2025 Sickle Cell Task Force Annual Report

As Required by
Texas Health and Safety Code,
Section 52.007

December 2025

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Executive Summary

Texas Health and Safety Code, Section 52.0007, requires the Sickle Cell Task Force (Task Force) to report on their work and recommend actions or policy changes, including recommendations on improving sickle cell disease (SCD) education for health care providers. The report is due to the Governor and Texas Legislature annually by December 1.

The purpose of the Task Force is to raise awareness of SCD and sickle cell trait (SCT). The Task Force also advises the Texas Department of State Health Services (DSHS) on implementing recommendations made in the 2018 Sickle Cell Advisory Committee Report or any other report the Texas Health and Human Services Commission (HHSC) Executive Commissioner determines appropriate.

This report provides updates on the Task Force's work with DSHS to implement 2018 recommendations. The Task Force also proposes the following recommended actions for 2025:

- Update Managed Care Organization (MCO) contract definition of Members with Special Health Care Needs (MSHCN) to specifically include SCD as an inclusion criterion.
- Evaluate options to increase Medicaid and Children's Health Insurance Program (CHIP) eligibility for individuals diagnosed with SCD until age 26 years.
- Use available resources to study the development of comprehensive medical home models and ways to create and fund comprehensive sickle cell care centers as a quality improvement project.
- Partner with Medicaid and CHIP Services to pursue SCD-specific quality metrics through one or more of Texas Medicaid's quality improvement programs.
- Develop sickle cell quality care plans for Medicaid and private payors.
- Update Texas Health Steps Online Provider Education module on SCD so it is more comprehensive and is eligible for continuing education (CE) credit.

- Update the Texas Health Steps Periodicity Schedule to include SCT counseling for teenagers who were diagnosed with SCT at birth or have unknown status.
- Study the feasibility of a state-level sickle cell quality rating system for health care facilities.
- Collaborate with HHSC to incorporate a reporting process for sickle cell care provided by health care facilities into an existing statewide system.
- Develop partnerships with Texas colleges and universities to create sickle cell awareness campaigns and identify funding for statewide awareness activities.
- Continue to support the efforts of the Texas Sickle Cell Data Collection (SCDC) Program to expand current data collection activities.

Introduction

SCD is the most common inherited blood disorder in the United States. The number of people living with SCD is expected to grow 30 percent by 2050.[1] SCD is caused by an abnormal protein, sickle hemoglobin, inside of the red blood cell. In people without SCD, hemoglobin carries oxygen to organs, muscles, and the brain to support normal body processes. However, in people with SCD, the red blood cell changes into a sickle shape. Sickle hemoglobin causes red blood cells to break down too fast, causing anemia (a low number of blood cells). Also, sickled red blood cells are no longer flexible and are unable to flow normally through blood vessels. This results in blockages leading to pain, organ damage, and stroke.

In 2015, the Texas Legislature established the Sickle Cell Advisory Committee to raise SCD and SCT awareness in Texas. The Sickle Cell Advisory Committee developed recommendations, including one to establish a Task Force to continue committee work. When the Sickle Cell Advisory Committee ended in 2018, new legislation established the Task Force. Over the past six years, the Task Force worked with DSHS to further explore implementation of Sickle Cell Advisory Committee recommendations regarding:

- A statewide public awareness campaign;
- Development of statewide SCD surveillance;
- Collaboration with Community Health Workers (CHWs); and
- Partnering with Medicaid and Medicare managed care and accountable care organizations.

Today, more than 90 percent of children with SCD will survive to adulthood. Unfortunately, the survival rate for adults with SCD still remains lower than adults who do not have SCD.[2] In a 2023 study of 2016-2018 Medicare and Medicaid data,

[1] Piel FB, Hay SI, Gupta S, Weatherall DJ, Williams TN. Global burden of sickle cell anaemia in children under five, 2010–2050: modelling based on demographics, excess mortality, and interventions. *PLoS Medicine*. 2013;10(7):e1001484. doi:10.1371/journal.pmed.1001484. Accessed September 19, 2025.
[2] Quinn CT, Rogers ZR, McCavit TL, Buchanan GR. Improved survival of children and adolescents with sickle cell disease. Blood. 2010;115(17):3447-3452. doi:10.1182/blood.V112.11.1425.1425. Accessed September 19, 2025.

individuals with SCD had an estimated life expectancy of 52.6 years, more than 20 years less than the national average.[3,4]

Many SCD patients do not receive recommended care.

- Antibiotic prophylaxis is recommended starting at two months to five years of age to reduce the risk of pneumococcal sepsis, a major cause of morbidity and mortality in infants and young children with SCD. However, 11 percent of eligible children with Medicaid received antibiotics.[5]
- The National Institutes of Health recommends using transcranial doppler ultrasound (examines blood flow in the brain) to identify children at risk of stroke from the ages of two to 16 years, but fewer than 36 percent receive the test annually.[6]
- Finally, the use of hydroxyurea, the only disease modifying therapy available for children starting at nine months of age, was prescribed in only 37 percent of children with SCD receiving Medicaid and CHIP.[7]

Serious gaps exist in the care received by children and adults with SCD, justifying the need for a Task Force to highlight activities and actions aimed at improving care and correcting gaps.

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[3] Boshen Jiao, Kate M. Johnson, Scott D. Ramsey, M. A. Bender, Beth Devine, Anirban Basu. Long-term survival with sickle cell disease: a nationwide cohort study of Medicare and Medicaid beneficiaries. Blood Adv. 2023; 7 (13): 3276–3283. doi:10.1182/bloodadvances.2022009202. Accessed September 19, 2025.

[4] Centers for Medicare & Medicaid Services. Improving Care for Sickle Cell Disease. Medicaid.gov website. https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement-initiatives/improving-care-for-sickle-cell-disease Accessed September 18, 2025

[5] Wilson-Frederick S, Hulihan M, Mangum A, et al. Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017. Center for Medicaid and CHIP Services, Division of Quality and Health Outcomes, Centers for Medicare & Medicaid Services; 2021. Accessed September 18, 2025. https://www.medicaid.gov/medicaid/quality-of-care/downloads/scd-rpt-jan-2021.pdf

[6] Ibid.

[7] Ibid.

Task Force Actions and Future Work

The following summarizes Task Force work since the 2024 annual report, including efforts to:

- Study the 2018 Sickle Cell Advisory Committee recommendations;
- Develop recommendations on improving health care provider SCD education; and
- Collaborate with HHSC to:
  - Address Medicaid provider SCD education by promoting existing or new education courses or facilitating development of new courses;
  - Explore methods for improving public school system SCD education and awareness; and
  - Support evidence-informed health care service initiatives for SCD.

Progress on 2018 Recommendations

Establish a Sickle Cell Task Force

House Bill (HB) 3405, 86th Legislature, Regular Session, 2019, established the Task Force. Task Force annual reports (2020, 2021, 2022, 2023, and 2024) summarize Task Force actions.

Refer to the DSHS Sickle Cell Task Force webpage for current Task Force members.

Develop Statewide Sickle Cell Awareness Campaigns

The Task Force and DSHS developed a Texas public awareness campaign in September 2021 that relaunches annually to promote sickle cell awareness during the national and state-designated Sickle Cell Awareness Month. The campaign includes SCD education information, patient experiences, and how the public can provide support through blood donations and hemoglobin testing. The Task Force also worked with DSHS on Texas public awareness articles for World Sickle Cell Day on June 19, 2025.

See Appendix A for more information.

Begin Statewide Sickle Cell Surveillance Throughout the Lifespan

In 2023, DSHS applied for and received funding from the Centers for Disease Control and Prevention (CDC) related to sickle cell data collection. The CDC program funds 16 states to support state-level sickle cell data collection to serve as a foundation for the development of ongoing surveillance.[8] DSHS has started the data collection process, and Task Force members serve on project multi-disciplinary project team.

As a result of Texas SCDC program activities, DSHS will better understand the number of individuals with SCD in Texas, describe their demographics, understand use of health care, and evaluate SCD outcomes.

In 2025, the Texas SCDC program published the following report:

- Emergency Department Visits by Individuals with Sickle Cell Disease in Texas, 2023.

Texas SCDC will continue working on other reports that explore the impact of sickle cell disease on patients.

Texas SCDC received approval from the DSHS Institutional Review Board in 2025 to initiate access to the following data sources:

- Newborn screening data;
- Birth and death records; and
- Hospital and emergency discharge records.

Newborn screening records are the primary sources for identifying confirmed SCD cases. Texas SCDC will identify probable SCD cases through administrative data, including hospital and emergency discharge records. Birth and death records are supplementary data sources that provide additional information on sociodemographic and health characteristics throughout the lifespan. The intention is to share aggregate data with the public through data reports, briefs, and dashboards over the course of the grant timeline.

[8] Centers for Disease Control and Prevention. Sickle Cell Data Collection (SCDC) Program. Cdc.gov website. cdc.gov/sickle-cell/scdc/index.html. Published June 3, 2020. Updated August 1, 2024. Accessed August 19, 2024.

Finally, the 89th Legislature passed HB 107 to authorize the development of a sickle cell registry and appropriated $1 million to support implementation. DSHS is currently reviewing how best to utilize these funds to support sickle cell data collection.

Partner with Medicaid and Medicare Managed Care Organizations and Accountable Care Organizations

The Task Force continues to collaborate with HHSC Medicaid and CHIP Services to carry out duties established by HB 1488, 88th Legislature, Regular Session, 2023. See the updates under Medicaid Provider SCD Education for the latest activity.

Utilize Community Health Workers to Improve Care

The Task Force continues to collaborate with the DSHS Community Health Worker Program to discuss ways to improve SCD education among community health workers.

Medicaid Provider SCD Education

HB 1488 requires the Task Force to include recommendations for improving health care provider education and to collaborate with HHSC to address SCD education for Medicaid providers, including emergency department providers.

The Task Force is partnering with the Texas SCDC program to develop education materials for college students and campus healthcare providers to learn about managing sickle cell disease and the transition into adult healthcare. The Texas SCDC program will continue this work and share developed education materials by partnering with Texas colleges and universities for a sickle cell awareness campaign.

2025 Recommended Actions

Update Medicaid MCO contract definition of Members with Special Health Care Needs to specifically include SCD as an inclusion criterion.

Under Texas's Medicaid-managed care program, contracted MCOs must identify and provide service coordination to members with special health care needs (MSHCN). An MSHCN is a member who

1. Is in one or more of the following groups: pregnant women identified as high risk, members with behavioral health conditions, or members with serious ongoing illness or a chronic complex condition that is anticipated to last for a significant period and requires ongoing therapeutic intervention and evaluation; or
2. Has been identified as MSHCN.

SCD has progressive complications such as pain crises, acute chest syndrome, stroke, and a constant red blood cell shortage. Given that SCD is a chronic illness, the Task Force recommends the state update the MCO contract definition of MSHCN to specifically list SCD as an inclusion criterion. Doing so will ensure that Medicaid recipients with SCD receive the additional services they need to manage the disease, mitigate complications, and prevent additional serious health outcomes.

Evaluate options to increase Medicaid and CHIP eligibility for individuals diagnosed with SCD until age 26 years.

The Task Force recommends HHSC evaluate options to increase Medicaid and CHIP services for any individual with SCD. During early adulthood, individuals with SCD have a higher chance of experiencing an increase in SCD-related complications, such as progressive organ damage and early death. Early adulthood is also a time when individuals with SCD may face a gap in health care coverage if they age out of Medicaid. Many individuals over 18 years old are only eligible for Medicaid if they have a disability and meet income requirements. Having a SCD diagnosis alone is not enough for an individual to be considered disabled. These individuals may not have access to a parent's health insurance plan either, which would provide continuous health care coverage until age 26 years.

Use available resources to study the development of comprehensive medical home models and ways to create and fund comprehensive sickle cell care centers as a quality improvement project.

Currently, no standards exist for providing care to patients with SCD. Establishing standards by creating sickle cell care models and comprehensive sickle cell care centers may improve care for patients with SCD. Given multiple barriers people face receiving high-quality sickle cell care, the Task Force recommends studying the development of comprehensive sickle cell medical home models for both urban and rural Texas communities as a quality improvement project. These models can be based off existing state models for patients with complex care needs and on the American Society of Hematology sickle cell expert recommendations.

Partner with Medicaid and CHIP Services to pursue SCD-specific quality metrics through one or more of Texas Medicaid's quality improvement programs.

The Task Force recommends partnering with Medicaid and CHIP Services to pursue SCD-specific quality metrics. Metrics would include rates of stroke screening, hydroxyurea prescriptions, penicillin prescriptions, etc., through one or more Texas Medicaid quality improvement programs, e.g., External Quality Review Organization. Monitoring these metrics would allow the state to better understand the sickle cell landscape, the treatments provided to sickle cell patients, and any potential gaps in care. See the 2024 External Quality Review of Medicaid and CHIP Managed Care Annual Technical Report as an example.

Develop sickle cell quality care plans for Medicaid and private payors.

To support initiatives to assist managed care plans in promoting timely, evidence-informed health care plan services to plan enrollees, the Task Force continues to recommend DSHS collaborate with HHSC to create quality care plans for individuals with SCD to guide Medicaid and private payors in prioritizing and reinforcing access to preventive care based on national, evidence-based guidelines from the American Society of Hematology and the National Heart, Lung, and Blood Institute at National Institutes of Health. The Task Force continues to work with HHSC Medicaid and CHIP Services and HHSC to explore plan complexities and encourage payors to implement quality care plans as part of their covered benefits and services.

Update Texas Health Steps Online Provider Education module on sickle cell disease so it is more comprehensive and is eligible for continuing education (CE) credit.

The Task Force recommends updating the Texas Health Steps Online Provider Education module on SCD to reflect most current SCD guidelines and resources. The current module is outdated. A newly revised module could help medical professionals understand sickling disorders and treatment options better. Additionally, it will support health care worker competency and engagement needed for effective treatment and disorder management for affected patients. Adding CE credit would also promote awareness efforts.

Update the Texas Health Steps Periodicity Schedule to include SCT counseling for teenagers who were diagnosed with SCT at birth or have unknown status.

While the Texas newborn screening panel includes testing for SCT, parents may not remember to share the results with their children as they age. The Task Force recommends Health and Human Services update the Texas Health Steps Periodicity Schedule to direct physicians and other medical professionals to provide SCT counseling to teenage patients who screened positive for SCT at birth or have unknown SCT status during a routine adolescent health care visit. Counseling should include SCT education and additional testing, if needed. Education and improved individual awareness of the trait could help adolescents understand potential risks and prepare them prior to family planning decisions. The Task Force recommends state agencies promote this practice through provider education efforts.

Study the feasibility of a state-level sickle cell quality rating system for health care facilities.

The Task Force recommends studying the feasibility of a state-level sickle cell quality rating system to set SCD standards for quality care. To allow for consumer comparison of health care institutions that provide care to individuals with SCD, a statewide reporting system can collect data to show low-performing and high-performing facilities and general compliance history to include allegations and surveyed substantiations. DSHS may use this data for quality improvement efforts at facilities with higher incidence and reporting rates. Publishing facility history and data reports may aid individuals with SCD in selecting an appropriate provider.

Collaborate with HHSC to incorporate a reporting process for sickle cell care provided by health care facilities into an existing statewide system.

The Task Force recommends DSHS collaborate with HHSC to incorporate a reporting process for health care facilities providing sickle cell care into an existing complaint and incident intake system. Patients may report issues with facility care received including hospital emergency departments. Facilities may also self-report. The program area that processes these reports could determine if a regional surveyor should investigate and recommend appropriate corrective actions, if necessary.

Develop partnerships with Texas colleges and universities to create sickle cell awareness campaigns and identify funding for statewide awareness activities.

The Task Force recommends DSHS coordinate with sickle cell community-based organizations to partner with Texas colleges and universities, including medical schools, to create and launch impactful and relevant public awareness campaigns and press releases. The goal should be to launch at least two statewide campaigns per year with an emphasis on September, Sickle Cell Awareness Month, and June 19, World Sickle Cell Day. Potential topics to spotlight include state-specific SCD data, newborn screening, trait or carrier status awareness, and National Collegiate Athletic Association requirements.

To promote statewide awareness activities, the Task Force could work with DSHS to establish a sickle cell awareness calendar to post on the DSHS website and share on relevant email distribution lists to stakeholders. Community organizations and health care institutions could submit their activities to DSHS. DSHS could consider adding these activities to the calendar along with state-run activities.

Additionally, the Task Force recommends the identification of dedicated, ongoing funding for statewide SCD and SCT awareness activities, including:

- Providing community SCD and SCT education;
- Improving detection of individuals with SCD and SCT;
- Coordinating service delivery for people with SCD; and
- Providing training for health professionals regarding SCD and SCT.

Continue to support the efforts of the Texas SCDC Program to expand current data collection activities.

Significant progress has been made in bolstering the state's capacity to conduct sickle cell surveillance. The Task Force supports the activities of the Texas SCDC Program to meet the goals of the CDC grant and recommends continued support towards the realization of a SCD registry.

Conclusion

During its sixth year, Task Force members worked with DSHS to advance Task Force activities and recommended actions developed during the preceding years. Through regular meetings and subject matter expert input, the Task Force recommends the next steps needed to raise public awareness of SCD and SCT in Texas, develop state-level SCD data reporting, and participate in nationwide surveillance programs. The Task Force recommends actions and plans for future work in 2026 to continue raising awareness in collaboration with public awareness campaign organizations, state agencies, and HHSC Medicaid and CHIP Services to improve care for individuals with SCD in Texas.

Appendix A. Sickle Cell Awareness

Per House Concurrent Resolution 117, 86th Legislature, Regular Session, 2019, September is Sickle Cell Awareness Month in Texas through 2029.

In 2021, HHSC and DSHS staff developed a Sickle Cell Awareness Month video featuring Task Force member, Dr. Titilope Fasipe. DSHS posted the video on YouTube on September 3, 2021. As of September 24, 2025, the video has 1,428 views.

DSHS Sickle Cell Disease and Sickle Cell Resources webpages received 32,758 views from September 1, 2024, through August 31, 2025, according to DSHS statistics.

DSHS promoted Sickle Cell Awareness Month by posting shared articles on the Newborn Screening website.

The Task Force worked with the Texas SCDC Program on the Sickle Cell Disease Photoblog, featuring the story of member Andre Harris as a patient advocate living with sickle cell disease. DSHS submitted the photoblog to the CDC.