Act No. 670 — "Lorri Burgess' Law" Senate Bill 298 of the Regular Legislative Session 2022

Focus Study: Availability and Utilization of Covered Medications, Treatments, and Services for Medicaid Members with Sickle Cell Disease During Calendar Year 2023

Final Report

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Louisiana Department of Health Bureau of Health Services Financing

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LOUISIANA DEPARTMENT OF HEALTH

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Executive Summary

This report is submitted pursuant to Act 670 (Senate Bill 298) of the 2022 Regular Louisiana Legislative Session, which requires the Louisiana Department of Health (LDH) to conduct an annual review of all medications and forms of treatment for sickle cell disease (SCD) that are eligible for coverage under the Louisiana Medicaid program. This is the third annual report submitted to the Senate Committee on Finance, the House Committee on Appropriations, and the Senate and House Committees on Health and Welfare.

Key findings from this year's report:

- The prevalence of SCD among Louisiana Medicaid managed care organization (MCO) full-benefit members (140.4 per 100,000 members) is almost twice that of Medicaid and Children's Health Insurance Program (CHIP) members nationwide (73.7 per 100,000 members).[1]
    - Prevalence varied between parishes, from 47.4 to 366.7 per 100,000 members for parishes with more than 10 members with SCD.
- All recommended medications, treatments, and services for SCD are covered for Medicaid members but may be underutilized. Notable examples include:
    - Approximately 15.7% of Louisiana Medicaid-enrolled children 2 to 16 years of age with SCD received an annual transcranial doppler (TCD) ultrasound screening.
    - Hydroxyurea was used by 34.4% of Louisiana Medicaid-enrolled children with SCD between the ages of 9 months and 20 years.
    - Pneumococcal vaccination was provided to 54.5% of Louisiana Medicaid-enrolled children younger than 2 years who had SCD.
- Medicaid-enrolled adults with SCD had a lower rate of accessing care from a hematologist compared to Medicaid-enrolled children with SCD.
    - Approximately 18% of adults with SCD had at least one hematology visit in 2023, compared to 59.3% of children with SCD.
- Emergency department (ED) visits and inpatient hospitalizations are more common among Louisiana Medicaid members with SCD compared to those without SCD. This disparity is particularly salient when comparing members with high healthcare utilization.
    - Among Louisiana Medicaid members, approximately one-third (33.6%) of children with SCD and nearly half (48.2%) of adults with SCD had an inpatient hospital stay in 2023, compared to 2.9% of children without SCD and 9.8% of adults without SCD.
        - Among Louisiana Medicaid members, 2.1% of children with SCD and 8.4% of adults with SCD had six or more inpatient hospital stays during 2023, whereas for members without SCD, this experience was far less common (0.03% of children and 0.24% of adults).
    - Among Louisiana Medicaid members, 71.6% of children with SCD and 83.3% of adults with SCD had an ED visit in 2023, compared to 31.7% of children without SCD and 38.8% of adults without SCD.
        - Among Louisiana Medicaid members, approximately 1 in 8 children with SCD (12.2%) and over a quarter of adults with SCD (26.9%) had six or more ED visits during 2023, whereas for members without SCD, this experience was far less common (0.84% of children and 2.7% of adults).

Introduction

SCD is a group of inherited disorders that affect the shape and function of red blood cells (RBCs) leading to anemia, pain, and other medical complications such as stroke, infections, and acute chest syndrome. People who inherit two sickle cell genes have a form of SCD commonly called sickle cell anemia, which is usually one of the most severe and prevalent forms of SCD. The prevalence of SCD among Louisiana Medicaid and CHIP members (140.4 per 100,000 members) is almost twice that of Medicaid and CHIP members nationwide (73.7 per 100,000 members).[1] The overall objective of this report is to assess the receipt of recommended care for SCD among Louisiana Medicaid members during Calendar Year (CY) 2023. The report also aims to understand the indications for emerging gene therapies for SCD. The following key questions were explored to meet this objective (as determined by specifications in Act 670):

1. What medications, treatments, and services are recommended for sickle cell disease?
2. Does Medicaid cover recommended medications, treatments, and services for sickle cell disease?
3. What is the utilization of covered services by Medicaid members with sickle cell disease?
4. Should LDH add additional medications, treatments, or services for coverage?

Focus Study Methodology and Results

Recommended Care and Medicaid Coverage

To identify recommended care for children and adults with SCD, Health Services Advisory Group, Inc. (HSAG) referenced the American Society of Hematology clinical guidelines;[2-5] the National Heart, Lung, and Blood Institute (NHLBI) guidelines;[6] and the Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017 by the Centers for Medicare and Medicaid Services (CMS).[1] Specific recommendations include, but are not limited to, the following:

- Annual TCD ultrasound screenings should be provided for children with sickle cell anemia, a specific type of SCD, from ages 2 to 16 years.
- Treatment with hydroxyurea should be offered to infants 9 months and older, children, and adolescents with sickle cell anemia, regardless of clinical severity, to reduce SCD-related complications (e.g., pain, dactylitis, acute chest syndrome, anemia).
    - Other disease-modifying therapies are not included in the published clinical guidelines at this time.
- Penicillin prophylaxis should be administered until age 5 in all children with sickle cell anemia.
- Vaccination against Streptococcus pneumoniae should be provided for all ages with SCD.
- Transfusions in certain circumstances, including, but not limited to surgery, acute chest syndrome, and stroke.
- Stem cell transplantation for patients with neurologic injury or recurrent acute chest syndrome at an early age.

All recommended medications, treatments, and services for SCD are currently covered by Louisiana Medicaid, including physical and behavioral health visits and hospital admissions. Table 1 summarizes all recommended treatments and Medicaid coverage. No additional medications, treatments, or services need to be added for coverage at this time. On behalf of LDH, HSAG developed a report in response to

House Concurrent Resolution 92 from the 2023 Regular Louisiana Legislative Session regarding the feasibility of funding the cell-based gene therapies (CGTs) lovotibeglogene autotemcel (Lyfgenia®) and exagamglogene autotemcel (Casgevy®) for all patients with SCD via Medicaid.[7] As of July 2024, the SCD CGT products are covered by Louisiana Medicaid, with prior authorization requirements.

Table 1 — Summary of Louisiana Medicaid Coverage of Recommended Treatments for SCD[7]

Treatment	Treatment Indication	Age Group	Covered[a]
Hydroxyurea (Droxia®, Hydrea®, or Siklos®)[b]	Disease-modifying therapy	All	Yes
Voxelotor (Oxbryta®)[c]	Disease-modifying therapy	4 years and older	Yes
L-glutamine (Endari®)[d]	Disease-modifying therapy	5 years and older	Yes
Crizanlizumab (Adakveo®)[e]	Disease-modifying therapy	16 years and older	Yes
Opioids	Pain	All	Yes
Penicillin	Reduce infection risk	All	Yes
Vaccinations	Reduce infection risk	All	Yes
Transfusions	Reduce complications	All	Yes
Stem cell transplant	Curative	All	Yes
CGTs (lovotibeglogene autotemcel [Lyfgenia] and exagamglogene autotemcel [Casgevy])[f]	Curative	12 years and older	Yes

[a] Some treatments require prior authorization.

[b] Droxia and Hydrea are registered trademarks of E.R. Squibb & Sons, LLC. Siklos is a registered trademark of Addmedica.

[c] Oxbryta is a registered trademark of Global Blood Therapeutics, Inc.

[d] Endari is a registered trademark of Emmaus Medical, Inc.

[e] Adakveo is a registered trademark of Novartis AG.

[f] Lyfgenia is a registered trademark of bluebird bio, Inc. Casgevy is a registered trademark of Vertex Pharmaceuticals, Inc.

In addition, all Medicaid members in Louisiana are entitled to a broad array of services that are often not covered by other payers, such as medical transportation, vision and dental services, and rehabilitation and other therapies.[8] Members may also qualify for and receive care management through their Medicaid MCO. Lastly, all children younger than 21 years are entitled to receive all medically necessary care through the Early and Periodic Screening, Diagnostic, and Treatment benefit.[9]

Methodology

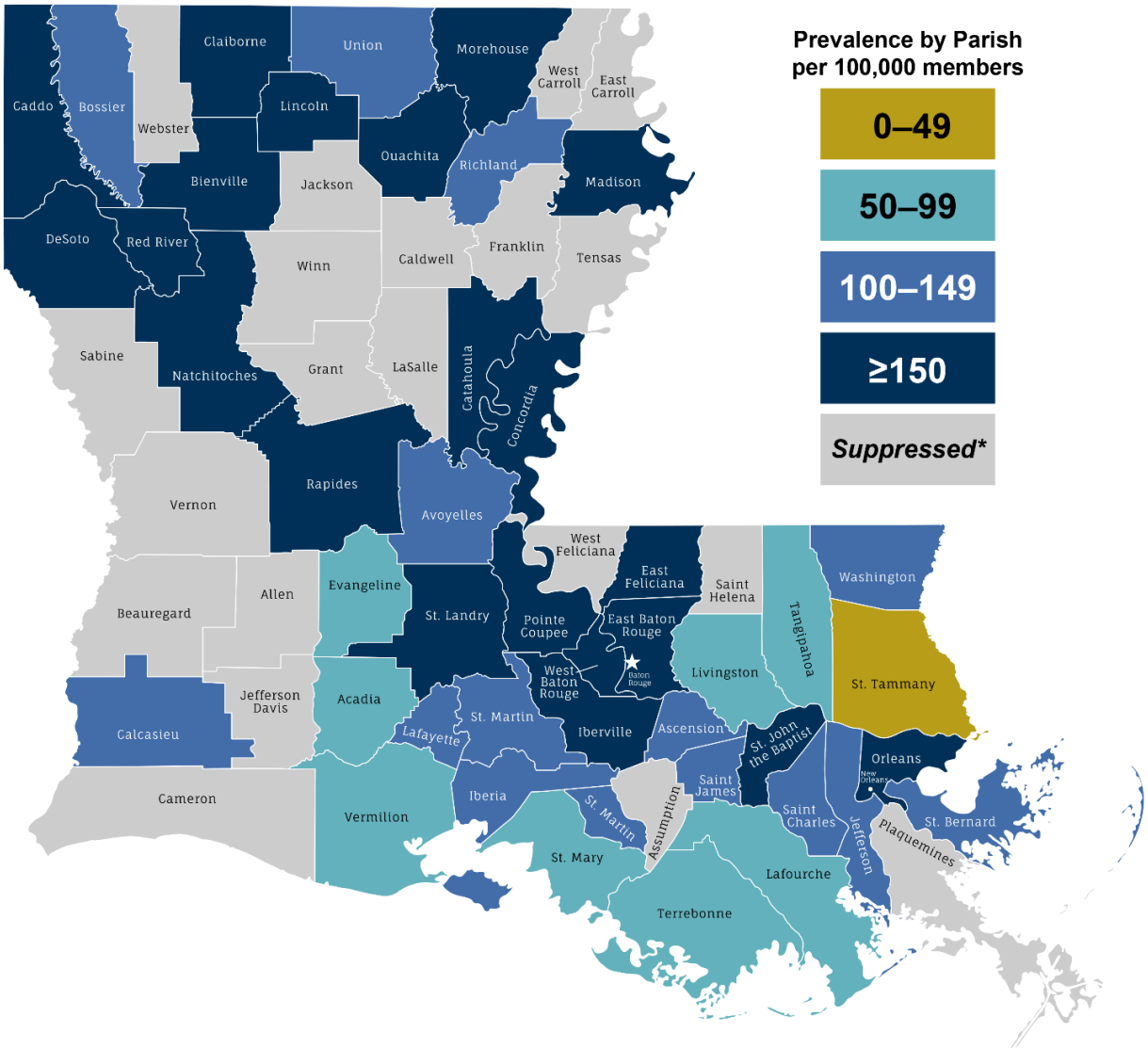
LDH contracted with its external quality review organization, HSAG, to conduct a review of all medications and forms of treatment for SCD that are eligible for coverage under the Louisiana Medicaid managed care program. For this updated report, HSAG conducted a targeted literature review and a review of the current national SCD clinical guidelines, package inserts for medications indicated for SCD, and LDH policies. For the review, HSAG identified measurable indicators of recommended care for SCD based on a review of the scientific literature and evidence-based clinical recommendations. LDH then reviewed and approved recommendations, which apply to members with SCD for CY 2023. HSAG provided LDH and the University of Louisiana Monroe (ULM) with study tables that represented the recommended measures. ULM consulted with LDH for coding specifications, extracted the corresponding claims data for Louisiana Medicaid managed care full-benefit members and populated the tables. Of note, the age used for members was the age at the beginning of the year (as of January 1,

2023). Numbers smaller than 10 are suppressed to protect the confidentiality of the records and are represented as "Suppressed" in the data tables. The evaluation is limited to those individuals enrolled in Louisiana Medicaid managed care health plans.

Parish-Level Counts and Prevalence in CY 2023

The Louisiana Medicaid member population with SCD is not distributed evenly across the state. In CY 2023, the overall prevalence rate of SCD per 100,000 members in Louisiana was 140.4 (Figure 1). The parishes with the highest prevalence rate of SCD per 100,000 members (all ages) were Caddo, DeSoto, Madison, Morehouse, and Red River. Each of these parishes had a prevalence rate of SCD greater than 250 per 100,000 members. The parishes with the highest number of members (all ages) with SCD were Caddo, East Baton Rouge, Jefferson, Lafayette, Orleans, and Ouachita. Each of these parishes had more than 100 members with SCD. Full data tables with parish-level counts and prevalence data are available in the Appendix — Parish-Level Counts and Prevalence Table.

Figure 1 — SCD Prevalence in Louisiana Parishes



* "Suppressed" is displayed for parishes with less than 10 members with SCD to protect the confidentiality of the records.

Children

Section 1.1 — Medicaid Enrollment of Children with Sickle Cell Disease

There were 1,339 children with SCD enrolled in a Louisiana Medicaid MCO for full-benefit coverage during CY 2023. Almost all the children (95.1%) were enrolled for 10 to 12 months of the study year (Table 2), which suggests they maintained coverage for the receipt of recommended treatments. The high enrollment among children also supports the use of Medicaid claims data to review the care and treatments they received.

Table 2 — Continuity of Medicaid Enrollment, CY 2023
Louisiana Children with SCD

Duration of Louisiana Medicaid Enrollment[a]	Children with SCD, n	Total Enrolled, %
1–6 months	29	2.2%
1–3 months	14	1%
4–6 months	15	1.1%
7–9 months	37	2.8%
10–12 months	1,273	95.1%
Total	1,339	100%

[a] Children younger than 21 years of age were included.

Section 1.2 — Prevalence of Sickle Cell Disease and Age Distribution

Children with SCD comprise 0.15% of the Louisiana Medicaid population younger than age 21. Of the children with SCD, 27.0% were between the ages of 0 and 5 years, 35.1% were between the ages of 6 and 12 years, and 37.9% were between the ages of 13 and 20 years (Table 3).

Table 3 — Prevalence of SCD, CY 2023
Louisiana Children

Age Group[a]	Members < 21 Years, n	Total Enrolled, %
Total enrollment, Louisiana Medicaid MCO full-benefit members < 21 years of age	887,722	100%
Ages < 21 years with SCD	1,339	0.15%
Ages 0–5 years	362	27%
Ages 6–12 years	470	35.1%
Ages 13–20 years	507	37.9%

[a] For encounters in CY 2023.

Section 1.3 — Receipt of Recommended Care

Infection Prevention

Individuals with SCD have an increased risk of severe bacterial infection resulting from reduced or absent function of the spleen. The result is an elevated risk of infection, and pneumococcal vaccination and all other age-appropriate vaccinations are recommended.[6] Just over half (54.5%) of children with SCD younger than 2 years received a pneumococcal vaccination. Less than one-fourth (23.6%) of members with SCD younger than 21 years received the influenza vaccination, and 2.1% received at least one dose of the COVID-19 vaccine (Table 4).

Table 4 — Receipt of Recommended Care: Infection Prevention, CY 2023 Louisiana Children With SCD		
Recommended Care[a]	**Members < 21 Years, n**	**Members Who Received Recommended Care, %**
Ages < 21 years	1,339	–
Received the influenza vaccination	316	23.6%
Received at least one COVID-19 vaccination[b]	28	2.1%
Ages < 2 years	110	–
Received at least one pneumococcal vaccination	60	54.5%

[a] All measures were calculated for encounters in CY 2023.

[b] The COVID-19 vaccine was approved for ages 5 to 11 years in October 2021 and for ages 6 months to 4 years in June 2022.

The purpose of prophylactic antibiotic therapy in children with SCD is to reduce the risk of pneumococcal infection.[6] Approximately 7.4% of children ages 3 months to 4 years received antibiotic prophylaxis, defined as at least a 300-day supply. Most children in this age group (82.0%) received at least a one-day supply of antibiotic prophylaxis (Table 5). Due to the data limitations, the rationale for the use of antibiotics cannot be determined.

Table 5 — Days' Supply of Antibiotic Prophylaxis,[a] CY 2023 Louisiana Children with SCD, Ages 3 Months to 4 Years		
Number of Days' Supply	**Among Children Who Received Any Antibiotic Prophylaxis,[b] n (%)**	**Among All 284 Children 3 Months to 4 Years With SCD,[b] (%)**
1–99 days	112 (48.1%)	39.4%
100–199 days	63 (27.0%)	22.2%
200–299 days	37 (15.9%)	13%
≥ 300 days	21 (9.0%)	7.4%
Total	233 (100%)	82%

[a] Included antibiotics: penicillin, amoxicillin, and erythromycin.

[b] 284 members with SCD were between 3 months and 4 years of age (21.2% of total members with SCD under age 21). Of these, 233 had at least a one-day supply of antibiotic prophylaxis (82.0% of members with SCD in this age group).

Prevention and Treatment of the Complications of Sickle Cell Disease

Disease-modifying therapies help reduce vaso-occlusive pain episodes and other vaso-occlusive complications.[6] The currently available disease-modifying therapies include hydroxyurea, L-glutamine oral powder, crizanlizumab, and voxelotor. For CY 2023, voxelotor was approved in children 4 years and older,[10] L-glutamine oral powder was approved in children 5 years and older,[11] and crizanlizumab was approved in children 16 years and older.[12] The CGTs Casgevy[13] and Lyfgenia[14] were approved for use in children ages 12 and older in December 2023; however, no children were found to have utilized this gene therapy in 2023.

Just over one-third of children between the ages of 9 months and 20 years (34.4%) filled a prescription for hydroxyurea; this percentage increased slightly when prescriptions for all disease-modifying agents were counted (35.6%). Filled prescriptions for disease-modifying therapies other than hydroxyurea were relatively uncommon, with 8.1% of patients between the ages of 4 and 20 years filling a prescription for

voxelotor and 0.96% of patients between the ages of 5 and 20 years filling a prescription for L-glutamine oral powder. In CY 2023, no children with SCD were found to have utilized the new CGTs (Table 6).

Transfusions are indicated to treat severe uncompensated anemia, severe vaso-occlusive events (e.g., acute stroke or acute chest syndrome), and preoperatively.[3] Overall, 11.7% of children with SCD younger than age 21 received a blood transfusion and 11 children (0.82%) received a stem cell transplant in CY 2023 (Table 6).

Table 6 — Receipt of Recommended Care: Prevention and Treatment of Complications, CY 2023 Louisiana Children with SCD

Recommended Care[a]	Members < 21 Years, n	Members Who Received Recommended Care, %
Ages < 21 years	1,339	-
Ages 9 months–20 years	1,308	-
Filled a prescription for hydroxyurea (Droxia, Hydrea, or Siklos) ≥ 1 time[b]	460	34.4%
Filled a prescription for any approved disease-modifying agent ≥ 1 time	477	35.6%
Ages 4–20 years	1,096	-
Filled a prescription for voxelotor (Oxbryta) ≥ 1 time	89	8.1%
Ages 5–20 years	1,039	-
Filled a prescription for L-glutamine oral powder (Endari) ≥ 1 time	10	0.96%
Ages 16–20 years	337	-
Filled a prescription for crizanlizumab (Adakveo) ≥ 1 time	10	3%
Ages 12–20 years	575	-
Received a CGT (exagamglogene autotemcel [Casgevy] or lovotibeglogene autotemcel [Lyfgenia])[c]	0	0%
Received a blood transfusion	156	11.7%
Received a stem cell transplant	11	0.82%

[a] All measures were calculated for encounters in CY 2023. The age ranges in this table are based on FDA approvals.
[b] Data for ages 9 months to 20 years, based on NHLBI guidelines.
[c] The CGTs Casgevy and Lyfgenia were approved for use in children 12 years of age and older in December 2023.

Section 1.4 — Healthcare Utilization

The National Academies of Sciences, Engineering, and Medicine recommend that individuals with SCD have both a primary care provider (PCP) and an SCD specialist co-manage their care.[15] Among members with SCD younger than 21 years of age, 95.8% had at least one PCP visit and 59.3% had at least one hematologist visit in CY 2023. However, 73.3% had at least two outpatient visits with the same PCP and 35.2% had at least two outpatient visits with the same hematologist in CY 2023 (Table 7).

Table 7 — Receipt of Recommended Care: Healthcare Utilization, CY 2023 Louisiana Children with SCD		
Recommended Care[a]	**Members < 21 Years, n**	**Members Who Received Recommended Care, %**
Ages < 21 years	1,339	-
Had at least one PCP visit	1,283	95.8%
Had at least one hematologist visit	794	59.3%
Had ≥ 2 outpatient visits with the same PCP	982	73.3%
Had ≥ 2 outpatient visits with the same hematologist	471	35.2%

[a] All measures were calculated for encounters in CY 2023.

For members with SCD, acute vaso-occlusive episodes (VOEs) unresponsive to or unable to take disease-modifying therapies may result in ED visits and inpatient hospitalizations. Approximately 71.6% of members with SCD younger than age 21 had at least one ED visit, compared to 31.7% of members younger than 21 without SCD. Among members younger than 21, 12.2% of members with SCD had six or more ED visits during CY 2023, compared to 0.84% for members of the same age without SCD. Among members younger than 21, members with SCD had an average of 2.9 ED visits in CY 2023, while members without SCD had an average of 0.57 ED visits. Members with SCD younger than 21 had an average of 1.7 ED visits for VOE during CY 2023 (Table 8).

Table 8 — Number of ED Visits,[a] CY 2023 Louisiana Children			
ED Visits	**Members < 21 Years With SCD, %**		**Members < 21 Years Without SCD, %— All-Cause**
	All-Cause	**VOE**	
Members with 0 ED visits	28.4%	56.4%	68.3%
Members with ≥ 1 ED visit	71.6%	43.6%	31.7%
Members with 1 ED visit	20.3%	17.4%	18.8%
Members with 2–5 ED visits	39.2%	20.2%	12.1%
Members with ≥ 6 ED visits	12.2%	6.0%	0.84%
Mean number of ED visits during the year	2.9	1.7	0.57

[a] ED data excluded dual-eligible members and members with other private insurance. ED visits were limited to one per day.

For children with SCD, 33.6% had at least one inpatient hospital stay in CY 2023, compared to 2.9% of children without SCD. Approximately 2.1% of children with SCD had six or more hospital stays during the year, compared to less than 1% (0.03%) of children without SCD. Among members younger than age 21, the average inpatient hospital days for members with SCD was 4.8 days, compared to 0.29 days for members without SCD (Table 9).

Table 9 — Number of Inpatient Hospital Stays,[a] CY 2023 Louisiana Children		
Hospital Stays	**Members < 21 Years With SCD, %**	**Members < 21 Years Without SCD, %**
Members with 0 hospital stays	66.4%	97.1%
Members with ≥ 1 hospital stay	33.6%	2.9%
Members with 1 hospital stay	18.2%	2.3%

Table 9 — Number of Inpatient Hospital Stays,[a] CY 2023 Louisiana Children		
Hospital Stays	**Members < 21 Years With SCD, %**	**Members < 21 Years Without SCD, %**
Members with 2–5 hospital stays	13.3%	0.48%
Members with ≥ 6 hospital stays	2.1%	0.03%
Mean number of hospital days during the year	4.8	0.29

[a] Hospitalization data excluded dual-eligible members and members with other private insurance. Hospitalizations with same-day discharge/readmit were counted as individual visits.

Section 1.5 — Preventive Care

The American Academy of Pediatrics recommends that children ages 3 and older should have one health screening per year, while children younger than age 3 should have more frequent screenings.[16] Additionally, the NHLBI guidelines recommend TCD ultrasound screenings to evaluate stroke risk.[6]

A little over half (55.9%) of members with SCD younger than age 21 received at least one health screening in CY 2023. Among children ages 2 to 16 years with SCD, 15.7% received any TCD screenings. Additionally, children should have dental examinations every six months beginning no later than their first birthday.[17] However, 55% of members with SCD between the ages of 2 and 20 years had at least one dental exam in CY 2023 (Table 10).

Table 10 — Receipt of Recommended Care: Preventive Care, CY 2023 Louisiana Children with SCD		
Recommended Care[a]	**Members < 21 Years, n**	**Members Who Received Recommended Care, %**
Ages < 21 years	1,339	-
Had at least one health screening	748	55.9%
Ages 2–16 years	968	-
Received any TCD screenings	152	15.7%
Ages 2–20 years	1,229	-
Had at least one dental exam	676	55%

[a] All measures were calculated for encounters in CY 2023.

Adults

Section 1.6 — Continuous Enrollment of Adults with Sickle Cell Disease

A total of 1,230 adults with SCD were enrolled in Louisiana Medicaid during CY 2023. Almost all the adults (87.4%) were enrolled for 10 to 12 months of the study year (Table 11), which suggests they maintained coverage for recommended treatments. The high enrollment among adults also supports the use of Medicaid claims data to review the care and treatments they received.

Table 11 — Continuity of Medicaid Enrollment, CY 2023
Louisiana Adults with SCD

Duration of Louisiana Medicaid Enrollment[a]	Adults With SCD, n	Total Enrolled, %
1–3 months	25	2%
4–6 months	52	4.2%
7–9 months	78	6.3%
10–12 months	1,075	87.4%
Total	1,230	100%

[a] Adults 21 and older were included.

Section 1.7 — Prevalence of Sickle Cell Disease and Age Distribution

Adults with SCD comprise 0.13% of the Medicaid population ages 21 and older. Of the adults with SCD, 81.6% were between the ages of 21 and 45, and 18.4% were between the ages of 46 and 75 (Table 12).

Table 12 — Prevalence of SCD, CY 2023
Louisiana Adults

Age Group[a]	Members ≥ 21 Years, n	Total Enrolled, %
Total enrollment, Louisiana Medicaid MCO full-benefit members ≥ 21 years of age	942,763	-
Ages ≥ 21 years with SCD	1,230	0.13%
Ages 21–45 years	1,004	81.6%
Ages 46–75 years	226	18.4%

[a] For encounters in CY 2023.

Section 1.8 — Receipt of Recommended Care

Infection Prevention

Adults with SCD should get all recommended vaccinations, including a yearly influenza vaccination and the COVID-19 vaccination.[19] Approximately one in six adults with SCD (16.3%) received an influenza vaccination. The COVID-19 vaccine was received by approximately 3.9% of adults with SCD (Table 13).

Table 13 — Receipt of Recommended Care: Infection Prevention, CY 2023
Louisiana Adults with SCD

Recommended Care[a]	Members ≥ 21 Years, n	Members Who Received Recommended Care, %
Ages ≥ 21 years	1,230	-
Received the influenza vaccination	200	16.3%
Received at least one COVID-19 vaccination	48	3.9%

[a] All measures were calculated for encounters in CY 2023.

Prevention and Treatment of the Complications of Sickle Cell Disease

Disease-modifying therapies help with reducing vaso-occlusive pain episodes and other vaso-occlusive complications.[6] The currently available disease-modifying therapies include hydroxyurea, voxelotor, L-glutamine oral powder, and crizanlizumab. The CGTs Casgevy and Lyfgenia were approved for adult use in December 2023. In CY 2023, 391 adults with SCD (31.8%) filled a prescription for any of the FDA-approved disease-modifying therapies. Filled prescriptions for disease-modifying therapies other than hydroxyurea were relatively uncommon, with 5.4% of adults with SCD filling a prescription for voxelotor, 2.1% filling a prescription for L-glutamine oral powder, and 4.6% filling a prescription for crizanlizumab. No adults with SCD received a stem cell transplant or the new CGTs (Table 14).

Transfusions are indicated to treat severe uncompensated anemia, severe vaso-occlusive events (e.g., acute stroke or acute chest syndrome), and preoperatively.[3] A blood transfusion was received by 14.6% of adults with SCD (Table 14).

Table 14 — Receipt of Recommended Care: Prevention and Treatment of Complications, CY 2023 Louisiana Adults with SCD

Recommended Care[a]	Members ≥ 21 Years, n	Members Who Received Recommended Care, %
Ages ≥ 21 years	1,230	-
Filled a prescription for hydroxyurea, voxelotor (Oxbryta), L-glutamine oral powder (Endari), or crizanlizumab (Adakveo) ≥ 1 time	391	31.8%
Filled a prescription for hydroxyurea (Droxia, Hydrea, or Siklos) ≥ 1 time	356	28.9%
Filled a prescription for voxelotor (Oxbryta) ≥ 1 time	67	5.4%
Filled a prescription for L-glutamine oral powder (Endari) ≥ 1 time	26	2.1%
Filled a prescription for crizanlizumab (Adakveo) ≥ 1 time	57	4.6%
Received a CGT (exagamglogene autotemcel [Casgevy] or lovotibeglogene autotemcel [Lyfgenia])[b]	0	0%
Received a blood transfusion	180	14.6%
Received a stem cell transplant	0	0%

[a] All measures were calculated for encounters in CY 2023.

[b] The CGTs Casgevy and Lyfgenia were approved for adult use in December 2023.

Section 1.9 — Healthcare Utilization

Individuals with SCD are recommended to have both a PCP and an SCD specialist co-manage their care.[16] Most (88.6%) adult members with SCD had at least one PCP visit, but 222 (18%) had at least one hematologist visit in CY 2023. Nearly three-quarters of the adult members with SCD (73.9%) had two or more outpatient visits with the same PCP, but 1 in 10 (10.7%) had two or more outpatient visits with the same hematologist (Table 15).

Table 15 — Receipt of Recommended Care: Healthcare Utilization, CY 2023
Louisiana Adults with SCD

Recommended Care[a]	Members ≥ 21 Years, n	Members Who Received Recommended Care, %
Ages ≥ 21 years	1,230	-
Had at least one PCP visit	1,090	88.6%
Had at least one hematologist visit	222	18%
Had ≥ 2 outpatient visits with the same PCP	909	73.9%
Had ≥ 2 outpatient visits with the same hematologist	131	10.7%

[a] All measures were calculated for encounters in CY 2023.

For members with SCD, acute VOEs unresponsive to or unable to take disease-modifying therapies may result in visits to EDs and inpatient hospitalization. Among adults, 83.3% of members with SCD had at least one ED visit, compared to 38.8% of members without SCD. Over one-fourth of adults with SCD (26.9%) had six or more ED visits during CY 2023, compared to 2.7% of adults without SCD. Among members 21 and older, members with SCD had an average of 7.2 ED visits in CY 2023, while members without SCD had on average less than one ED visit (0.92). Adults with SCD averaged 4.5 ED visits for VOE (Table 16).

Table 16 — Number of ED Visits,[a] CY 2023
Louisiana Adults

ED Visits	Members ≥ 21 Years with SCD, %		Members ≥ 21 Years without SCD, %— All-Cause
	All-Cause	VOE	
Members with 0 ED visits	16.7%	51.7%	61.2%
Members with ≥ 1 ED visit	83.3%	48.3%	38.8%
Members with 1 ED visit	16.7%	14.5%	19.1%
Members with 2–5 ED visits	39.7%	17.9%	17.1%
Members with ≥ 6 ED visits	26.9%	15.9%	2.7%
Mean number of ED visits during the year	7.2	4.5	0.92

[a] ED data excluded dual-eligible members and members with other private insurance. ED visits were limited to one per day.

Of adults with SCD, 548 (48.2%) had at least one inpatient hospital stay in CY 2023, compared to 9.8% of adults without SCD (Table 17). Approximately 1 in 12 adults with SCD (8.4%) had six or more hospital stays during the year, compared to 0.24% of adults without SCD. Among members 21 and older, the average inpatient hospital length of stay for members with SCD was approximately 11.6 days, 10 days longer than the average 1.1 days for members without SCD (Table 17).

Table 17 — Number of Inpatient Hospital Stays,[a] CY 2023 Louisiana Adults		
Hospital Stays	**Members ≥ 21 Years with SCD, %**	**Members ≥ 21 Years without SCD, %**
Members with 0 hospital stays	51.8%	90.2%
Members with ≥ 1 hospital stay	48.2%	9.8%
Members with 1 hospital stay	21.9%	7.3%
Members with 2–5 hospital stays	17.8%	2.3%
Members with ≥ 6 hospital stays	8.4%	0.24%
Mean number of hospital days during the year	11.6	1.1

[a] Hospitalization data excluded dual-eligible members and members with other private insurance. Hospitalizations with same-day discharge/readmit were counted as individual visits.

Discussion

The national data[1] available for comparison were not from the same year as Louisiana Medicaid data examined in this report (2017 versus 2023), and the national data only examined individuals with continuous enrollment. Despite these limitations to making direct comparisons, the national data suggested that Louisiana Medicaid members ages 2 to 16 with SCD were receiving fewer TCD ultrasound screenings (15.7%) compared to their counterparts across the country, U.S. Medicaid and CHIP members ages 3 to 16 with SCD (36.6%). All other comparisons revealed similar rates between the national data and the Louisiana Medicaid data.

The CMS Sickle Cell Disease Action Plan[18] released in September 2023 aims to improve the access, quality, and experience of healthcare for individuals living with SCD. Priorities include addressing challenges such as higher rates of ED visits and hospitalizations in individuals with SCD, vulnerability in the transition from pediatric to adult care, and gaps in receiving the clinically recommended standard care, such as ultrasound screenings for primary stroke prevention. These challenges identified by CMS also exist in the Louisiana Medicaid SCD population.

- Louisiana Medicaid-enrolled adults and children with SCD have higher rates of ED visits and hospitalizations when compared to those without SCD. Almost three-fourths of Louisiana Medicaid-enrolled children with SCD (71.6%) had an ED visit in CY 2023, compared to 2.9% of Louisiana Medicaid-enrolled children without SCD. Similarly, 83.3% of Louisiana Medicaid-enrolled adults with SCD had an ED visit, compared to 9.8% of adults without SCD. The percentage of Louisiana Medicaid members with at least one inpatient hospital stay was also higher for members with SCD than for those without SCD in both adults and children.
- Many patients with SCD experience challenges during the transition from pediatric to adult care. Comparing Louisiana Medicaid-enrolled adults to children, it is notable that 18% of adults with SCD had at least one hematologist visit in 2023, whereas 59.3% of children with SCD were seen by a hematologist. In addition, 10.7% of adults with SCD and 35.2% of children with SCD had two or more outpatient visits to the same hematologist.
- Gaps in the receipt of clinically recommended standard care, such as TCD ultrasound screenings for primary stroke prevention, have been identified as a challenge for patients with SCD. NHLBI guidelines recommend annual TCD ultrasound screenings for children with sickle cell anemia, a specific type of SCD, from ages 2 to 16.[6] However, about 1 in 6 (15.7%) Louisiana Medicaid-enrolled children ages 2 to 16 with SCD received a TCD ultrasound screening in 2023.

While this report examined CY 2023 data, the two CGTs approved in December 2023 were not utilized but have the potential to impact future acute care utilization. However, these approaches require significant medical treatment and monitoring over several months, use scientific techniques available in a limited number of specialized facilities, and present significant risks not only arising from the treatment but from attendant procedures required to support the treatment. As a result, uptake of these therapies is likely to be limited.

Study Strengths and Limitations

This report used claims data to assess the receipt of recommended care for SCD among Louisiana Medicaid members during CY 2023. The use of claims data enabled the identification of structured data for a sizeable group of patients with SCD over the desired period and allowed comparisons with data from the CY 2021 and CY 2022 reports. Limitations of the study include the following:

- National comparison data were not available for all recommended care measures, and the most recent available national data were from a different year (2017) than the study year (2023).
- The analysis does not stratify by type of SCD even though a consideration of the proportion of less severe forms of SCD may partially explain lower utilization rates for certain types of care. It is important to note that the national data used for comparisons also are not stratified by type of SCD.
- The claims data used for the analysis do not include indications for why medications or procedures were prescribed. Therefore, therapies with broader indications (e.g., antibiotics, stem cell transplants, transfusions) cannot be attributed directly to SCD. However, it is plausible, given the guideline recommendations for these treatments, that they were used for SCD. Pain management was not analyzed for this report as it is difficult to assess the indication and nature of the pain events in claims data.

Despite these limitations, the report provides a comprehensive overview of the utilization of healthcare among adult and pediatric patients with SCD in Louisiana.

Conclusion

Study findings show that covered medications, treatments, and services are available to Louisiana Medicaid members with SCD but may be underutilized. There are multiple opportunities to better ensure that adults and children with SCD receive the recommended care. These opportunities include, but are not limited to:

- Annual TCD ultrasound screening to evaluate stroke risk, which was used in 15.7% of Louisiana Medicaid-enrolled children ages 2 to 16 with SCD.
- Treatment with hydroxyurea to reduce vaso-occlusive pain episodes and other vaso-occlusive complications was used by 34.4% of Louisiana Medicaid-enrolled children with SCD.
- Pneumococcal vaccination to prevent severe bacterial infection was provided to 54.5% of Louisiana Medicaid-enrolled children younger than age 2 who had SCD.
- Routine preventive care with a hematologist to co-manage care, which was less common in adults with SCD than in children with SCD, indicating challenges in transitions of care.

Appendix — Parish-Level Counts and Prevalence Table

Table A-1 — Location of SCD Members — All Ages[a]				
Parish	**Total Number of Members, n**	**Number of Members with SCD, n**	**Percentage of Members with SCD in Each Parish, %**	**Prevalence Rate of SCD per 100,000 Members, n**
Acadia	26,734	20	0.07%	74.8
Allen	8,807	Suppressed	Suppressed	Suppressed
Ascension	38,059	46	0.12%	120.9
Assumption	6,839	Suppressed	Suppressed	Suppressed
Avoyelles	17,638	26	0.15%	147.4
Beauregard	14,203	Suppressed	Suppressed	Suppressed
Bienville	6,160	11	0.18%	178.6
Bossier	40,498	49	0.12%	121.0
Caddo	101,547	281	0.28%	276.7
Calcasieu	77,675	84	0.11%	108.1
Caldwell	4,955	Suppressed	Suppressed	Suppressed
Cameron	791	0	0%	0
Catahoula	4,518	10	0.22%	221.3
Claiborne	5,284	13	0.25%	246.0
Concordia	9,736	20	0.21%	205.4
DeSoto	11,017	28	0.25%	254.2
East Baton Rouge	164,370	311	0.19%	189.2
East Carroll	3,516	Suppressed	Suppressed	Suppressed
East Feliciana	6,895	16	0.23%	232.1
Evangeline	14,804	14	0.09%	94.6
Franklin	10,214	Suppressed	Suppressed	Suppressed
Grant	7,998	Suppressed	Suppressed	Suppressed
Iberia	33,019	46	0.14%	139.3
Iberville	12,727	26	0.20%	204.3
Jackson	5,235	Suppressed	Suppressed	Suppressed
Jefferson	166,121	200	0.12%	120.4
Jefferson Davis	12,257	Suppressed	Suppressed	Suppressed
LaSalle	5,665	Suppressed	Suppressed	Suppressed
Lafayette	86,550	116	0.13%	134.0
Lafourche	31,408	19	0.06%	60.5
Lincoln	16,299	35	0.21%	214.7
Livingston	51,981	26	0.05%	50.0
Madison	5,727	21	0.37%	366.7
Morehouse	13,141	35	0.27%	266.3

Table A-1 — Location of SCD Members — All Ages[a]				
Parish	**Total Number of Members, n**	**Number of Members with SCD, n**	**Percentage of Members with SCD in Each Parish, %**	**Prevalence Rate of SCD per 100,000 Members, n**
Natchitoches	15,187	32	0.21%	210.7
Orleans	158,850	313	0.2%	197.0
Ouachita	71,965	131	0.18%	182.0
Plaquemines	7,618	Suppressed	Suppressed	Suppressed
Pointe Coupee	7,613	12	0.16%	157.6
Rapides	54,156	96	0.18%	177.3
Red River	3,872	11	0.28%	284.1
Richland	9,853	10	0.1%	101.5
Sabine	9,515	Suppressed	Suppressed	Suppressed
St. Bernard	21,850	28	0.13%	128.2
St. Charles	15,495	21	0.14%	135.5
St. Helena	3,313	Suppressed	Suppressed	Suppressed
St. James	7,688	11	0.14%	143.1
St. John The Baptist	19,586	30	0.15%	153.2
St. Landry	43,490	71	0.16%	163.3
St. Martin	20,252	25	0.12%	123.4
St. Mary	23,161	12	0.05%	51.8
St. Tammany	80,202	38	0.05%	47.4
Tangipahoa	63,778	59	0.09%	92.5
Tensas	1,984	Suppressed	Suppressed	Suppressed
Terrebonne	45,197	27	0.06%	59.7
Union	9,882	13	0.13%	131.6
Vermilion	23,103	18	0.08%	77.9
Vernon	15,442	Suppressed	Suppressed	Suppressed
Washington	22,386	31	0.14%	138.5
Webster	16,604	Suppressed	Suppressed	Suppressed
West Baton Rouge	9,778	19	0.19%	194.3
West Carroll	5,154	Suppressed	Suppressed	Suppressed
West Feliciana	3,209	Suppressed	Suppressed	Suppressed
Winn	5,301	Suppressed	Suppressed	Suppressed
Unknown[b]	12,613	Suppressed	Suppressed	Suppressed
Louisiana (Total)	1,830,485	2,569	0.14%	140.4

[a] Analysis used the parish associated with the last date of eligibility.

[b] Parish of residence unknown, assumed Louisiana resident.

Note: Numbers smaller than 10 are suppressed to protect the confidentiality of the records and are represented as "Suppressed" in the data tables.

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