2024 Sickle Cell Task Force Annual Report

As Required by
Texas Health and Safety Code
Section 52.0007

December 2024

Table of Contents

Executive Summary

Texas Health and Safety Code, Section 52.0007, requires the Sickle Cell Task Force (Task Force) to report on the Task Force's 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 highlights updates on the Task Force's work with DSHS to implement 2018 recommendations. The Task Force also proposes the following recommended actions for 2024:

- Evaluate options to increase Medicaid and Children's Health Insurance Program (CHIP) eligibility for individuals diagnosed with SCD until age 26.
- Use available resources to study development of comprehensive medical home models and ways to create and fund comprehensive sickle cell care centers as a quality improvement project.
- Develop sickle cell quality care plans for Medicaid and private payors.
- Promote incorporating newborn screening trait status checks and follow-up testing into routine adolescent care.
- Establish 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 promote and identify funding for statewide awareness activities.

- Work with the University of Texas School of Public Health in Houston – Center for Health Care Data to develop a sickle cell report from the All-Payor Claims Database.
- Collaborate with DSHS to meet the goals of the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) program.
- Publish a Texas sickle cell surveillance dashboard to include information from a newly established statewide sickle cell data collection system.

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 causes blockages leading to pain and organ damage.

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 a set of recommendations, including one to establish a Sickle Cell Task Force to continue the committee's work. When the Sickle Cell Advisory Committee ended in 2018, new legislation established the Task Force. Over the past five years, the Task Force worked with DSHS to further explore implementation of the Sickle Cell Advisory Committee's 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 August 19, 2024.
[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 August 19, 2024.

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

See the 2023 Task Force Annual Report for key issues impacting those with SCD and SCT.

[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 October 21, 2024.
[4] Centers for Medicare & Medicaid Services. Improving Care for Sickle Cell Disease. Medicaid.gov website. medicaid.gov/medicaid/quality-of-care/quality-improvement-initiatives/improving-care-for-sickle-cell-disease/index.html. Accessed October 21, 2024.

Task Force Actions and Future Work

The following summarizes the Task Force's work since the 2023 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 through promotion of existing or new education courses or facilitating development of new courses;
    - Explore methods for improving public school system SCD education and awareness; and
    - Support evidenced-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, and 2023) summarize Task Force actions.

HB 1488, 88th Legislature, Regular Session, 2023, expanded Task Force membership from seven to 13 members. Solicitation of new members occurred in 2024 with the expectation for new members to join by 2025. The Task Force webpage has a list of 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 a Texas public awareness campaign for World Sickle Cell Day on June 19, 2024. See Appendix A for more information.

Begin Statewide Sickle Cell Surveillance Throughout the Lifespan.

In 2023, DSHS applied for and received funding from the CDC related to sickle cell data collection (SCDC). The CDC SCDC program funds 16 states to support state-level sickle cell data collection to serve as a foundation for development of ongoing surveillance.[5] DSHS has started the data collection process, and Task Force members serve on the project's multi-disciplinary project team.

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

In 2025, the expected SCDC data will include:

- Newborn screening data;
- Birth and death records;
- Clinical records;
- Hospital and emergency discharge; and
- Medicaid eligibility and claims.

Newborn screening and clinical records are the primary sources for identifying confirmed SCD cases. Probable SCD cases will be identified through administrative data, including hospital and emergency discharge, and Medicaid. 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.

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

The Task Force collaborated with HHSC Medicaid and CHIP Services to carry out duties established by HB 1488. For more information see the *Medicaid Provider SCD Education* section below.

[5] 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.

Utilize Community Health Workers (CHWs) to Improve Care.

The Task Force met with DSHS CHW Program staff to discuss ways to educate CHWs about SCD. The Task Force created a document for CHWs to share with patients, including resources for learning about their SCT status.

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 collaborated with HHSC Medicaid and CHIP Services to assess gaps in provider education and create a resource document. See Appendix B.

Future Task Force work includes promoting existing provider education resources and developing new resources, if needed.

Public School System SCD Education and Awareness

HB 1488 requires HHSC to collaborate with the Task Force to explore methods for improving SCD education and awareness within the public school system. In collaboration with HHSC, the Task Force developed a document with existing educational resources for public schools. See Appendix C.

Evidence-Informed Health Care Service Initiatives for SCD

HB 1488 requires HHSC to collaborate with the Task Force to support initiatives to assist managed care plans in promoting timely, evidence-informed health care services to plan enrollees. HHSC Medicaid and CHIP Services surveyed Managed Care Organizations (MCOs) on their protocols and shared results with the Task Force. The Task Force will determine if each organization's protocols align with national clinical practice guidelines and protocols for SCD treatment and meet medical necessity criteria.

Future Task Force work includes continuing to review MCO protocols, provide input, and make recommendations to support initiatives to assist managed care plans in promoting timely, evidence-informed health care services to plan enrollees diagnosed with SCD.

2024 Recommended Actions

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

Given that SCD is a chronic illness with progressive complications, the Task Force recommends HHSC evaluate options to increase Medicaid and CHIP services for any individuals with SCD until age 26 to cover the transition period into adulthood. 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.[6] 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 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.

Use available resources to study 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.

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

[6] Howell KE, Kayle M, Smeltzer MP, et al. Gaps during pediatric to adult care transfer escalate acute resource utilization in sickle cell disease. *Blood Adv*. 2024;8(14):3679-3685. doi:10.1182/bloodadvances.2023011268. Accessed October 21, 2024.

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's work with HHSC Medicaid and CHIP Services to survey MCOs on their sickle cell protocols can serve as a starting point for DSHS and HHSC to explore plan complexities and encourage payors to implement quality care plans as part of their covered benefits and services.

Promote incorporating newborn screening trait status checks and follow-up testing into routine adolescent care.

While the Texas newborn screening panel includes testing for SCT, parents may not remember to share newborn screening results with their children as they age. The Task Force recommends health care providers follow up with their patients who screened positive for SCT at birth by providing SCT education and additional testing, if needed, during routine adolescent health care visits. Doing so would improve awareness of the trait and any risks to the adolescent while preparing them prior to family planning decisions. The Task Force recommends state agencies promote this practice through provider education.

Establish a state-level health care facility sickle cell quality rating system.

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 health care facility sickle cell care 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 promote and identify funding for statewide awareness activities.

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.

Additionally, 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/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 for DSHS consideration in addition to state-run programming.

Work with the University of Texas School of Public Health in Houston – Center for Health Care Data to develop a sickle cell All-Payor Claims Database report.

The Task Force should work with the Center for Health Care Data at the University of Texas Health Science Center in Houston School of Public Health to create a report regarding SCD care using data acquired from the All-Payor Claims Database. Claims data reported by public and private payors includes information such as

demographics, hospital utilization, prescriptions, and health care claims. Reporting this data would help provide the state with an idea of SCD prevalence and the costs of delayed rather than preventative SCD care. Such a report would also help DSHS identify areas of improvement for SCD care.

Collaborate with DSHS to meet the goals of the Centers for Disease Control and Prevention SCDC program.

The Task Force recommends DSHS work with other state agencies, health care institutions, and other stakeholders to carry out the goals of the CDC SCDC program. Participation in this national system will enhance the care of Texas individuals with SCD and include Texas as a key member of the national push to improve SCD care.

Publish a Texas sickle cell surveillance dashboard to include information from a newly established statewide sickle cell data collection system.

The Task Force recommends DSHS create and distribute sickle cell dashboard that incorporates available data from the DSHS Texas Syndromic Surveillance System, Medicaid reports, DSHS Center for Health Statistics, and DSHS Newborn Screening Unit. Data should include the number of babies born annually with SCD or SCT, demographic characteristics, geographical distribution, hospital utilization data, non-medical drivers of health, insurance payor sources, and mortality data of individuals with SCD.

The Task Force recommends DSHS establish and maintain a statewide, population-based sickle cell data collection system to improve treatment, access, and care to people with SCD in Texas. This system should be modeled after other existing data collection systems like the DSHS Texas Birth Defects Registry and Texas Cancer Registry. Information from the data collection system should be included within the surveillance dashboard.

Conclusion

During its fifth year, Task Force members worked with DSHS to advance Task Force activities and recommended actions developed during the preceding four 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 2025 to continue raising awareness in collaboration with public awareness campaign organizations, state agencies, and Texas HHSC Medicaid and CHIP Services to improve care for individuals with SCD in Texas.

Appendix A. Public Awareness Campaigns

Sickle Cell Awareness Month

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 Sickle Cell Task Force member, Dr. Titilope Fasipe, which DSHS posted on YouTube on September 3, 2021. As of August 19, 2024, the video has 1,339 total views, with 241 views during fiscal year 2024.

DSHS Sickle Cell Disease and Sickle Cell Resources webpages received 1,760 page views in September 2023 compared to 1,619 page views in August 2023 and 818 page views in October 2023, according to DSHS statistics.

World Sickle Cell Day

DSHS also worked to promote World Sickle Cell Day on June 19, 2024, focusing on spreading awareness and advocating for better treatments. This included the following social media posts:

- Texas DSHS Facebook
    - June 19, 2024 (Link)
- Texas DSHS Twitter/X
    - June 19, 2024 (Link)
- Texas DSHS Instagram
    - June 19, 2024 (Link)

Appendix B. Provider Education Resources

Texas Medicaid providers have multiple options to continue learning about SCD. Providers can access national resources, including the CDC, the American Society of Hematology, and the National Institutes of Health National Heart, Lung, and Blood Institute.

Texas also offers provider educational resources for people living with SCD. HHSC offers a free course via the Texas Health Steps online portal, "Sickle Cell Disease and Trait: What Texas Health Steps Providers Need to Know."

Texas is a member of the Heartland Southwest Sickle Cell Disease Network. The Network is funded by the U.S. Health Resources and Services Administration with a focus on improving the care and quality of life of people with SCD in eight states. One goal of the network is to support provider education through monthly online educational sessions based on the Project ECHO telementoring model. Each SCD TeleECHO clinic session includes a presentation by a sickle cell expert, a case presentation, and a group discussion.

Resources

American College of Emergency Physicians

- Emergency Department Sickle Cell Care Coalition Resources (Link)
- Guidance on Evaluation and Management of Patients with Sickle Cell Disease in the Emergency Department (Link)

American Society of Hematology (ASH)

- ASH Clinical Practice Guidelines on Sickle Cell Disease (Link)
- ASH Center for Sickle Cell Disease Initiatives (Link)
- SCD Resources for Clinicians (Link)
- Sickle Cell Disease Centers Workshop (Link)

Centers for Disease Control and Prevention

- Sickle Cell Disease (Link)

- About Sickle Cell Disease (Link)
- Complications of Sickle Cell Disease (Link)
- Fact Sheets on Sickle Cell Disease (Link)
- Sickle Cell Information for Health Care Providers (Link)

Foundation for Women and Girls with Blood Disorders

- Education (Link)
- Learning Action Networks (Link)

International Association of Sickle Cell Nurses and Professional Associates

- Sickle Cell Disease Nursing Bootcamp (Link)

National Heart, Lung, and Blood Institute

- Blood Diseases and Disorders Education Program (Link)
- Sickle Cell Disease: Research, Programs, and Progress (Link)
- Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014 (Link)
- What is Sickle Cell Disease? (Link)

National Institute for Children's Health Quality

- Sickle Cell Disease Treatment Demonstration Program Regional Collaboratives Program Compendium of Tools and Materials (Link)
- Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program National Coordinating Center (Link)
- Sickle Cell Disease Treatment Demonstration Program (Link)
- Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program Model Protocol (Link)

Regional Project ECHOs

- Pacific Sickle Cell Regional Collaborative Telementoring (Link)
- Heartland Southwest SCD Network – SCD TeleECHO Clinic (Link)
- Sickle Cell Treatment & Outcomes Research in the Midwest – STORM TeleECHO (Link)
- University of Alabama at Birmingham - Project ECHO (Link)
- Sickle Cell Disease Advanced Practice Provider Opportunities Resources and Training (SAPPORT) (Link)
- Education and Mentoring to BRing Access to CarE (EMBRACE) (Link)

Texas DSHS

- Sickle Cell Grand Rounds (Link)
- DSHS Newborn Screening Program - Sickle Cell Resources (Link)
- DSHS Awareness Campaign Video - Sickle Cell Awareness Month – YouTube (Link)

Texas Health Steps

- Quick Course – Sickle Cell Disease and Trait: What Texas Health Steps Providers Need to Know (Link)

Appendix C. School System Resources

Texas Health and Safety Code, Section 52A.003, states the Texas Education Agency (TEA), in collaboration with SCD community-based organizations, must provide information on SCD and sickle cell trait to public school districts and district staff, including school nurses, teachers, and coaches.

TEA provides an educational resource for teachers and staff that includes a description of sickle cell anemia, pain crisis and complications of sickle cell, warning signs of pain crisis and complications, signs of stroke, managing pain in the school setting, and modifications and classroom guidelines for students with sickle cell anemia.

Each student diagnosed with SCD must have an individualized health plan (IHP) that requires school nurses to educate students and staff on SCD, how it is transmitted, the signs and symptoms, what can be done to reduce the risk of some of the problems, and what to do when symptoms occur. Some independent school districts include SCD information on their websites.

Resources

Section 504 of the Rehabilitation Act of 1973 and Individualized Education Program resources

- Children's Hospital of Philadelphia - Sickle Cell School Outreach (Link)

U.S. Department of Education

- Section 504 Protections for Students with SCD (Link)
- Return to School Roadmap: Development and Implementation of Individualized Education Programs (Link)

Centers for Disease Control and Prevention

- Tips for Supporting Students with Sickle Cell Disease (Link)

Disorder Comics or Cartoons

- Understanding Sickle Cell Disease – Jumo Health – YouTube (Link)

- When Lightning Strikes: Next Step STRIVE Comic Book (Link)

Houston Independent School District

- Health & Medical Services – Sickle Cell Disease (Link)

TEA

- School Health – Students with Special Health Needs – Sickle Cell (Link)
- Section 504 (Link)

Texas School Nurses Organization

- IHP templates – Sickle Cell IHP (Link)