

Sickle cell disease is a group of inherited red blood cell blood disorders. It is one of the most frequently inherited blood disorders in the United States affecting approximately 100,000 Americans[1]. This report describes the population demographics and healthcare utilization patterns of TennCare enrollees with sickle cell disease. It outlines clinical programs specifically designed to provide health care coordination and covers health care access and utilization patterns for individuals with sickle cell disease. The report discusses specific opportunities and challenges for this population, describes feedback received from stakeholders, and discusses the adequacy of TennCare covered medications, treatments, and services to meet the needs of enrollees with sickle cell disease. As of December 2023, TennCare provides healthcare coverage to approximately 1.7 million Tennesseans. All medical data provided in the report is based upon TennCare claims data from Calendar Year 2022 (CY2022).

[1] https://www.cdc.gov/ncbddd/sicklecell/data.html

TENNCARE SICKLE CELL DISEASE KEY POPULATION STATISTICS

Enrollee Demographics

Throughout 2022 TennCare provided healthcare coverage to over 1,400 enrollees diagnosed with sickle cell disease. 55.3% of enrollees were between 0-21 years of age and 44.4% were over age 21. The average enrollee age was 21 years. In 2022, there were 172 TennCare enrollees whose primary residence was in the East grand region, 332 in the Middle grand region, and 894 in the West grand region. Approximately 89% of the TennCare sickle cell disease population lives in urban areas and 9% in rural areas.[2]

Medical Services and Expenditures

In CY2022, TennCare expenditures for all medical services provided for enrollees with sickle cell disease totaled $31.3 million.[2] Table 1 shows the breakout of the total expenditures by categories of service.

TABLE 1 – Medical Expenditures by Cost Category [2]

Calendar Year	Cost Category	Total Cost
2022	Medication Costs	$14,583,240
2022	Professional Outpatient Services	$1,556,214
2022	Inpatient Services	$8,098,123
2022	Emergency Department Services	$1,597,345
2022	Labs and Ancillary Services	$5,482,374
2022	TOTAL	$31,317,297

All enrollees with sickle-cell disease have a comprehensive medical and pharmacy benefit available through their TennCare coverage and are assigned a TennCare primary care provider. All three MCOs also offer a focused sickle cell care management program to assist enrollees if they wish to have the support. Approximately 62% of all outpatient services for these enrollees were provided by a Primary Care Provider or a Hematology/Oncology specialist.

TENNCARE PHARMACY BENEFIT FOR SICKLE CELL DISEASE (SCD)

TennCare covers all drugs approved by the FDA for the coverage of sickle cell disease. This includes an extensive formulary of medications linked here:
https://www.optumrx.com/content/dam/openenrollment/pdfs/Tenncare/home-page/preferred-drug-list/Preferred%20Drug%20List%20(PDL).pdf

[2] Data from TennCare medical claims for CY 2022.

Currently, in the U.S., the American Society of Hematology Clinical Practice Guidelines on Sickle Cell Disease provide evidence-based, expert, consensus guidance for the treatment of sickle cell disease, linked here. TennCare references the most recent version of these guidelines. https://www.hematology.org/education/clinicians/guidelines-and-quality-care/clinical-practice-guidelines/sickle-cell-disease-guidelines

The recommendations address treatment of both adult and pediatric sickle cell disease. Treatment options for sickle cell disease are different for each patient and are based on individualized symptoms and care plans. Progressive organ damage is one of the primary causes of early death in the sickle cell population and the treatment of both the sickle cell disease and the chronic conditions that result from sickle cell disease is paramount for the long-term health of individuals with sickle cell disease. Many people with sickle cell disease will require lifelong supportive care such as red blood cell transfusions, pain management strategies, vaccinations, and antibiotic prophylaxis. Additionally, patients who experience acute vaso-occlusive crises will often require additional clinical care depending on the severity of their crisis. This care may be delivered in specialized sickle cell treatment centers, emergency rooms, or inpatient settings. Other patients may be placed on disease-modifying agents. Hydroxyurea (Droxia, Siklos) has been and remains a key guideline-recommended agent for the treatment of sickle cell disease. Pharmaceutical-grade L-glutamine (Endari) received FDA approval for the treatment of sickle cell disease in July 2017. Crizanlizumab-tmca (Adakveo) and voxelotor (Oxbryta), were FDA-approved under rapid approval pathways for the treatment of sickle cell disease in November 2019. Both medications are accessible for TennCare enrollees with sickle cell disease who meet the clinical coverage criteria for these treatments.

TennCare's pharmacy benefit focuses on providing effective and appropriate FDA-approved outpatient prescription drugs when medically necessary, including medications and related therapies used in the treatment of sickle cell disease. All medications that have an FDA-approval for treating sickle cell disease are covered by TennCare through our pharmacy and/or medical benefit. Most agents have clinical criteria outlined to help support evidence-based pharmacy coverage. Other agents such as Adakveo are available via the medical benefit. TennCare continuously collaborates with its managed care partners to ensure seamless access through the medical benefit for members with SCD.

Currently, preferred formulary drugs used in the management of sickle cell disease are available to enrollees without prior authorization. Hydroxyurea and Droxia are recommended for use in the prevention of pain crises or vaso-occlusive episodes. Non-steroidal anti-inflammatory drugs such as prescription ibuprofen, oral diclofenac and topical gel, meloxicam, and ketorolac are readily available without authorization for use in the management of mild to moderate acute pain episodes. Oral antibiotics and vaccines for use in the prevention of infection are also available without prior approval.

Certain non-preferred medications, such as Siklos, Endari, and Oxbryta require prior approval before a prescription can be dispensed. Endari (l-glutamine powder) is indicated to reduce the

acute complications of sickle cell disease in adult and pediatric patients ≥ 5 years of age. Oxbryta (voxelotor) is FDA-approved for individuals with sickle cell disease ≥ 4 years of age and was granted priority review, fast track, orphan drug, rare pediatric disease, and breakthrough therapy designations. In October 2022, initial prior authorization criteria for Endari, Oxbryta, and Siklos was modified to require only a diagnosis, > 3 month trial or intolerance of hydroxyurea, and weight-based dosing, if applicable (Endari), in an effort to reduce barriers to care and continue support of appropriate care.

The enrollee, physician, or an authorized agent of the healthcare provider can initiate routine utilization management processes such as prior approval and step therapy for ensuring requested drugs requiring prior approval meet the clinical criteria for medical necessity. Pre-approvals for drugs requiring authorization are processed within 24 hours of the initial request that includes identifying information, clinical reason for the use of the drug under review, and any previous treatment for the treated condition. If the review for a pharmacy service is denied, there remain multiple pathways to access medication services including peer-to-peer review, a 72-hour emergency supply, and a reconsideration of the original prior approval review via medical appeal. A peer-to-peer review is available to the prescriber for a clinical discussion or to gather more information on any pre-approval outcome. The prescriber can speak directly with a peer physician or pharmacist about their individual patient, patient's condition, and care options. If the request is emergent in nature, and prior approval is warranted, pharmacists can dispense up to a 72-hour emergency supply of the medication while it is under review at no cost to the enrollee.

As new medications and therapeutic options for sickle cell disease are introduced to the clinical landscape, the TennCare medical and pharmacy benefit is routinely updated to allow for coverage of new medications as medically indicated. TennCare's formulary protocol is routinely advanced, as frequently as weekly, based on new drug availability, indications, route of administration, and according to nationally recognized guidelines, compendia, and established medical and pharmacy treatment standards. Routine updates safeguard access to critical medications for rare, chronic, and acute illness including sickle cell disease.

As a reminder, the covered outpatient pharmacy formulary is shaped based on input from the TennCare Pharmacy Advisory Committee (PAC). The TennCare PAC is comprised of members appointed by both executive and legislative representatives as outlined in state statute. The Committee makes recommendations regarding access to medications and related product guidance in conjunction with state clinicians. Committee members must be practicing primary or specialty physicians, pharmacists, or mid-level practitioners. The committee also includes enrollee advocates. In conjunction with TennCare clinicians, the PAC is responsible for developing, managing, updating, and administering the TennCare pharmacy formulary and review criteria.

Additionally, TennCare continues to follow the emerging clinical pipeline of new treatment options, which advance rapidly. There have been significant developments in the treatment of sickle cell, and research is ongoing to address the needs of sickle cell disease management. TennCare closely tracks the FDA approval processes of all emerging sickle cell treatments based on review of clinical trials. As new therapeutics are determined to be safe and effective, TennCare works quickly to ensure they are reviewed for potential inclusion in the TennCare benefit. On December 8, 2023, the FDA approved the first two cell-based gene therapies for SCD, exagamglogene autotemcel (Casegevy) and lovotibeglogene autotemcel (Lyfgenia). These new therapies provide unique opportunities to develop innovative strategies to manage access and utilization while ensuring safety and efficacy. Both new treatments, now that FDA approval was been granted, are covered through the TennCare MCOs when medically indicated. TennCare is currently in communication with the Sickle Cell Centers about these new therapies and working to develop streamlined coverage pathways as well as operational infrastructure to ensure medically appropriate access as these new therapeutic agents begin to be utilized. Given these therapeutics are first of their kind and authorized clinical centers are being established, all MCOs will utilize interim coverage of gene-based therapies through single patient rider pathways until final coverage pathways can be jointly established.

Table 2 describes medication use by the population with sickle cell disease:

TABLE 2 – Medication Use by TennCare Enrollees with Sickle Cell Disease in 2022[2]			
Calendar Year	**Number of Enrollees Receiving Prescriptions**	**Percentage of Enrollees Receiving Prescriptions**	**Average number of Prescriptions for Enrollees**
2022	1,514	96.9%	21.4

Table 3 describes opioid use by the population with sickle cell disease:

TABLE 3 – Opioid Use by TennCare Enrollees with Sickle Cell Disease in 2022[2]				
Calendar Year	**Number of Enrollees Receiving Opioids**	**Percentage of Enrollees Receiving Opioids**	**Number of Opioids Prescribed**	**Total Cost**
2022	551	35.3%	100,461	$66,152

Among patients with sickle cell disease, vaso-occlusive crises are recurrent and unpredictable attacks of acute pain. These pain crises are often treated with prescription analgesics, including topical and oral non-steroidal anti-inflammatory drugs and opioids. Each of these treatments are available for enrollees experiencing acute pain crisis and related and recurrent pain syndromes stemming from sickle cell disease progression.

TennCare provides additional accommodations for enrollees with sickle cell related to the opioid benefit. Enrollees with sickle cell disease can often experience acute pain crises and live with

chronic pain related to their disease. All enrollees with sickle cell disease currently can access up to a 45-day supply of 60 Morphine Milligram Equivalents (MME) of opioids per day in any 90-day period for acute pain management. Additionally, enrollees with sickle cell experienced in opioids for the management of chronic pain are eligible to exceed the daily opioid threshold as prescribed by their provider up to 200 MME per day indefinitely with periodic review for ongoing medical need. Based on direct feedback provided through TennCare's partnerships and sickle cell forums from clinical providers who treat members with sickle cell disease, TennCare is proposing changes to its opioid policies to better support these members. TennCare is actively working on a rule amendment and intends to file a rule notice in early 2024. The proposed rule amendment, informed by provider feedback, seeks to better support members with SCD who experience more frequent or aggressive pain crisis episodes with timely pain management.

TENNCARE SICKLE CELL DISEASE POPULATION HEALTH AND CARE COORDINATION

TennCare provides a comprehensive Population Health program through its Managed Care Organizations for all enrollees, and especially those with sickle cell disease, to help coordinate care and support clinical needs.

Population Health and Care Coordination Programs

TennCare's Population Health program provides additional clinical support and care coordination for enrollees across the entire care continuum to offer health education, promote healthy behaviors, and disease self-management. Enrollees with additional needs can receive care coordination and thorough care management services through MCO care managers to help them access other needed services. MCOs evaluate the entire enrollee population, according to the enrollee's clinical risk based on predictive modeling from medical diagnoses and service utilization. Enrollees can be engaged in care management through referrals, utilization management data, and health risk assessment results.

Initial health assessments are offered and conducted with every enrollee within ninety days of becoming TennCare eligible. These health assessments help TennCare enrollees learn about their potential health risks and partner with their MCO for the services and clinical care needed to help address these risks. Health assessment information is used to connect individual enrollees with appropriate intervention approaches and maximize the impact of the services provided.

Using all of these clinical inputs, MCOs stratify all enrollees into different risk level programs ranging from minimal clinical risk to high clinical risk. Each risk-level has targeted supports that match their risk and identified needs. Some examples of risk stratifications include:

- ***No Risk*** (Wellness): enrollees with no identified health risks

ENROLLEE STORY

A 19-year-old female with sickle cell disease was referred to case management due to high inpatient utilization. The member had graduated from high school and had previously enrolled in Cosmetology school but had to leave school due to the frequency of her sickle cell pain crises. These crises frequently resulted in emergency room visits and inpatient admissions. The member had also attempted to work at a fast-food restaurant but had to quit her job because of frequent sickle cell disease (SCD) exacerbations.

The MCO Care Management team was able to connect with the member through her grandmother, who had raised her. The member had moved back in with her grandmother for support, and her grandmother was actively working to encourage her to take her medication on a regular basis. The Care Manager (CM) also partnered with the member to discuss the importance of daily adherence to hydroxyurea, her medication for SCD management. The CM also learned that she was not making it to SCD clinic appointments at Regional One due to the distance from home and lack of transportation. The CM provided her with the information for Tennessee Carriers for transportation and provided her grandmother with information about the mileage reimbursement program. The member was subsequently able to keep her scheduled clinic appointments, and her medication adherence also improved.

Further, since receiving education from her CM about lifestyle modifications to better manage SCD symptoms, the member has been more mindful about drinking water regularly and taking frequent breaks. She is now interviewing for a job as a sitter and aspires to return to Cosmetology school soon. In 2022, she had 3 inpatient admissions for sickle cell disease issues; in 2023, she only had 1 inpatient admission. Her CM has developed a strong partnership and is continuing to provide support and education to both the member and her grandmother, helping to empower them in better managing their health.

- ***Low Risk:*** includes enrollees with rising risk and chronic health care needs, as well as low risk maternity
- ***High Risk:*** includes enrollees with high-risk needs (complex case management and chronic care management), as well as high risk maternity

Enrollees with sickle cell disease are included into the stratification along with the entire population. Individuals with sickle cell disease may be stratified in the low-risk or high-risk programs reflecting their underlying sickle cell disease and the accompanying chronic conditions. Most individuals with sickle cell disease would fall into the high-risk category.

Care Coordination is impactful for enrollees with sickle cell disease as it assists with acute healthcare needs, health service needs, or risks which need immediate attention. The goal of Population Health and Care Coordination Services is to make sure enrollees get the services they need to prevent or reduce adverse health outcomes. The care management team can also work with an enrollee's primary care provider to help communication with specialists and other care providers as well as to provide wrap around care and support for the enrollee.

Clinical care coordination teams generally consist of a Nurse Case Manager, Behavioral Health Case Manager, Behavioral Health Peer Support, Social Worker, Dietitian, Health Educator, Long Term Services and Supports Care Coordinator, Pharmacy Specialist, Medical Director, Health Navigator, and Enrollee Resource Coordinator.

Member Outreach and Engagement

TennCare utilizes a variety of methods to conduct outreach to enrollees. The MCOs outreach to individuals telephonically, by interactive voice response (IVR), secure enrollee portals, and by

mail. MCOs conduct face-to-face interactions, teleconference calls, and text messaging when appropriate and with enrollee consent. MCOs also partner with providers in a collaborative effort to reach or re-engage individuals. TennCare provides the ability for an enrollee to speak with a registered nurse 24-hours a day for help finding doctors, schedule appointments, get to urgent care centers or walk in clinics, or speak directly with a doctor's office about their health care needs.

At a minimum, enrollees in a low-risk category receive at least four communications each year, addressing self-management education increasing the knowledge of their chronic health condition. These communications emphasize the importance of medication adherence and appropriate behavioral changes, the management of the emotional aspect of their health condition, and self-efficacy and support. MCOs also offer individual support for self-management if the enrollee desires it, including health coaching and a 24/7 NurseLine. Low-risk enrollees who would like engagement with a care manager can also opt-in to care management and receive interactive support.

Enrollees in the high-risk program receive intensive care coordination. Monthly interactive contacts by the MCO nurture the development of a supportive enrollee and health coach relationship, disease specific management skills, development and implementation of an individualized care plan, problem solving techniques, self-efficacy, and referrals to link the enrollee with medical, social, educational, and other programs and services to address any identified needs. Enrollees may choose to opt-out of any of these care coordination programs.

Support for Health-Related Social Needs

The medical evidence continues to establish that up to 80% of an individual's health is directly influenced by health-related social needs, often referred to as the social determinants of health (SDOH). Needs like transportation, food security, and safe housing can all have a major impact on an individual's health. TennCare has been working to help identify and provide referrals and resources to individuals who may be able to benefit from these services through community organizations and other supports. TennCare MCOs work closely with enrollees to screen for social determinants of health during interactive contacts. When needs are identified, specific referrals and resources are provided to begin addressing these needs.

MCOs also use Online SDOH Search Engines and Portals. SDOH platforms provide an online directory of social service organizations that are accessed by Case Management as well as by enrollees and providers. Individuals can search for free and reduced cost services by zip code. Service domains include food, housing, education, transportation, legal support, and others. Each domain contains sub-categories to address specific needs such as skills and training, utility assistance, and food delivery.

Non-emergency medical transportation (NEMT) is a covered benefit for TennCare enrollees attending an approved service that helps provide access to care when they document that they do not have access to transportation. The program offers three levels of service, curb-to-curb, door-to-door, and bed-to-bed. NEMT includes pharmacy visits to pick up prescriptions.

Each MCO has utilized innovative solutions to offer on-demand rides for enrollees with certain NEMT needs. For example, the MCOs have partnered with ride-sharing companies to offer on-demand ride shares in addition to traditional NEMT transportation options to better meet the needs of sickle cell disease enrollees when sickle cell disease clinics identify transportation needs for their patients.

ENROLLEE STORY

A Nurse Case Manager (NCM) in the Memphis area began working with a 24-year-old male with sickle cell disease (SCD) while he was inpatient due to sickle cell crisis. In the prior 6 months he had also had 2 emergency room visits and 2 additional inpatient hospital stays. He had not completed an annual wellness visit. This member was identified through a process that helps identify potential members who are at risk for readmission.

During childhood and adolescence, the member's care had been managed by his mother, with oversight and assistance from a pediatric sickle cell specialty clinic. However, as the member transitioned into adulthood, the Nurse Case Manager recognized that he needed additional education on managing his sickle cell disease on his own.

The NCM provided education to the member about interventions to help with managing sickle cell disease such as contacting his hematologist when he feels a pain crisis beginning, with the goal of receiving treatment in the office to avoid more serious pain crisis complications that could also require an ER visit or hospital stay. The NCM also provided information about positive lifestyle changes that can reduce the risk of crisis such as lowering stress and avoiding dehydration, exertion, and exposure to sickness and cold. Additionally, the NCM reviewed with the member the list of recommended health maintenance appointments for individuals with SCD, including checkups with his PCP and hematologist, a cardiac evaluation, and annual eye exams. Lastly, they discussed warning signs associated with various complications of SCD.

To supplement the verbal information that the NCM had provided to the member, the NCM sent the member electronic Healthwise educational materials on Sickle Cell Disease Condition Basics, When to Call a Doctor, Self-Care, Pain Management Overview, and Preventing Problems and Staying Healthy. Through these conversations, the member successfully learned to better manage his SCD as an adult.

Since case management engagement, he has had 0 emergency room visits and 0 inpatient hospital stays. He completed his annual physical and an ophthalmology exam, kept all scheduled hematology appointments, and utilized the Healthwise educational materials as a resource for health management. He expressed gratitude for the education and understands the importance of preventive care.

ADDITIONAL MCO-SPECIFIC INITIATIVES FOR SICKLE CELL DISEASE

In addition to the programs described above that all TennCare MCOs provide, each MCO has specific care coordination programs to ensure appropriate access to care and improved health outcomes for individuals with sickle cell disease.

BlueCare Tennessee

Throughout 2023, a BlueCare interdisciplinary workgroup met to review best practices and member data, and to conduct face to face visits to sickle cell specialty centers across the state. During the months of May to July, a BlueCare team visited specialty clinics in person at Regional One, St. Jude, Methodist LeBonheur, Vanderbilt and Erlanger to gather provider feedback to inform member interventions and improve member and provider experience. BlueCare shared utilization and prescribing patterns for the overall sickle cell membership, care management services provided by BlueCare

Population Health, and how to schedule transportation. A new Provider Guide was shared, which includes covered services and benefits specific to the needs of members with sickle cell disease. Input was gathered from specialty providers on barriers (including medications and covered services), clinic services offered, and opportunities for partnership.

Utilizing feedback gathered from specialty providers as well as analysis of internal data, BlueCare developed new member interventions to further tailor and increase outreach efforts to members with SCD. An educational Sickle Cell Guide will be mailed annually to all members with a diagnosis of SCD and addresses healthy habits for living with SCD, annual PCP visits for children and adults, vaccinations, medications, transportation, planning for pregnancy, planning for appointments, and BlueCare care team resources. New care management cohorts are being developed, anticipated to begin December 2023, that will trigger outreach by a Social Worker or Nurse Case Manager to members in the transition age range and will address connection to an adult PCP and/or specialist, medication adherence, ER and inpatient utilization, social needs, transportation benefits, and referrals to Behavioral Health case management as necessary. Regionally located Social Workers are also taking a "feet on the street" approach and are available to meet with members and clinic care management staff if needed.

In July 2023, BlueCare partnered with The Methodist Comprehensive Sickle Cell Center's Community Health Fair, which brought community partners together to spread awareness and provide health services and screenings including flu vaccines, COVID-19 vaccines, Sickle Cell trait testing, mental health resources, diabetes screenings, cholesterol screening, blood pressure checks, and dental screenings. Approximately 100 event attendees received information from the BlueCare Dietician and Social Worker about how to manage Sickle Cell from a dietary perspective and about social resources.

In September 2023, BlueCare was a proud sponsor of the 2nd Annual Sickle Cell Warrior Walk / 5K, organized by the Breaking the Sickle Cell Cycle Foundation, Inc. in Nashville. A BlueCare team also participated in the event.

UnitedHealthcare Community Plan of Tennessee

UnitedHealthcare Community and State Plan (UHCCSP) has continued to partner with multiple Sickle Cell Centers throughout the year to identify collaborative opportunities to address systemic barriers to care for members with sickle cell disease. This year, UHCCSP proactively identified members attributed to the Centers who had indications of high utilization and who may require additional collaboration and support. The Centers also identified members with unmet needs who may not have been identified in the initial process. UHCCSP provided Case Management, connection to resources for social needs, and connection to PCP and behavioral health care for these members.

In addition, UHCCSP undertook a detailed analysis this year of members with sickle cell disease in order to better understand these members' demographics, healthcare utilization, and connection to primary care and behavioral health services. From this analysis, UHCCSP learned the following:

- Members with SCD are primarily located in urban regions of the state (Nashville, Chattanooga, Knoxville, and Memphis), with Shelby County having over 3 times more members than the next most populous urban county (Davidson)
- Members are attributed to a wide variety of PCPs across the state, with only 39% of members with SCD attributed to the 15 most common PCPs for UHCCSP members
- Members are not typically seeing their PCP on a regular basis, with 60% of members with SCD not having had a PCP visit in the last year
- Approximately 35% of members with SCD are attributed to a Patient Centered Medical Home (PCMH), and 17% to a Tennessee Health Link (THL) clinic

From this analysis, UHCCSP identified strategies to better help members align with PCPs, who provide an ongoing home for preventative care. UHCCSP has particularly emphasized a strategy to align members to Patient Center Medical Home and Tennessee Health Link providers, who are trusted providers skilled at coordinating high quality, comprehensive services for members with complex health conditions. This work has included leadership and clinical collaboration directly with Sickle Cell providers on improving the coordination of care for members with sickle cell disease.

UHCCSP continues to prioritize engagement in Population Health programs and to conduct case rounds to link specialty care, primary care, and Sickle Cell Centers to ensure that members are accessing the appropriate array of care needed to stabilize their condition and maintain their health.

Wellpoint (formerly Amerigroup Community Care)

Wellpoint employs a dedicated Nurse Case Manager to conduct outreach to all low-risk members with sickle cell disease, while the Complex Nurse Case Managers in each region provide outreach to the high-risk members. The sickle cell disease program has a goal set for the dedicated nurse to maintain a 50% engagement rate with this membership to ensure they are receiving the care that they need. Wellpoint recognizes that maintaining engagement requires a multifaceted approach that emphasizes compassionate care, continuous education, and community support. Acknowledging the unique challenges these members face and ongoing education about the disease, its management, and potential complications is crucial for empowering these members to take an active role in their care. The engagement rate for the year-to-date is 52%.

Wellpoint utilizes several strategies to coordinate high quality care for members with sickle cell disease. First, Wellpoint has developed a heat map to identify the location of members with sickle cell disease in relation to the Centers of Excellence. The heat map helps to identify members in outlying areas who may have additional needs such as transportation, need for telehealth

options, or other social needs. Second, Wellpoint utilizes Pediatric and Adult Checklists when engaging with members with SCD to ensure member needs are evaluated comprehensively and reliably. Third, Wellpoint utilizes an ED Report to identify members with SCD who are frequently seen in emergency room settings, then creates referrals to Physical Health Complex Case Managers for these members.

To identify unmet behavioral health needs among members with sickle cell disease and mental illness, Wellpoint aims to screen 100% of members with SCD who also have a diagnosis of anxiety or depression with the PHQ9 screening tool. Members with unmet behavioral health needs are referred to the behavioral health team and behavioral health providers. These efforts have been very important in identifying, screening, and engaging members with SCD who also have co-occurring mental health diagnoses.

In 2023, Wellpoint also continued Case Management outreach to providers at the Sickle Cell Centers of Excellence. In these exchanges, Case Managers provided region-specific contact information and education about MCO care coordination activities to facilitate increased collaboration between providers and MCOs.

TENNCARE COLLABORATIONS

Tennessee and TennCare has a complete network of committed sickle cell disease providers. This network participates in a CDC-funded surveillance program for sickle cell disease. Tennessee is one of only eleven states in the nation participating in the program (https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc-data.html). This program provides a link between the CDC and the TN provider community coordinating the collection and sharing of data from multiple sources with a goal of reducing knowledge gaps about sickle cell disease care. TennCare is a supporter of this program and will continue to identify opportunities learned from the program to improve care for its enrollees.

TENNCARE OPPORTUNITIES

As described, TennCare provides comprehensive coverage for any enrollee with sickle cell disease. Enrollees can receive all clinically indicated medications, treatments, and services through their MCO or the pharmacy benefit. Additionally, through add-on services provided by TennCare's MCO population health teams, enrollees can access programs and services that further meet their needs due to sickle cell disease and optimize their clinical outcomes. Opportunities do still exist to improve the health outcomes and to better support cost-effective care for these enrollees.

Enrollees with sickle cell disease often have multiple chronic medical conditions that increase the clinical risk and complexity of their medical journey. Some enrollees also face behavioral health challenges alongside medical challenges. TennCare's MCOs are continuing efforts to improve

methods of engagement for members with medical complexity. As highlighted above, the MCOs are utilizing a variety of outreach methods to connect with members, build trust, and provide the supports needed to manage multiple diagnoses and specialty needs. The MCOs are also partnering directly with Sickle Cell Centers across the state to identify areas in which increased supports are needed for enrollees. TennCare and the MCOs will continue prioritizing efforts to strengthen outreach and engagement efforts so that all members with medical complexity who desire support have the opportunity to participate in MCO educational and case management services.

Additionally, enrollees with sickle cell disease often have unmet health-related social needs such as transportation, food, and housing that disproportionately drive their health outcomes. Through its Health Starts initiative, TennCare is working to build new systems that better address members' social needs. Started in 2021, the Health Starts initiative supports providers across the state who are implementing social needs screenings into workflows and designing systems to connect members to community resources when needs are identified. Health Starts is also supporting pilots of community health workers within provider practices statewide to help address social needs. In 2024, TennCare plans to bring a technology support to the Health Starts initiative to allow referrals from providers to reach community organizations seamlessly, and to facilitate feedback from community organizations to providers after action is taken on a referral. This new technology support represents an enormous opportunity to strengthen communication between providers and community organizations and thus better connect members to the community resources they need.

Other new technology is emerging in the realm of therapeutics; with recent FDA approval of two novel gene therapies, TennCare now has the opportunity to develop clinically appropriate pathways for access to Casegevy and Lyfgenia. In this design, TennCare's responsibility is to help engineer systems for accessibility while also monitoring safety and emerging clinical trial data. Designing successful clinical pathways for the novel gene therapies will require strong communication with the clinical sites and providers who are offering these therapies. We believe this communication and collaboration will build naturally on the current foundation of robust partnerships between the MCOs, providers, and the Sickle Cell Centers. TennCare recognizes that additional therapeutic and curative treatments for SCD, including gene therapies, will continue to emerge, and that the experience of designing operational systems for Casegevy and Lyfgenia in 2024 will also inform thoughtful approaches to other novel therapeutics in the future.

Finally, as highlighted in the two enrollee stories above, the transition from adolescence to young adulthood and from pediatrics to adult medicine continues to represent an area of ongoing opportunity for TennCare. As young people navigate emerging independence, those with chronic diseases also face transitions in primary care providers and specialists and new responsibility for their own appointments and medication adherence. Without support through these transitions and strong coordination of care, critical aspects of care may fall through the cracks. Over the past year, the MCOs have made significant progress in their efforts to support age-based transitions of care by increasing digital and electronic outreach and focusing on holistic member assessment,

including connections to PCP, social needs, medication adherence, disease and transportation education, and screening for behavioral health needs. Prioritization of smooth and well-coordinated transitions of care for this population remains a continued and relevant area of opportunity for the MCOs moving forward.

RECOMMENDATIONS TO THE LEGISLATURE

TennCare has solicited input from multiple stakeholders and incorporated their feedback into this report. Throughout 2023, TennCare continued to meet with multiple different stakeholders including industry, sickle cell provider groups, researchers, legislators, patient advocates, and enrollees who all provided valuable feedback. TennCare remains committed to receiving ongoing feedback related to better supporting enrollees with sickle cell disease or as feedback to this report.

As described earlier in this report, based on direct feedback from sickle cell providers and enrollees, TennCare will be filing a rule notice in CY 2024 to allow for therapeutic flexibility to better support sickle cell members requiring treatments for severe pain. TennCare will follow the standard rule-making procedures and appreciates the opportunity to receive the state Legislature's support for the proposed rule amendment.

Many of the additional opportunities highlighted in this report already have targeted initiatives underway through partnerships with the provider community. No further specific legislation at this time is recommended as TennCare is actively working to address areas of improvement that can continue to be accomplished through existing partnerships and pathways available to TennCare. The structure of the TennCare program readily allows TennCare to continue to make significant strides to accomplish these efforts in partnership with its enrollees and providers. TennCare will continue to update this report on an annual basis and remains deeply committed to its mission to provide high-quality, cost-effective care for all Tennesseans, including those with sickle cell disease.