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 Members With Sickle Cell Disease During Calendar Year 2024

Final Report

Prepared by: Health Services Advisory Group, Inc., on behalf of the

Louisiana Department of Health

Bureau of Health Services Financing

March 2026

LOUISIANA DEPARTMENT OF HEALTH

Contents

Executive Summary 2
Introduction 4
Focus Study Methodology and Results 5
Recommended Care and Medicaid Coverage 5
Methodology 6
Parish-Level Counts and Prevalence in CY 2024 7
Children 8
Section 1.1—Medicaid Enrollment of Children With Sickle Cell Disease 8
Section 1.2—Prevalence of Sickle Cell Disease and Age Distribution 8
Section 1.3—Receipt of Recommended Care 8
Section 1.4—Healthcare Utilization 10
Section 1.5—Preventive Care 12
Adults 13
Section 1.6—Continuous Enrollment of Adults With Sickle Cell Disease 13
Section 1.7—Prevalence of Sickle Cell Disease and Age Distribution 13
Section 1.8—Receipt of Recommended Care 13
Section 1.9—Healthcare Utilization 14
Discussion 17
Study Strengths and Limitations 19
Conclusion 20
Recommendations 21
Appendix A—Parish-Level Counts and Prevalence Table 22
Appendix B—Top Diagnosis Codes for ED Visits and Hospital Stays Among Children With SCD 24
Appendix C—Top Diagnosis Codes for ED Visits and Hospital Stays Among Adults With SCD 25
Bibliography 26

Executive Summary

This report is submitted pursuant to Act No. 670 (Senate Bill 298) of the 2022 Regular 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 Medicaid program.[1] This is the fourth annual report submitted to the Senate Committee on Finance, the House Committee on Appropriations, and the Senate and House Committees on Health and Welfare.

As found in prior reports, coverage for members with SCD is adequate under the Medicaid program for calendar year (CY) 2024. Additional key findings from this year's report include:

- The prevalence of SCD among Louisiana Medicaid and Children's Health Insurance Program (CHIP) members (148.4 per 100,000 members) is almost twice that of Medicaid and CHIP members nationwide (73.7 per 100,000 members).[2] SCD represents a broad spectrum of diagnoses and varying disease severity which may impact utilization patterns identified in this report.
- All recommended medications, treatments, and services for SCD are covered for members including the new Cell and Gene Therapy (CGT) treatments which are potentially curative.
- Disease Modifying Therapies (DMTs) were used at least once by 35.1% of enrolled children with SCD and 33.7% of enrolled adults with SCD, which may represent an opportunity for improvement depending on clinical appropriateness and individual patient factors.
- Almost all (96.7%) children with SCD had a primary care provider (PCP) visit and over half (57.9%) had a visit with a hematologist. Similarly, most adults with SCD (91.1%) had a PCP visit, while 18.9% had a visit with a hematologist, suggesting an opportunity for further study to determine if increased utilization of hematology services would be beneficial.
- Emergency department (ED) visits and inpatient hospitalizations were more common among Medicaid members with SCD compared to those without SCD.
    - Children with SCD had an average of 2.9 ED visits, while members without SCD averaged less than one (0.57) ED visit. Adults with SCD had an average of 7.2 ED visits, while members without SCD averaged less than one (0.92) ED visit.
    - Over a third (37.4%) of children with SCD and 48.6% of adults with SCD had an inpatient hospital stay, compared to 2.6% of children without SCD and 9.3% of adults without SCD.
- While most (58.4%) children with SCD had a health screening, by contrast, 17.2% of Louisiana Medicaid-enrolled children 2 to 16 years of age with SCD received an annual transcranial doppler (TCD) ultrasound screening, which may be an opportunity for improvement and warrants further study by SCD type.

Due to limitations of the analysis, utilization rates identified in this report may not necessarily reflect poor provider performance but may be partially explained by varying severity of disease, clinical appropriateness, and patient factors. Further study of these factors and barriers to access is warranted to identify effective interventions to improve the quality of care for all members with SCD. As LDH continues to update and revise the Sickle Cell Disease Registry, it will be important to include surveillance for preventive care measures to strengthen the ability of the care systems to support individuals with SCD to achieve their fullest health potential.[3] Key interventions to increase access to a shared care model or other strategies to drive better integration of specialty and primary care merit

exploration, as do interventions to improve the transition from pediatric to adult care. Additionally, preventive screenings and increased appropriate use of hydroxyurea and other DMTs could reduce healthcare utilization such as ED visits.

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 develop sickle cell anemia (i.e., hemoglobin (Hb)-SS disease), the most common and usually one of the most severe forms of SCD. The prevalence of SCD among Louisiana Medicaid and CHIP members (148.4 per 100,000 members) in 2024 is almost twice that of Medicaid and CHIP members nationwide (73.7 per 100,000 members) in 2017.[2] The overall objective of this report is to determine whether recommended medications, treatments, and services for SCD are eligible for coverage under the Louisiana Medicaid program; whether the covered care is adequate to meet the needs of enrollees with SCD; and whether LDH should provide additional care to Louisiana Medicaid members with SCD.[1] This report assesses the receipt of recommended care for SCD during CY 2024 among Louisiana Medicaid members with a diagnosis of Hb-SS disease with crisis, sickle-cell disease without crisis, sickle-cell/Hb-C disease, sickle-cell thalassemia, and other sickle-cell disorders. The following key questions (KQs) were explored to meet this objective (as determined by specifications in Act 670):[1]

KQ1. What medications, treatments, and services are recommended for sickle cell disease?

KQ2. Does Medicaid cover recommended medications, treatments, and services for sickle cell disease?

KQ3. What is the utilization of covered services by Medicaid members with sickle cell disease?

KQ4. 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, HSAG referenced the American Society of Hematology clinical guidelines;[4-8] the National Heart, Lung, and Blood Institute (NHLBI) guidelines;[9] and the Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017 by the Centers for Medicare & Medicaid Services (CMS).[2] 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 most recent published clinical guidelines.
- Antibiotic prophylaxis should be administered until 5 years of age 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. There are not currently additional medications, treatments, or services that need to be added for coverage, but it should be noted that voxelotor (Oxbryta®) was voluntarily removed from the market in September of 2024.[10] In 2025, Louisiana Medicaid began participation in CMS' CGT Access Model with the goal of improving access to CGTs, such as lovotibeglogene autotemcel (LYFGENIA®) and exagamglogene autotemcel (CASGEVY®), for patients with SCD.[11,12]

Table 1—Summary of Louisiana Medicaid Coverage of Recommended Treatments for SCD[12]

Treatment	Treatment Indication	Age Group	Covered[a]
Hydroxyurea (Droxia®, Hydrea®, Siklos®, or Xromi®)[b]	Disease-modifying therapy	All ages	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 ages	Yes
Penicillin	Reduce infection risk	All ages	Yes
Vaccinations	Reduce infection risk	All ages	Yes
Transfusions	Reduce complications	All ages	Yes
Stem cell transplant	Curative	All ages	Yes

Table 1—Summary of Louisiana Medicaid Coverage of Recommended Treatments for SCD[12]			
Treatment	**Treatment Indication**	**Age Group**	**Covered[a]**
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. Xromi® is a registered trademark of Nova Bio-Pharm Technologies, Ltd.

[c] Oxbryta® is a registered trademark of Global Blood Therapeutics, Inc. Note: Oxbryta was voluntarily removed from the market in September 2024.[10]

[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, behavioral health services, and rehabilitation and other therapies.[13] Members may also qualify for and receive care management through their Medicaid managed care organization (MCO). Lastly, all children younger than 21 years of age are entitled to receive all medically necessary care through the Early and Periodic Screening, Diagnostic, and Treatment benefit.[14]

Methodology

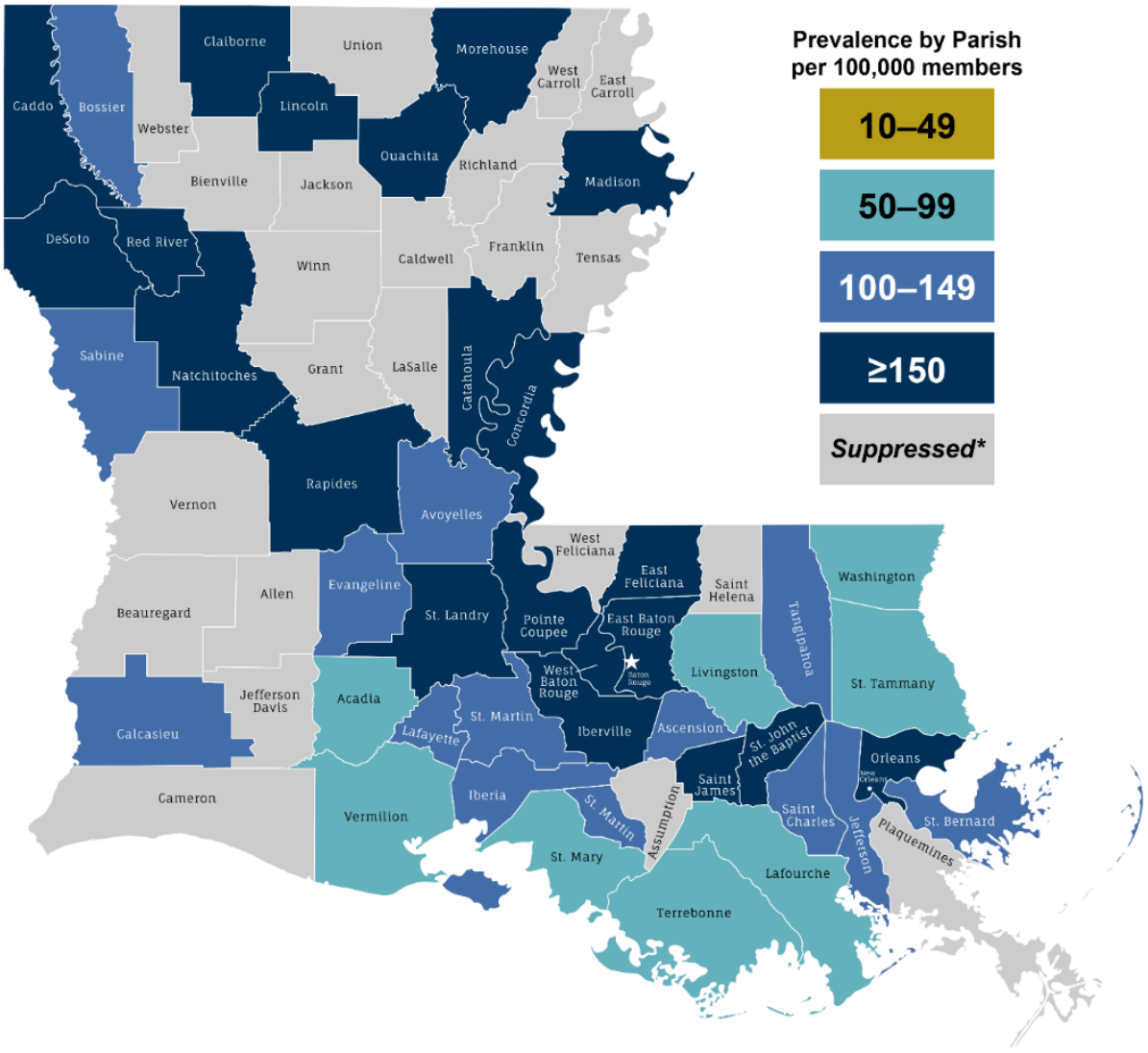
LDH contracted with its external quality review organization (EQRO), HSAG, to conduct a review of all medications and forms of treatment for SCD that are eligible for coverage under the Louisiana Medicaid managed care program. For this updated report, HSAG conducted a targeted literature review and a review of the current SCD 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 2024. 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, member age was calculated as of the beginning of the year (January 1, 2024). Results with values less than 10 members were suppressed to protect the confidentiality of the members and are represented in the data tables as "Suppressed." The evaluation is limited to those individuals enrolled in a Louisiana Medicaid managed care health plan with a sickle cell diagnosis of Hb-SS disease with crisis, sickle-cell disease without crisis, sickle-cell/Hb-C disease, sickle-cell thalassemia, or other sickle-cell disorders.

To gain more insight into the higher rates of ED visits and hospital stays for members with SCD, ULM reviewed the principal International Classification of Diseases, 10th revision, Clinical Modification (ICD-10-CM) diagnosis codes for each encounter, defined as the code in the first diagnosis field. These principal diagnosis codes are summarized under the associated three-character diagnosis codes (e.g., D57.00, D57.1, D57.219, etc., are summarized under the three-character code of D57).

Parish-Level Counts and Prevalence in CY 2024

The Louisiana Medicaid member population with SCD is not distributed evenly across the state. In CY 2024, the overall prevalence rate of SCD per 100,000 members in Louisiana was 148.4 (Figure 1). The parishes with the highest prevalence rate of SCD per 100,000 members (all ages) in descending order were Madison, Claiborne, Morehouse, Caddo, Red River, and DeSoto. 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 in descending order were Orleans, East Baton Rouge, Caddo, Jefferson, Ouachita, and Lafeyette. Each of these parishes had more than 100 members with SCD. Full data tables with parish-level counts and prevalence data are available in Appendix A—Parish-Level Counts and Prevalence Table.

Figure 1—SCD Prevalence by Parish



* "Suppressed" is displayed for parishes with less than 10 members with SCD so the results are not included in order to protect the confidentiality of those members.

Children

Section 1.1—Medicaid Enrollment of Children With Sickle Cell Disease

There were 1,333 children with SCD enrolled in a Medicaid MCO for full-benefit coverage during CY 2024. Almost all the children (93.5%) 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 2024 Louisiana Children With SCD

Duration of Louisiana Medicaid Enrollment[a]	Children With SCD, n	Total Enrolled, %
1–3 months	11	0.83%
4–6 months	35	2.6%
7–9 months	40	3.0%
10–12 months	1,247	93.5%
Total	1,333	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 0.16% of the Louisiana Medicaid population younger than 21 years of age. Of the children with SCD, 27.8% were between the ages of 0 and 5 years, 33.8% were between the ages of 6 and 12 years, and 38.3% were between the ages of 13 and 20 years (Table 3).

Table 3—Prevalence of SCD, CY 2024 Louisiana Children

Age Group[a]	Members < 21 Years, n	Total Enrolled, %
Ages < 21 years with SCD	1,333	0.16%
Ages 0–5 years	371	27.8%
Ages 6–12 years	451	33.8%
Ages 13–20 years	511	38.3%
Total enrollment, Louisiana Medicaid MCO full-benefit members < 21 years of age	843,375	100%

[a] For encounters in CY 2024.

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.[9] Approximately three out of every five (58.3%) children with SCD younger than 2 years of age received a pneumococcal vaccination. Just over one-fourth (25.2%) of members with SCD younger than 21 years of age received the influenza vaccination (Table 4).

Table 4—Receipt of Recommended Care: Infection Prevention, CY 2024 Louisiana Children With SCD

Recommended Care[a]	Members < 21 Years, n	Members Who Received Recommended Care, %
Ages < 21 years	1,333	-
Received the influenza vaccination	336	25.2%

Table 4—Receipt of Recommended Care: Infection Prevention, CY 2024 Louisiana Children With SCD		
Recommended Care[a]	**Members < 21 Years, n**	**Members Who Received Recommended Care, %**
Received at least one coronavirus disease 2019 (COVID-19) vaccination[b]	See footnote[c]	See footnote[c]
Ages < 2 years	115	-
Received at least one pneumococcal vaccination	67	58.3%

[a] All measures were calculated for encounters in CY 2024.

[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.

[c] Less than 10 members are in this category, so the results are not included in order to protect the confidentiality of those members.

The purpose of prophylactic antibiotic therapy in children with SCD is to reduce the risk of pneumococcal infection.[9] Approximately 8.4% of children with SCD ages 3 months to 4 years received antibiotic prophylaxis, defined as at least a 300-day supply. Most children with SCD in this age group (82.9%) received at least a one-day supply of antibiotic prophylaxis (Table 5). Due to the data limitations, the rationale for the use of antibiotics and other clinical factors, excluding antibiotic use (e.g., drug allergies or other contraindications), cannot be determined.

Table 5—Days' Supply of Antibiotic Prophylaxis,[a] CY 2024 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 298 Children 3 Months to 4 Years With SCD,[b] (%)**
1–99 days	120 (48.6%)	40.3%
100–199 days	60 (24.3%)	20.1%
200–299 days	42 (17.0%)	14.1%
≥ 300 days	25 (10.1%)	8.4%
Total	247 (100.0%)	82.9%

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

[b] 298 members with SCD were between 3 months and 4 years of age (22.4% of total members with SCD under 21 years of age). Of these, 247 had at least a one-day supply of antibiotic prophylaxis (82.9% 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.[9] The currently available disease-modifying therapies include hydroxyurea, L-glutamine oral powder, and crizanlizumab, and voxelotor (voluntarily withdrawn from the market in September 2024). For CY 2024, voxelotor was approved in children 4 years of age and older,[15] L-glutamine oral powder was approved in children 5 years of age and older,[16] and crizanlizumab was approved in children 16 years of age and older.[17] Hydroxyurea was recommended for patients 9 months to 20 years of age based on NHLBI guidelines;[9] however, recent approval in April 2024 of Xromi included an indication for pediatric patients 6 months of age and older.[18] CASGEVY[19] and LYFGENIA[20] were approved for use in children 12 years of age and older in December 2023.

Just over one-third of children between the ages of 6 months and 20 years (33.3%) filled a prescription for hydroxyurea; this percentage increased slightly when prescriptions for all disease-modifying agents were counted (35.1%). Filled prescriptions for disease-modifying therapies other than hydroxyurea were

relatively uncommon, with 8.9% of patients between the ages of 4 and 20 years filling a prescription for voxelotor and 1.1% of patients between the ages of 5 and 20 years filling a prescription for L-glutamine oral powder. Overall, prescribing practices for DMTs may differ based on the severity of the disease, tolerance to treatment, and individualized care plans. In CY 2024, no children with SCD were found to have utilized the new CGTs, which is expected given the decision to pursue this type of treatment is complex and the process may take up to a year to complete (Table 6).

Transfusions are indicated to treat severe uncompensated anemia, severe vaso-occlusive events (e.g., acute stroke or acute chest syndrome), and preoperatively.[5] Overall, 11.8% of children with SCD younger than 21 years of age received a blood transfusion, and 12 children (0.9%) received a stem cell transplant in CY 2024 (Table 6).

Table 6—Receipt of Recommended Care: Prevention and Treatment of Complications, CY 2024 Louisiana Children With SCD

Recommended Care[a]	Members < 21 Years, n	Members Who Received Recommended Care, %
Ages 6 months–20 years	1,296	-
Filled a prescription for hydroxyurea (Droxia, Hydrea, Siklos, or Xromi) ≥ 1 time[b]	432	33.3%
Filled a prescription for any approved disease-modifying agent ≥ 1 time	455	35.1%
Ages 4–20 years	1,089	-
Filled a prescription for voxelotor (Oxbryta) ≥ 1 time[c]	97	8.9%
Ages 5–20 years	1,019	-
Filled a prescription for L-glutamine oral powder (Endari) ≥ 1 time	11	1.1%
Ages 16–20 years	330	-
Filled a prescription for crizanlizumab (Adakveo) ≥ 1 time	See footnote[e]	See footnote[e]
Ages 12–20 years	577	-
Received a CGT (exagamglogene autotemcel [CASGEVY] or lovotibeglogene autotemcel [LYFGENIA])[d]	0	0%
Received a blood transfusion	157	11.8%
Received a stem cell transplant	12	0.9%
Ages < 21 years	1,333	100%

[a] All measures were calculated for encounters in CY 2024. The age ranges in this table are based on Food and Drug Administration (FDA) approvals.

[b] Data for ages 6 months to 20 years included, based on NHLBI guidelines and Xromi approval.

[c] Voluntarily withdrawn from market in September 2024.

[d] The CGTs CASGEVY and LYFGENIA were approved for use in children 12 years of age and older in December 2023.

[e] Less than 10 members are in this category, so the results are not included in order to protect the confidentiality of those members.

Section 1.4—Healthcare Utilization

The National Academies of Sciences, Engineering, and Medicine recommend that individuals with SCD have both a PCP and an SCD specialist co-manage their care.[21] Among members with SCD younger than 21 years of age, 96.7% had at least one PCP visit, and 57.9% had at least one hematologist visit in CY 2024.

However, 74.1% had at least two outpatient visits with the same PCP, and 33.6% had at least two outpatient visits with the same hematologist in CY 2024 (Table 7).

Table 7—Receipt of Recommended Care: Healthcare Utilization, CY 2024 Louisiana Children With SCD

Recommended Care[a]	Members < 21 Years, n	Members Who Received Recommended Care, %
Had at least one PCP visit	1,289	96.7%
Had at least one hematologist visit	772	57.9%
Had ≥ 2 outpatient visits with the same PCP	988	74.1%
Had ≥ 2 outpatient visits with the same hematologist	448	33.6%
Ages < 21 years	1,333	100%

[a] All measures were calculated for encounters in CY 2024.

For members with SCD, acute vaso-occlusive episodes (VOEs) that do not respond to or cannot be managed with disease-modifying therapies may lead to ED visits and inpatient hospitalizations. Approximately 75.6% of members with SCD younger than 21 years of age had at least one ED visit, compared to 31.5% of members younger than 21 years of age without SCD. Among members younger than 21 years of age, about one in eight (12.6%) members with SCD had six or more ED visits during CY 2024, compared to approximately one in 116 (0.86%) for members of the same age without SCD. Among members younger than 21 years of age, members with SCD had an average of 2.9 ED visits in CY 2024, while members without SCD had an average of 0.57 ED visits. In terms of ED visits for VOE specifically, members with SCD younger than 21 years of age had an average of 1.6 ED visits during CY 2024 (Table 8).

Table 8—Number of ED Visits,[a] CY 2024 Louisiana Children

ED Visits	Members < 21 Years With SCD, %		Members < 21 Years Without SCD, %– All-Cause
	All-Cause	VOE	
Members with 0 ED visits	24.4%	53.8%	68.7%
Members with ≥ 1 ED visit	75.6%	46.2%	31.5%
Members with 1 ED visit	24.1%	20.4%	18.8%
Members with 2–5 ED visits	38.9%	19.9%	11.9%
Members with ≥ 6 ED visits	12.6%	5.9%	0.86%
Mean number of ED visits during the year	2.9	1.6	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, 37.4% had at least one inpatient hospital stay in CY 2024, compared to 2.6% of children without SCD. About one in 50 (1.9%) children with SCD had six or more hospital stays during the year, compared to approximately one in 5,000 (0.02%) children without SCD. Among members younger than 21 years of age in CY 2024, the average number of inpatient hospital days for members with SCD was 3.3 days, compared to 0.19 days for members without SCD (Table 9).

Table 9—Number of Inpatient Hospital Stays,[a] CY 2024 Louisiana Children		
Hospital Stays	**Members < 21 Years With SCD, %**	**Members < 21 Years Without SCD, %**
Members with 0 hospital stays	62.6%	97.5%
Members with ≥ 1 hospital stay	37.4%	2.6%
Members with 1 hospital stay	21.6%	2.2%
Members with 2–5 hospital stays	13.9%	0.40%
Members with ≥ 6 hospital stays	1.9%	0.02%
Mean number of hospital days during the year	3.3	0.19

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

Principal diagnosis codes for sickle-cell disorders (D57) account for 51.1% of ED visits and 70.7% of hospital stays for children with SCD. Most of the remaining principal diagnosis codes for children with SCD were related to infections. Of the ED visits and hospital stays for sickle-cell disorders (D57) for children with SCD, most had a diagnosis specifying crisis or acute chest syndrome (83.7% for ED visits and 91.7% for hospital stays). Data tables with the top three-character diagnosis codes for ED visits and hospital stays for children with SCD are available in Appendix B—Top Diagnosis Codes for ED Visits and Hospital Stays Among Children With SCD.

Section 1.5—Preventive Care

The American Academy of Pediatrics recommends that children 3 years of age and older should have one health screening per year, while children younger than 3 years of age should have more frequent screenings.[22] Additionally, the NHLBI guidelines recommend TCD ultrasound screenings to evaluate stroke risk.[9]

Around three out of every five (58.4%) members with SCD younger than 21 years of age received at least one health screening in CY 2024. Among children ages 2 to 16 years with SCD, 17.2% received at least one TCD screening of some kind. Actual rates of screening among children for whom the screening is indicated may be higher since the data used for this analysis include all types of SCD and are not limited to the specific types for which annual screening is recommended. Additionally, all children should have dental examinations every six months beginning no later than their first birthday.[23] However, 57.7% of members with SCD between the ages of 2 and 20 years had at least one dental exam in CY 2024 (Table 10).

Table 10—Receipt of Recommended Care: Preventive Care, CY 2024 Louisiana Children With SCD		
Recommended Care[a]	**Members < 21 Years, n**	**Members Who Received Recommended Care, %**
Ages < 21 years	1,333	-
Had at least one health screening	778	58.4%
Ages 2–16 years	944	-
Received any TCD screenings	162	17.2%
Ages 2–20 years	1,218	-
Had at least one dental exam	703	57.7%

[a] All measures were calculated for encounters in CY 2024.

Adults

Section 1.6—Continuous Enrollment of Adults With Sickle Cell Disease

A total of 1,185 adults with SCD were enrolled in Louisiana Medicaid during CY 2024. Most adults (82.1%) 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 2024 Louisiana Adults With SCD

Duration of Louisiana Medicaid Enrollment[a]	Adults With SCD, n	Total Enrolled, %
1–3 months	41	3.5%
4–6 months	75	6.3%
7–9 months	96	8.1%
10–12 months	973	82.1%
Total	1,185	-

[a] Adults 21 years of age and older were included.

Section 1.7—Prevalence of Sickle Cell Disease and Age Distribution

Adults with SCD comprise 0.14% of the Medicaid population 21 years of age and older. Of the adults with SCD, 82.2% were between the ages of 21 and 45 years, and 17.8% were between the ages of 46 and 75 years (Table 12).

Table 12—Prevalence of SCD, CY 2024 Louisiana Adults

Age Group[a]	Members ≥ 21 Years, n	Total Enrolled, %
Ages ≥ 21 years with SCD	1,185	0.14%
Ages 21–45 years	974	82.2%
Ages 46–75 years	211	17.8%
Total enrollment, Louisiana Medicaid MCO full-benefit members ≥ 21 years of age	853,328	100%

[a] For encounters in CY 2024.

Section 1.8—Receipt of Recommended Care

Infection Prevention

According to the 2024 Centers for Disease Control and Prevention (CDC) immunization schedule, adults with SCD should get all recommended vaccinations, including a yearly influenza vaccination and the COVID-19 vaccination.[24] However, approximately one in six adults with SCD (16.5%) received an influenza vaccination. The COVID-19 vaccine was received by approximately 2.0% of adults with SCD (Table 13).

Table 13—Receipt of Recommended Care: Infection Prevention, CY 2024 Louisiana Adults With SCD

Recommended Care[a]	Members ≥ 21 Years, n	Members Who Received Recommended Care, %
Ages ≥ 21 years	1,185	-
Received the influenza vaccination	196	16.5%
Received at least one COVID-19 vaccination	24	2.0%

[a] All measures were calculated for encounters in CY 2024.

[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.

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.[9] The currently available disease-modifying therapies include hydroxyurea, voxelotor (voluntarily withdrawn from market in September 2024), L-glutamine oral powder, and crizanlizumab. The CGTs CASGEVY and LYFGENIA were approved for use in December 2023. In CY 2024, 399 adults with SCD (33.7%) 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 5.3% of adults with SCD filling a prescription for voxelotor, 4.1% filling a prescription for crizanlizumab, and 2.0% filling a prescription for L-glutamine oral powder. In addition, the CGTs were not utilized, which was expected given the decision to pursue this type of treatment is complex and the process may take up to a year to complete (Table 14).

Transfusions are indicated to treat severe uncompensated anemia, severe vaso-occlusive events (e.g., acute stroke or acute chest syndrome), and preoperatively.[5] A blood transfusion was received by 15.6% of adults with SCD (Table 14).

Table 14—Receipt of Recommended Care: Prevention and Treatment of Complications, CY 2024 Louisiana Adults With SCD

Recommended Care[a]	Members ≥ 21 Years, n	Members Who Received Recommended Care, %
Filled a prescription for hydroxyurea, voxelotor (Oxbryta), L-glutamine oral powder (Endari), or crizanlizumab (Adakveo) ≥ 1 time	399	33.7%
Filled a prescription for hydroxyurea (Droxia, Hydrea, or Siklos) ≥ 1 time	364	30.7%
Filled a prescription for voxelotor (Oxbryta) ≥ 1 time	63	5.3%
Filled a prescription for L-glutamine oral powder (Endari) ≥ 1 time	24	2.0%
Filled a prescription for crizanlizumab (Adakveo) ≥ 1 time	48	4.1%
Received a CGT (exagamglogene autotemcel [CASGEVY] or lovotibeglogene autotemcel [LYFGENIA])[b]	0	0.0%
Received a blood transfusion	185	15.6%
Received a stem cell transplant	See footnote[c]	See footnote[c]
Ages ≥ 21 years	1,185	100%

[a] All measures were calculated for encounters in CY 2024.

[b] The CGTs CASGEVY and LYFGENIA were approved for adult use in December 2023.

[c] Less than 10 members are in this category, so the results are not included in order to protect the confidentiality of those members.

Section 1.9—Healthcare Utilization

Individuals with SCD are recommended to have both a PCP and an SCD specialist co-manage their care.[21] Most (91.1%) adult members with SCD had at least one PCP visit, but approximately one in five (18.9%) had at least one hematologist visit in CY 2024. Nearly three-quarters of the adult members with SCD (73.6%) had two or more outpatient visits with the same PCP, but approximately one in 10 (10.0%) had two or more outpatient visits with the same hematologist (Table 15).

Table 15—Receipt of Recommended Care: Healthcare Utilization, CY 2024 Louisiana Adults With SCD		
Recommended Care[a]	**Members < 21 Years, n**	**Members Who Received Recommended Care, %**
Had at least one PCP visit	1,079	91.1%
Had at least one hematologist visit	224	18.9%
Had ≥ 2 outpatient visits with the same PCP	872	73.6%
Had ≥ 2 outpatient visits with the same hematologist	119	10.0%
Ages ≥ 21 years	1,185	100%

[a] All measures were calculated for encounters in CY 2024.

For members with SCD, acute VOEs that do not respond to or cannot be managed with disease-modifying therapies may lead to visits to the ED and hospital admissions. Among adults, 84.3% of members with SCD had at least one ED visit, compared to 38.5% of members without SCD. Approximately 29.5% of adults with SCD had six or more ED visits during CY 2024, compared to approximately 2.8% of adults without SCD. Among members 21 years of age and older, members with SCD had an average of 7.2 ED visits in CY 2024, while members without SCD averaged less than one (0.92) ED visit. Adults with SCD averaged 4.8 ED visits for VOE during CY 2024 (Table 16).

Table 16—Number of ED Visits,[a] CY 2024 Louisiana Adults			
ED Visits	**Members ≥ 21 Years With SCD, %**		**Members < 21 Years Without SCD, %– All-Cause**
	All-Cause	**VOE**	
Members with 0 ED visits	15.7%	50.7%	61.7%
Members with ≥ 1 ED visit	84.3%	49.3%	38.5%
Members with 1 ED visit	17.4%	15.1%	18.9%
Members with 2–5 ED visits	37.4%	16.1%	16.8%
Members with ≥ 6 ED visits	29.5%	18.0%	2.8%
Mean number of ED visits during the year	7.2	4.8	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, about half (48.6%) had at least one inpatient hospital stay in CY 2024, compared to 9.3% of adults without SCD (Table 17). Approximately one in 13 adults with SCD (7.4%) had six or more hospital stays during the year, compared to approximately one in 700 adults without SCD (0.14%). Among members 21 years of age and older, the average number of hospital days during the year for members with SCD was approximately 9.6 days, more than a full week longer than the average of 0.81 days for members without SCD (Table 17).

Table 17—Number of Inpatient Hospital Stays,[a] CY 2024 Louisiana Adults		
Hospital Stays	**Members ≥ 21 Years With SCD, %**	**Members < 21 Years Without SCD, %**
Members with 0 hospital stays	51.4%	90.8%
Members with ≥ 1 hospital stay	48.6%	9.3%
Members with 1 hospital stay	22.6%	7.4%
Members with 2–5 hospital stays	18.6%	1.8%
Members with ≥ 6 hospital stays	7.4%	0.14%
Mean number of hospital days during the year	9.6	0.81

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

Principal diagnosis codes for sickle-cell disorders (D57) accounted for 61.5% of ED visits and 67.0% of hospital stays for adults with SCD. Most of the remaining principal diagnosis codes for ED visits were related to other pain, infections, or maternal complications. Of the SCD-related adult ED visits and hospital stays, most had a diagnosis specifying crisis or acute chest syndrome (89.5% for ED visits and 99.2% for hospital stays). Adults with SCD were also hospitalized for infections; maternal care; type 1 diabetes; and behavioral health conditions, such as schizophrenia, schizoaffective disorders, bipolar disorder, and major depressive disorder. Data tables with the top three-character diagnosis codes for ED visits and hospital stays for adults with SCD are available in Appendix C—Top Diagnosis Codes for ED Visits and Hospital Stays Among Adults With SCD.

Discussion

The national data[2] available for comparison were from a different year (2017) than the Louisiana Medicaid data examined in this report (2024), and only included individuals with continuous enrollment. While these differences limit the ability to make direct comparisons, the national data indicated that Louisiana Medicaid members ages 2 to 16 years with SCD received fewer TCD ultrasound screenings (17.2%) compared to their counterparts across the country, United States Medicaid and CHIP members 3 to 16 years of age with SCD (36.6%). For all other comparisons, the rates between the national data and the Louisiana Medicaid data were similar.

The CMS Sickle Cell Disease Action Plan[25] was released in September 2023 and 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. Over three-fourths of Louisiana Medicaid-enrolled children with SCD (75.6%) had an ED visit in CY 2024, compared to 31.5% of Louisiana Medicaid-enrolled children without SCD. Similarly, in Louisiana Medicaid-enrolled adults with SCD, 84.3% had an ED visit, compared to 38.5% of adults without SCD. The percentage of Louisiana Medicaid members with at least one inpatient hospital stay was also much higher for members with SCD than for those without SCD in both adults and children.
    - SCD-related pain crises are the most frequent cause of ED visits and hospitalizations among members with SCD; increased utilization of hydroxyurea and other disease-modifying therapies identified in this report along with individualized pain management plans could reduce the frequency of ED and hospital visits.[4]
    - Other healthcare encounters are linked to conditions that may be preventable through targeted public health interventions. These include targeted outreach efforts to boost vaccination rates for influenza and COVID-19, as well as enhanced care coordination to reduce maternal complications such as anemia and behavioral health crises associated with conditions like schizophrenia and bipolar disorder. Chronic pain related to SCD may also play a role in triggering behavioral health crises.[26]
- Many individuals with SCD experience challenges during the transition from pediatric to adult care. In 2024, approximately 18.9% of Louisiana Medicaid-enrolled adults with SCD had at least one visit with a hematologist, compared to 57.9% of children with SCD. Similarly, just 10.0% of adults had two or more outpatient visits with the same hematologist, while 33.6% of children met that threshold—highlighting a significant drop in continuity of specialized care during the transition to adulthood.
- Gaps in the receipt of clinically recommended standard care, such as TCD ultrasound screenings for primary stroke prevention, remain a challenge for individuals with SCD. According to NHLBI guidelines, children ages 2 to 16 with sickle cell anemia, a specific form of SCD, should receive annual TCD screenings.[9] However, in 2024, approximately 17.2% of Louisiana Medicaid-enrolled children in this age group with SCD received the recommended screening, indicating a potential opportunity for improvement. However, the actual rates of screening among children for whom

the screening is indicated may be higher since the data used for this analysis include all types of SCD and are not limited to the specific types for which annual screening is recommended.

While this report examined CY 2024 data, the two CGTs approved in December 2023 were not yet utilized during that period. This is expected given that the decision to pursue this type of treatment is complex and the process may take up to a year to complete. Louisiana Medicaid's participation in CMS' CGT Access Model may help expand access to these innovative treatments moving forward.[11]

Study Strengths and Limitations

This report used claims data to assess the receipt of recommended care for SCD among Louisiana Medicaid members during CY 2024. Claims data offer several advantages, including broad coverage, cost-effectiveness, and the ability to track real-world healthcare utilization and patient care patterns over time. They also support benchmarking across populations using standardized information. 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)[2] than the study year (2024).
- The analysis does not differentiate between types of SCD, even though a higher proportion of individuals with less severe forms may help explain lower utilization rates for certain types of care. It is also important to note that the national comparison data are similarly not stratified by SCD type.
- 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. Likewise, claims data do not include indications for why medications or procedures may have been determined as inappropriate for the patient. This includes allergies to medications, contraindications, and individualized treatment plans.

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, pursuant to Act No. 670 (Senate Bill 298) of the 2022 Regular Louisiana Legislative Session,[1] LDH provided adequate coverage for all recommended medications, treatments, and services to meet the needs of Louisiana Medicaid members with SCD. Underutilization of services was identified and may represent opportunities to ensure that more adults and children with SCD receive the recommended care. These opportunities include, but are not limited to, the following:

- Although an annual TCD ultrasound screening is recommended to evaluate stroke risk for children with SCD 2 to 16 years of age, approximately 17.2% of members in this age group utilized this covered service. This finding warrants further study by SCD type.
- DMTs were used at least once by 35.1% of enrolled children with SCD and 33.7% of enrolled adults with SCD, which may represent an opportunity for improvement depending on clinical appropriateness and individual patient factors.
- Pneumococcal vaccination is a service intended to prevent severe bacterial infection, and it was provided to 58.3% of Louisiana Medicaid-enrolled children younger than 2 years of age who had SCD. Influenza vaccination was provided to 25.2% of Louisiana Medicaid-enrolled children and 16.5% of Louisiana Medicaid-enrolled adults.
- Routine preventive care with a hematologist to co-manage care was less common in adults with SCD (18.9%) than in children with SCD (57.9%), indicating potential challenges in transitions of care.
- Targeted public health strategies, such as outreach to improve vaccination rates and enhanced care coordination, could help reduce ED visits and hospitalizations by preventing infections, maternal complications, and behavioral health crises.

Due to limitations of the analysis, utilization rates identified in this report may not necessarily reflect poor provider performance but may be partially explained by varying severity of disease, clinical appropriateness, and patient factors. Further study of these factors and barriers to access is warranted to identify effective interventions to improve the quality of care for all members with SCD.

Recommendations

Medicaid members with SCD can benefit from additional assessments to identify barriers to care (e.g., geographic disparities in the availability of specialists). Interventions to increase access to a shared care model or other strategies to drive better integration of specialty and primary care merit exploration.[27] Given the lower rates of adult members with at least one hematologist visit compared to children, improving transitions from pediatric to adult care warrants consideration for a collaborative performance improvement project. MCO interventions to enhance case management and care coordination for members with SCD are merited. In addition, the co-located care delivery model with pediatric and adult providers practicing in the same location can improve continuity of care and ensure a smoother care transition for young adults.[28,29]

ED visits and inpatient hospitalizations were more common as expected for individuals with SCD than for those without. Increasing utilization of preventive care, such as TCD ultrasound screening, disease-modifying therapies, and vaccinations, may help to reduce these events. As LDH continues to update and revise their Louisiana Sickle Cell Disease Registry, it will be important to include surveillance for these preventive care measures to strengthen the ability of the care systems to support individuals with SCD to achieve their fullest health potential.[3] It is also important to educate providers about NHLBI guidelines which could improve delivery of clinically recommended standard of care.[30] For example, integrating a clinical decision support tool with best practice alerts into the existing electronic health records[31] could be applied to improve the use of TCD ultrasound screenings.

Louisiana Medicaid's continued participation in CMS' CGT Access Model will increase access to CGT treatments by introducing lower prices that will make it easier for Louisiana Medicaid to pay for these curative treatments. Within the model framework, CMS will negotiate pricing discounts and outcome-based rebates between pharmaceutical manufacturers and Louisiana Medicaid.[11] It is hoped that participation in CMS models that result in improved access to care at lower prices will translate into improved outcomes for Louisiana Medicaid members.

Appendix A—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	24,707	22	0.09%	89.0
Allen	8,159	See footnote[c]	See footnote[c]	See footnote[c]
Ascension	35,583	52	0.15%	146.1
Assumption	6,164	See footnote[c]	See footnote[c]	See footnote[c]
Avoyelles	16,472	23	0.14%	139.6
Beauregard	13,262	See footnote[c]	See footnote[c]	See footnote[c]
Bienville	5,799	See footnote[c]	See footnote[c]	See footnote[c]
Bossier	37,841	44	0.12%	116.3
Caddo	94,561	261	0.28%	276.0
Calcasieu	72,920	83	0.11%	113.8
Caldwell	4,545	See footnote[c]	See footnote[c]	See footnote[c]
Cameron	768	See footnote[c]	See footnote[c]	See footnote[c]
Catahoula	4,079	10	0.25%	245.2
Claiborne	4,946	15	0.30%	303.3
Concordia	9,073	18	0.20%	198.4
DeSoto	10,300	27	0.26%	262.1
East Baton Rouge	154,019	300	0.19%	194.8
East Carroll	3,308	See footnote[c]	See footnote[c]	See footnote[c]
East Feliciana	6,291	15	0.24%	238.4
Evangeline	13,701	14	0.10%	102.2
Franklin	9,544	See footnote[c]	See footnote[c]	See footnote[c]
Grant	7,434	See footnote[c]	See footnote[c]	See footnote[c]
Iberia	30,669	35	0.11%	114.1
Iberville	11,848	24	0.20%	202.6
Jackson	4,844	See footnote[c]	See footnote[c]	See footnote[c]
Jefferson	152,310	197	0.13%	129.3
Jefferson Davis	11,327	See footnote[c]	See footnote[c]	See footnote[c]
LaSalle	5,144	See footnote[c]	See footnote[c]	See footnote[c]
Lafayette	81,871	122	0.15%	149.0
Lafourche	28,991	20	0.07%	69.0
Lincoln	15,295	24	0.16%	156.9
Livingston	48,670	28	0.06%	57.5
Madison	5,359	24	0.45%	447.8
Morehouse	12,186	34	0.28%	279.0
Natchitoches	14,191	33	0.23%	232.5
Orleans	144,273	312	0.22%	216.3
Ouachita	67,869	125	0.18%	184.2
Plaquemines	6,793	See footnote[c]	See footnote[c]	See footnote[c]
Pointe Coupee	7,012	15	0.21%	213.9

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
Rapides	50,488	84	0.17%	166.4
Red River	3,626	10	0.28%	275.8
Richland	9,080	See footnote[c]	See footnote[c]	See footnote[c]
Sabine	8,742	11	0.13%	125.8
St. Bernard	20,156	29	0.14%	143.9
St. Charles	14,298	19	0.13%	132.9
St. Helena	3,178	See footnote[c]	See footnote[c]	See footnote[c]
St. James	6,992	14	0.20%	200.2
St. John The Baptist	18,219	39	0.21%	214.1
St. Landry	40,664	65	0.16%	159.8
St. Martin	18,902	24	0.13%	127.0
St. Mary	21,241	12	0.06%	56.5
St. Tammany	74,154	50	0.07%	67.4
Tangipahoa	60,493	64	0.11%	105.8
Tensas	1,844	See footnote[c]	See footnote[c]	See footnote[c]
Terrebonne	41,735	34	0.08%	81.5
Union	9,087	See footnote[c]	See footnote[c]	See footnote[c]
Vermilion	21,658	20	0.09%	92.3
Vernon	14,334	See footnote[c]	See footnote[c]	See footnote[c]
Washington	21,250	21	0.10%	98.8
Webster	15,245	See footnote[c]	See footnote[c]	See footnote[c]
West Baton Rouge	9,096	19	0.21%	208.9
West Carroll	4,742	See footnote[c]	See footnote[c]	See footnote[c]
West Feliciana	2,889	See footnote[c]	See footnote[c]	See footnote[c]
Winn	4,899	See footnote[c]	See footnote[c]	See footnote[c]
Unknown[b]	7,563	See footnote[c]	See footnote[c]	See footnote[c]
Louisiana (Total)	1,696,703	2,518	0.15%	148.4

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

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

[c] Less than 10 members are in this category, so the results are not included in order to protect the confidentiality of those members.

Appendix B—Top Diagnosis Codes for ED Visits and Hospital Stays Among Children With SCD

Table B-1—ED Visits: Top Three-Character Principal ICD-10-CM Diagnosis Codes, CY 2024 Louisiana Children With SCD

Rank	Principal Diagnosis Code	Diagnosis Code Description	Number of Encounters, n	Percentage of Total Encounters, %[a]
1	D57	Sickle-cell disorders	1,757	51.1%
2	J06	Acute upper respiratory infections of multiple and unspecified sites	86	2.5%
2	R50	Fever of other and unknown origin	86	2.5%
3	J02	Acute pharyngitis	75	2.2%
4	B34	Viral infection of unspecified site	65	1.9%
5	R10	Abdominal and pelvic pain	55	1.6%
6	J18	Pneumonia, unspecified organism	48	1.4%
7	M79	Other and unspecified soft tissue disorders, not elsewhere classified	46	1.3%
7	U07	COVID-19	46	1.3%
8	K59	Other functional intestinal disorders	45	1.3%
9	R07	Pain in throat and chest	43	1.3%
10	J10	Influenza due to other identified influenza virus	37	1.1%

[a] Percentage is out of 3,437 total encounters.

Table B-2—Hospital Stays: Top Three-Character Principal ICD-10-CM Diagnosis Codes, CY 2024 Louisiana Children With SCD

Rank	Principal Diagnosis Code	Diagnosis Code Description	Number of Encounters, n	Percentage of Total Encounters, %[a]
1	D57	Sickle-cell disorders	624	70.7%
2	J18	Pneumonia, unspecified organism	23	2.6%
3	A41	Other sepsis	16	1.8%
4	O99	Other maternal diseases classifiable elsewhere but complicating pregnancy, childbirth and the puerperium	13	1.5%
5	J10	Influenza due to other identified influenza virus	10	1.1%

[a] Percentage is out of 883 total encounters.

Note: Ranks 6–10 include multiple diagnosis codes, all with fewer than 10 encounters each, which are suppressed so the results are not included in order to protect the confidentiality of those members.

Appendix C—Top Diagnosis Codes for ED Visits and Hospital Stays Among Adults With SCD

Table C-1—ED Visits: Top Three-Character Principal ICD-10-CM Diagnosis Codes, CY 2024 Louisiana Adults With SCD

Rank	Principal Diagnosis Code	Diagnosis Code Description	Number of Encounters, n	Percentage of Total Encounters, %[a]
1	D57	Sickle-cell disorders	4,254	61.5%
2	R07	Pain in throat and chest	202	2.9%
3	M54	Dorsalgia	108	1.6%
4	R10	Abdominal and pelvic pain	79	1.1%
5	O99	Other maternal diseases classifiable elsewhere but complicating pregnancy, childbirth and the puerperium	72	1.0%
6	M79	Other and unspecified soft tissue disorders, not elsewhere classified	71	1.0%
7	M25	Other joint disorder, not elsewhere classified	67	0.97%
8	N39	Other disorders of urinary system	59	0.85%
9	J06	Acute upper respiratory infections of multiple and unspecified sites	53	0.77%
10	O26	Maternal care for other conditions predominantly related to pregnancy	51	0.74%

[a] Percentage is out of 6,920 total encounters.

Table C-2—Hospital Stays: Top Three-Character Principal ICD-10-CM Diagnosis Codes, CY 2024 Louisiana Adults With SCD

Rank	Principal Diagnosis Code	Diagnosis Code Description	Number of Encounters, n	Percentage of Total Encounters, %[a]
1	D57	Sickle-cell disorders	1,022	67.0%
2	A41	Other sepsis	54	3.5%
3	O99	Other maternal diseases classifiable elsewhere but complicating pregnancy, childbirth and the puerperium	50	3.3%
4	F20	Schizophrenia	31	2.0%
5	F25	Schizoaffective disorders	29	1.9%
6	F31	Bipolar disorder	22	1.4%
7	O34	Maternal care for abnormality of pelvic organs	14	0.92%
8	E10	Type 1 diabetes mellitus	13	0.85%
9	F33	Major depressive disorder, recurrent	11	0.72%

[a] Percentage is out of 1,525 total encounters.

Note: Rank 10 includes multiple diagnosis codes, all with fewer than 10 encounters each, which are suppressed so the results are not included in order to protect the confidentiality of those members.

Bibliography

1. Legislature of Louisiana. *Lorri Burgess' Law, Act No. 670, 2022 Regular Session, Senate Bill No. 298*. 2022. https://www.legis.la.gov/legis/ViewDocument.aspx?d=1290057
2. Wilson-Frederick SM, Hulihan M, Magnum T, et al. *Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017.* Baltimore, MD: Centers for Medicare & Medicaid Services; 2023. https://www.medicaid.gov/medicaid/quality-of-care/downloads/scd-rpt-mar-2023.pdf.
3. Louisiana Department of Health. Louisiana Sickle Cell Disease Registry. Baton Rouge, LA; 2025. https://ldh.la.gov/page/sickle-cell-disease-database-Louisiana.
4. Brandow AM, Carroll CP, Creary S, et al. American Society of Hematology 2020 guidelines for sickle cell disease: management of acute and chronic pain. *Blood Advances.* 2020;4(12):2656-2701. doi: 10.1182/bloodadvances.2020001851.
5. Chou ST, Alsawas M, Fasano RM, et al. American Society of Hematology 2020 guidelines for sickle cell disease: transfusion support. *Blood Advances.* 2020;4(2):327-355. doi: 10.1182/bloodadvances.2019001143.
6. DeBaun MR, Jordan LC, King AA, et al. American Society of Hematology 2020 guidelines for sickle cell disease: prevention, diagnosis, and treatment of cerebrovascular disease in children and adults. *Blood Advances.* 2020;4(8):1554-1588. doi: 10.1182/bloodadvances.2019001142.
7. Liem RI, Lanzkron S, T DC, et al. American Society of Hematology 2019 guidelines for sickle cell disease: cardiopulmonary and kidney disease. *Blood Adv.* 2019;3(23):3867-3897. doi: 10.1182/bloodadvances.2019000916.
8. Kanter J, Liem RI, Bernaudin F, et al. American Society of Hematology 2021 guidelines for sickle cell disease: stem cell transplantation. *Blood Advances.* 2021;5(18):3668-3689. doi: 10.1182/bloodadvances.2021004394.
9. National Institutes of Health, National Heart Lung and Blood Institute. *Evidence-Based Management of Sickle Cell Disease Expert Panel Report*. 2014. https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease
10. Pfizer Inc. Pfizer Voluntarily Withdraws All Lots of Sickle Cell Disease Treatment OXBRYTA® (Voxelotor) From Worldwide Markets. 2024. https://www.pfizer.com/news/press-release/press-release-detail/pfizer-voluntarily-withdraws-all-lots-sickle-cell-disease.
11. Centers for Medicare & Medicaid Services. CGT (Cell and Gene Therapy) Access Model. Baltimore, MD; 2025. https://www.cms.gov/priorities/innovation/innovation-models/cgt.
12. Louisiana Department of Health. *Louisiana Medicaid Preferred Drug List (PDL)/Non-Preferred Drug List (NPDL).* 2025. https://ldh.la.gov/assets/HealthyLa/Pharmacy/PDL.pdf.
13. Louisiana Department of Health. *Medicaid Services Chart.* Baton Rouge, LA 2025. https://ldh.la.gov/assets/docs/Making_Medicaid_Better/Medicaid_Services_Chart.pdf.
14. Centers for Medicare & Medicaid Services. Early and Periodic Screening, Diagnostic, and Treatment. Baltimore, MD: Centers for Medicare & Medicaid Services; 2025. https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html.
15. Oxbryta. Package insert. Pfizer Inc; 2023.
16. Endari. Package insert. Emmaus Medical Inc; 2020.
17. Adakveo. Package insert. Novartis Pharmaceuticals Corporation; 2024.
18. Xromi. Package Insert. Nova Bio-Pharm Technologies Ltd; 2024.
19. Casgevy. Package insert. Vertex Pharmaceuticals Inc; 2024.
20. Lyfgenia. Package insert. bluebird bio Inc; 2023.
21. National Academies of Sciences Engineering and Medicine. *Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action.* Washington, DC: The National Academies Press; 2020.

22. American Academy of Pediatrics. *Recommendations for Preventive Pediatric Health Care.* Itasca, Il: American Academy of Pediatrics; 2025. https://www.aap.org/en/practice-management/care-delivery-approaches/periodicity-schedule/.
23. American Academy of Pediatric Dentistry. Periodicity of examination, preventive dental services, anticipatory guidance/counseling, and oral treatment for infants, children, and adolescents. The Reference Manual of Pediatric Dentistry. Chicago, Il: American Academy of Pediatric Dentistry; 2022:253-265.
24. Centers for Disease Control and Prevention. Recommended Adult Immunization Schedule for Ages 19 Years or Older. 2024. https://www.cdc.gov/vaccines/hcp/imz-schedules/downloads/past/2024-adult.pdf.
25. Centers for Medicare & Medicaid Services. *Action Plan: CMS Sickle Cell Disease.* Baltimore, MD: US Department of Health & Human Services; 2023. https://www.cms.gov/files/document/sickle-cell-disease-action-plan.pdf.
26. Wilson SR. Mental health disorders are prevalent and influence outcomes in patients with sickle cell disease. *The Hematologist.* 2023;20(6). doi: 10.1182/hem.V20.6.202366.
27. Center for Medicare & Medicaid Innovation. *Person-Centered Innovation – An Update on the Implementation of the CMS Innovation Center's Strategy.* Baltimore, MD: US Department of Health and Human Services; 2022.
28. Howell KE, Saulsberry-Abate AC, Mathias JG, et al. Transition care continuity promotes long-term retention in adult care among young adults with sickle cell disease. *Pediatric Blood & Cancer.* 2021;68(10):e29209. doi: 10.1002/pbc.29209.
29. Madrazo-Aguirre K, Ribeil J, Sobata AE. Initial outcomes in a sickle cell disease transition clinic. *Health Care Transitions.* 2024;2(2024):100056. doi: 10.1016/j.hctj.2024.100056.
30. Smeltzer MP, Howell KE, Treadwell M, et al. Identifying barriers to evidence-based care for sickle cell disease: results from the Sickle Cell Disease Implementation Consortium cross-sectional survey of healthcare providers in the USA. *BMJ Open.* 2021;11(11):e050880. doi: 10.1136/bmjopen-2021-050880.
31. Mainous AG, 3rd, Carek PJ, Lynch K, et al. Effectiveness of clinical decision support based intervention in the improvement of care for adult sickle cell disease patients in primary care. *Journal of the American Board of Family Medicine.* 2018;31(5):812-816. doi: 10.3122/jabfm.2018.05.180106.

Louisiana Department of Health
628 N. 4th St., Baton Rouge, LA 70802
225-342-9500
ldh.la.gov

@ladepthealth