2023 Sickle Cell Task Force Annual Report

As Required by

Texas Health and Safety Code,

Section 52.0007

December 2023

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Executive Summary

Texas Health and Safety Code, Section 52.0007, requires the Sickle Cell Task Force (Task Force) to submit a report to the Governor and the Legislature by December 1 of each year. The report is required to summarize the Task Force's work from September 2022-August 2023 and recommend actions or policy changes, including improving sickle cell disease (SCD) education for health care providers. House Bill (H.B.) 3405, 86th Legislature, Regular Session, 2019, established the Task Force. H.B. 1488, 88th Legislature, Regular Session, 2023, expanded Task Force activities, increased membership, and extended the duration of the Task Force. This is the Task Force's fourth annual legislative report.

The purpose of the Task Force is to study and advise the Texas Department of State Health Services (DSHS) on implementing recommendations made in the *2018 Sickle Cell Advisory Committee Report* published by the Sickle Cell Advisory Committee (expired on September 1, 2018) or any other report the Health and Human Services Commission (HHSC) Executive Commissioner determines is appropriate.

This report highlights the Task Force's work with DSHS to implement the 2018 Sickle Cell Advisory Committee recommendations, which focused on:

- A statewide public awareness campaign
- Development of statewide SCD surveillance
- Collaboration with community health workers (CHWs)
- Partnering with Medicaid/Medicare managed care and accountable care organizations

The Task Force proposes the following recommended actions for 2023:

- Evaluate options to increase Medicaid and Children's Health Insurance Program (CHIP) eligibility for individuals diagnosed with SCD until age 26.
- Partner with Medicaid and CHIP Services to develop comprehensive medical home models.
- Develop sickle cell quality care plans for Medicaid and private payors.
- 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.
- Identify funding for statewide awareness activities and develop partnerships with Texas colleges and universities to create sickle cell awareness campaigns.
- 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.
- Publish an annual Texas sickle cell surveillance report to include information from a newly established statewide sickle cell data collection system.
- Collaborate with DSHS to meet the goals of the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection Program.

Introduction

The Task Force was established by Texas Health and Safety Code, Chapter 52. Statute directs the HHSC Executive Commissioner to establish and maintain a task force to raise awareness of SCD and sickle cell trait (SCT). In August 2019, the HHSC Executive Commissioner delegated the creation and administrative support of the Task Force to DSHS.

The purpose of the Task Force is to study and advise DSHS on implementing recommendations made in the *2018 Sickle Cell Advisory Committee Report* published by the Sickle Cell Advisory Committee or any other report the Executive Commissioner determines is appropriate.

Texas Health and Safety Code, Section 52.0007, requires the Task Force to prepare and submit an annual report to the Governor and the Legislature by December 1. The report summarizes the Task Force's work throughout the year and recommended actions or policy changes endorsed by the Task Force including improving SCD education for health care providers.

In accordance with the statute, this report outlines the following:

- A summary of Task Force activities from September 2022-August 2023
- Proposed actions for implementing the 2018 Sickle Cell Advisory Committee recommendations
- Recommendations for improving SCD education for health care providers

In 2016, the Texas Legislature established the Sickle Cell Advisory Committee to raise awareness of SCD and SCT in Texas. The two-year Sickle Cell Advisory Committee developed a set of recommendations, including one to establish a Sickle Cell Task Force to continue the Sickle Cell Advisory Committee's work. When the Sickle Cell Advisory Committee ended in 2018, new legislation established the Task Force in 2019. The Task Force worked with DSHS over the past four years to further explore the implementation of the Sickle Cell Advisory Committee recommendations regarding:

- A statewide public awareness campaign
- Development of statewide SCD surveillance

- Collaboration with CHWs
- Partnering with Medicaid/Medicare managed care and accountable care organizations.

SCD is one of the most common inherited blood disorders in the United States (U.S.). The number of people with SCD in the U.S. is expected to grow by 30 percent by 2050, making the Task Force's work even more timely.[1] Although SCD was previously associated with high mortality in young children, advances in treatment and preventive care have led to improved survival. Today, more than 90 percent of children with SCD survive to adulthood. When many of these children reach the age of transition from pediatric to adult care, they are unable to find adult specialists or centers with expertise in SCD. Unfortunately, survival rates for adults with SCD have changed little in the past 30 years. This is attributed to barriers to care such as lack of insurance and limited numbers of adult comprehensive sickle cell programs.[2]

About 2,000 babies are born in the U.S. with SCD every year.[3] The CDC, National Center on Birth Defects and Developmental Disabilities, and Division of Blood Disorders consider SCD a significant health and global concern.[4] Texas newborns with SCD are identified through the DSHS Newborn Screening program, but there are no statewide SCD surveillance programs in Texas.[5] Managing SCD and utilizing health services is difficult for people living with this chronic illness.

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[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 15, 2023.

[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-2009-07-233700. Accessed August 15, 2023.

[3] American Academy of Pediatrics Section on Hematology/Oncology. Sickle Cell Disease: Information for Parents. Healthychildren.org Web site. healthychildren.org/English/health-issues/conditions/chronic/Pages/Sickle-Cell-Disease-in-Children.aspx. Published 2022. Updated September 2, 2022. Accessed September 7, 2023.

[4] National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. About CDC's Work on Sickle Cell Disease. Cdc.gov Web site. cdc.gov/ncbddd/sicklecell/about.html. Published July 31, 2018. Updated December 16, 2020. Reviewed July 6, 2023. Accessed September 7, 2023.

[5] Texas Department of State Health Services. Screened Disorders. Dshs.texas.gov Web site. dshs.texas.gov/newborn-screening-program/newborn-screening-disorders. Updated 2023. Accessed September 7, 2023.

In 2021, the Centers for Medicare and Medicaid Services (CMS) published the first comprehensive data-focused report on state-level health care utilization and health characteristics for people with SCD receiving Medicaid and CHIP services. In the CMS report, which examined 2017 data, Texas had the fourth highest number of Medicaid and CHIP beneficiaries with SCD (2,604) after Florida, Georgia, and New York. The report encompassed 41,995 individuals with SCD, which is almost half the reported national population of individuals with SCD.[6]

The report found a considerable discrepancy between recommended and actual therapy received, including low rates of annual stroke screening in children, low utilization of hydroxyurea (a disease-modifying therapy) in both children and adults, as well as a lack of vaccinations and antibiotic prophylaxis. They found only 36 percent of patients with SCD between the ages of 2 to 16 received an annual stroke screen with a transcranial doppler ultrasound (TCD). A TCD is the main method to identify children at risk of stroke, a common severe morbidity of SCD. They also found that prescriptions for the most well-known disease-modifying therapy, hydroxyurea, were extremely low at 37 percent of children and 35 percent of adults. Young children with SCD are 300 times more likely to develop an invasive pneumococcal infection than children without SCD, and the report found only 59 percent of children under age 2 had received the appropriate vaccinations, including the 13-valent pneumococcal vaccine. The other mainstay of infection prevention is antibiotic prophylaxis with daily oral penicillin, which the report found was extremely low (only 11 percent of 15-month-olds to age 4 with at least 300 days of prescriptions).[6]

The lack of sickle cell specific knowledge among medical providers contributes to the identified discrepancies in care. In a 2020 survey of 100 providers (which included pediatric, internal medicine, and family medicine physicians who care for at least 10 patients with SCD), only 33 percent of physicians reported familiarity with the 2014 National Heart, Lung, and Blood Institute Sickle Cell Guidelines while another survey of family practice physicians reported only 20 percent were

[6] Wilson-Frederick, S., M. Hulihan, A. Mangum, T. Khan, M. Geibel, R. Malsberger, S. Verghese, R. Borck, R. Fox, and M. Rosenbach. Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017. Baltimore, MD: Center for Medicaid and CHIP Services, Division of Quality and Health Outcomes, Centers for Medicare & Medicaid Services, 2021. medicaid.gov/medicaid/quality-of-care/downloads/scd-rpt-jan-2021.pdf. Published January 2021. Accessed September 7, 2023.

comfortable with overall SCD management.[7,8] Similarly, in a survey among 300 obstetrician/gynecologists, 40 percent reported their SCD training was inadequate.[9] Patients also highlighted provider knowledge as a barrier to receiving care. Fifty-six percent of patients with SCD reported provider inexperience and lack of training in the care of people with SCD as frequently encountered barriers.[10]

The CMS report also identified high health care costs associated with SCD due to increased utilization of emergency services and hospitalizations.[6] Studies from 2015 show the national financial impact was $2.98 billion in annual direct costs for adults with SCD and $60.8 billion in direct costs for children with SCD.[11] A National Institutes of Health (NIH) study found $1.7 million as the average cost insurers pay per individual with SCD according to 2007-2018 U.S. commercial claims data. This study also estimated, that for persons living with SCD, the lifetime cost of health care not covered by insurance was $44,000.[12] Although health care costs seem significant, the biggest impact is seen in income loss due to missed work or lack of employment, which has been estimated at $3 million annually for people with SCD and $2.8 million for their caregivers.[13]

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[7] 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. Published 2021 Nov 17. doi:10.1136/bmjopen-2021-050880. Accessed September 1, 2023.
[8] Mainous AG 3rd, Tanner RJ, Harle CA, Baker R, Shokar NK, Hulihan MM. Attitudes toward Management of Sickle Cell Disease and Its Complications: A National Survey of Academic Family Physicians. *Anemia*. 2015;2015:853835. doi:10.1155/2015/853835. Accessed September 1, 2023.
[9] Azonobi IC, Anderson BL, Byams VR, Grant AM, Schulkin J. Obstetrician-gynecologists' knowledge of sickle cell disease screening and management. *BMC Pregnancy Childbirth*. 2014;14:356. Published 2014 Oct 14. doi:10.1186/1471-2393-14-356. Accessed September 1, 2023.
[10] Phillips S, Chen Y, Masese R, et al. Perspectives of individuals with sickle cell disease on barriers to care. *PLoS One*. 2022;17(3):e0265342. Published 2022 Mar 23. doi:10.1371/journal.pone.0265342. Accessed September 1, 2023.
[11] D. S. PRO26 Cost of illness of Sickle Cell Disease in the US, Payer's Perspective: (CRESCENT). *Value in Health.* 2021;24(Supplement 1):S202. Published 2021 June 4. doi:10.1016/j.jval.2021.04.1011. Accessed August 15, 2023.
[12] Johnson KM, Jiao B, Ramsey SD, Bender MA, Devine B, Basu A. Lifetime medical costs attributable to sickle cell disease among nonelderly individuals with commercial insurance. *Blood Adv*. 2023;7(3):365-374. doi:10.1182/bloodadvances.2021006281. Accessed August 15, 2023.
[13] Holdford D, Vendetti N, Sop DM, Johnson S, Smith WR. Indirect Economic Burden of Sickle Cell Disease. *Value in Health*. 2021;24(8):1095-1101. Published 2021 Aug. doi:10.1016/j.jval.2021.02.014. Accessed August 15, 2023.

Gaps in care also exist for individuals with SCD because of documented disparities in health care funding, research funding opportunities, specialist care access, and speed of developing new medical therapies. There are discrepancies in both NIH and private research funding for SCD when compared to other rarer inherited diseases such as cystic fibrosis (CF). For instance, in 2006 it was first reported that funding for SCD was $1,130 per person, but CF funding was $9,340 per person. Over time, this difference continues to widen. In 2020, funding fell to $914 per person with SCD while funding rose to $10,497 per person with CF. Furthermore, patients with CF had three times more novel therapies approved than patients with SCD during the same period.[14]

A key driver of health disparities in SCD is the lack of a national surveillance system to characterize the state of health of the population and identify patterns of complications and adherence to treatment guidelines. In contrast, CF has a national organization, the Cystic Fibrosis Foundation, that funds and accredits 130 national CF centers where patients are tracked as part of a national registry.[14] For SCD, the CDC Sickle Cell Data Collection Program had funding to support two states, Georgia and California, from 2005 to 2016, and seven states received funding to participate in 2021 (Minnesota, Wisconsin, Michigan, Indiana, Alabama, Tennessee, and North Carolina).[15] A new CDC request for applications was released in February 2023 to add participating states. In September 2023, the CDC announced 13 new states were awarded funds, including Texas. This increases the total number of participating states to 22. However, this is still an underrepresentation of the SCD population in the U.S.

In 2020, the National Academies of Sciences, Engineering, and Medicine published *Addressing Sickle Cell Disease, A Strategic Plan and Blueprint for Action*. The strategic plan sets forth a vision to create long, healthy lives for individuals living with SCD by addressing the following eight areas:

- Establish a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with SCD across the life span.

[14] Farooq F, Mogayzel PJ, Lanzkron S, Haywood C, Strouse JJ. Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated With Research Productivity. *JAMA Netw Open*. 2020;3(3):e201737. Published 2020 Mar 2. doi:10.1001/jamanetworkopen.2020.1737. Accessed August 15, 2023.
[15] Centers for Disease Control and Prevention. Sickle Cell Data Collection (SCDC) Program. cdc.gov web site. cdc.gov/ncbddd/hemoglobinopathies/scdc-data.html. Published June 3, 2020. Updated June 27, 2023. Accessed September 7, 2023.

- Establish organized systems of care that provide both clinical and nonclinical supportive services to all persons living with SCD.
- Strengthen the evidence base for interventional and disease management and implement widespread efforts to monitor the quality of SCD care.
- Increase the number of qualified health professionals providing SCD care.
- Improve SCD awareness and strengthen advocacy efforts.
- Address barriers to accessing current and pipeline therapies for SCD.
- Implement efforts to advance understanding of the full impact of SCT on individuals and society.
- Establish and fund a research agenda to inform effective programs and policies across the lifespan.[16]

The Task Force is positioned to be a key player in guiding Texas to achieve these goals. The Task Force currently consists of seven members appointed by the HHSC Executive Commissioner and is required to meet at least three times a year per Task Force bylaws. Current membership includes physicians specializing in hematology, members of community-based organizations (CBOs) who serve SCD populations, members of the public who have SCD or SCT or are the parent of a child with SCD or SCT, and a representative of a health-related institution. Refer to Appendix A for a list of Task Force members.

H. B. 1488, 88th Legislature, Regular Session, 2023, expanded Task Force membership to include the following six additional members:

- A member of the public who has SCD or SCT
- A Texas Education Agency representative
- An HHSC representative
- A physician with experience addressing the needs of individuals with SCD and SCT
- A researcher from a public-health related or academic institution with experience addressing SCD and SCT
- A health care professional with experience addressing the needs of individuals with SCD or SCT

H.B. 1488 also widened the scope of Task Force duties, requiring them to collaborate with HHSC to:

[16] 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. doi:10.17226/25632. Accessed August 15, 2023.

- Include recommendations for improving SCD education for health care providers in their annual report.
- Support initiatives to assist managed care plans in promoting timely, evidence-informed health care services to plan enrollees diagnosed with SCD.
- Address SCD education for Medicaid providers.
- Explore methods for improving SCD education and awareness within the public school system and provide recommendations to the Texas Education Agency on those methods.

Task Force Actions and Future Work

As required by Texas Health and Safety Code, Chapter 52, the following summarizes the Task Force's work since their 2022 annual report, including their efforts to develop recommendations on improving health care provider SCD education.

During the fourth year of operations, the Task Force held four meetings. The Task Force has four subcommittees: Public Awareness Campaigns, Medicaid Contracts, Sickle Cell Surveillance, and Legislatively Mandated Report. Each subcommittee met with subject matter experts regarding Task Force activities.

Summary of Progress

Establish a Sickle Cell Task Force

H.B. 3405, 86th Legislature, Regular Session, 2019, established the Task Force. The 2018 Sickle Cell Advisory Committee recommendations and the Task Force annual reports (2020, 2021, and 2022) summarize prior Task Force actions.

H.B. 1488, 88th Legislature, Regular Session, 2023, expanded Task Force activity and membership. In response, the Task Force formed a new health care provider education-focused subcommittee with plans to start meeting in 2024. The Legislature extended the operations of the Task Force to August 31, 2035.

Develop Statewide Sickle Cell Awareness Campaigns

The Task Force worked with DSHS to develop a Texas public awareness campaign in September 2021 (Appendix B) that is relaunched annually for national and state-designated Sickle Cell Awareness Month to promote sickle cell awareness. This campaign includes SCD education information, patient experiences, and how the public can provide support through blood donations and hemoglobin testing. In 2023, DSHS approved a request from *Scholastic Magazines+* to feature the campaign-related video as part of their sickle cell-related education. The Task Force also worked with DSHS on a Texas public awareness campaign for World Sickle Cell Day on June 19, 2023 (See Appendix B for more information).

The Task Force also reviewed the University of Texas Human Dimensions of Organizations (HDO) Program's final recommendation report developed in the Fall

2022 semester. The HDO recommendations provided various strategies for the Task Force to consider for increasing awareness of SCD and SCT across the state (recommendations may be viewed here).

To provide statewide education to health care professionals, public health researchers, and the public, the Task Force submitted a request to present at DSHS Grand Rounds. The request was accepted and the presentation, entitled *Sickle Cell Disease: A Story of Discovery and Progress,* was given on May 31, 2023. It was attended by 230 participants.

Begin Statewide Sickle Cell Surveillance Throughout the Lifespan

The Task Force Sickle Cell Surveillance Subcommittee met with DSHS to review available Texas sickle cell surveillance data and to develop a recommended DSHS surveillance structure. The subcommittee reported their work at each Task Force meeting. As a result of subcommittee efforts, DSHS applied for and was awarded a funding opportunity from the CDC to implement a sickle cell data collection system. The information gained from the collection system will help DSHS:

- Determine the number of people with SCD
- Describe the population of affected individuals
- Understand their health care and health outcomes
- Connect to community stakeholders

The subcommittee continued work with DSHS to update annual data for a third *Sickle Cell Disease in Texas Syndromic Surveillance Systems Report, 2022*, which was presented to the Task Force at their August 2023 meeting. The report included demographic, geographical, and hospital system-level data for emergency and urgent care visits. In addition, HHSC prepared a report and presented updated 2020 Texas state-level data regarding patients receiving stroke screening, hydroxyurea, prophylactic penicillin, and immunizations to the Task Force Sickle Cell Surveillance Subcommittee. The subcommittee requested additional surveillance data elements needed for a robust vital statistics sickle cell report. In response to this request, mortality and newborn screening data was presented at the August 2023 Task Force meeting. The Center for Health Data (CHCD) at the University of Texas Health Science Center in Houston School of Public Health, which manages the All-Payor Claims Database, did not have data to present this year but anticipates their first report in 2024.

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

The Task Force met with HHSC Medicaid and CHIP Services to understand Medicaid support, programs, and reimbursement practices. The Task Force also educated Medicaid and CHIP health plan providers to reinforce national sickle cell clinical care guidelines and review statewide comprehensive care gaps for individuals with SCD.

For 2024, the Task Force intends to discuss and define medical home models for SCD care, lifespan eligibility/waivers, access to Federal Drug Administration-approved SCD medications, and new Medicaid-related Task Force directives in H.B. 1488, 88th Legislature, Regular Session, 2023.[17,18] The Task Force will explore a tiered recommendation development for health care facilities and providers based on comprehensive care capabilities for individuals with SCD. The Task Force will study the feasibility of a Medicaid and CHIP Services discounted drug plan modeled after the federal 340B Drug Pricing Program to potentially provide outpatient SCD medications to Texas Medicaid clients at significantly lower prices.

Utilize Community Health Workers to Improve Care

The Task Force engaged with DSHS to learn about opportunities to increase CHW access to the latest SCD and SCT education. Furthermore, the Task Force will review and discuss CHW optimization opportunities for Texas high-need areas.

Health Care Provider Education Improvement Recommendations

H.B. 1488, 88th Legislature, Regular Session, 2023, requires the Task Force to include health care provider recommendations in their annual report. The Task Force began work on this requirement by including this topic on their August 2023 meeting agenda and established a subcommittee to start work in 2024, after the appointment of new Task Force members.

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[17] American Society of Hematology. Hydroxyurea for Sickle Cell Disease, Treatment Information from the American Society of Hematology. Hematology.org/education/patients web site. hematology.org/-/media/hematology/files/patients/hydroxyurea-booklet.pdf. Accessed September 7, 2023.

[18] Sickle Cell Disease Coalition. SCD Therapy Fact Sheets. scdcoalition.org/resources web site. exotic-castanets.cloudvent.net/pdfs/SCDFactSheets-Finalflyers-2022.pdf. Published May 25, 2021. Updated 2022. Accessed September 7, 2023.

2023 Recommended Actions

Texas Health and Safety Code, Chapter 52, directs the Task Force to include recommended actions or policy changes in this report. In response, the Task Force advises DSHS to consider the following items to enhance Task Force productivity and complement current progress.

Evaluate options to increase Medicaid and CHIP eligibility for individuals diagnosed with sickle cell disease 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 to early adulthood, unless they are eligible for disability coverage.

Partner with Medicaid and CHIP Services to develop comprehensive medical home models

Given multiple barriers people face accessing high-quality sickle cell care, the Task Force recommends the development of comprehensive sickle cell medical home models for both urban and rural Texas communities in partnership with Medicaid and CHIP Services. [19] Developing these models can be based off existing state models for patients with complex care needs and on sickle cell expert recommendations from the American Society of Hematology.[20]

Develop sickle cell quality care plans for Medicaid and private payors

The Task Force recommends DSHS collaborate with HHSC to work on the creation of quality care plans for individuals with SCD to guide Medicaid and private payors in prioritizing and reinforcing access to preventative care based on national,

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[19] Nowogrodzki, Anna. No adult left behind: bridge the health-care gap for sickle-cell disease. *Nature*. 2021;596:S13-S15. Published 2021 Aug 25. doi:10.1038/d41586-021-02143-z. Accessed August 15, 2023.

[20] Kanter J, Smith WR, Desai PC, et al. Building access to care in adult sickle cell disease: defining models of care, essential components, and economic aspects. *Blood Adv*. 2020;4(16):3804-3813. Published 2020 Aug 25. doi:10.1182/bloodadvances.2020001743. Accessed August 15, 2023.

evidence-based guidelines from the American Society of Hematology and the National Heart, Lung, and Blood Institute at National Institutes of Health. DSHS and HHSC could jointly explore plan complexities and encourage payors to implement quality care plans as part of their covered benefits and services.

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

The Task Force recommends DSHS evaluate 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, DSHS should include a statewide reporting system to collect data regarding low-performing facilities and recognition of high-performing facilities. DSHS may use this data for quality improvement efforts at low-performing facilities. Publishing 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 already existing complaint and incident intake system. Patients may report issues with care received in these facilities including hospital emergency departments. Facilities may also self-report. The program area that processes these reports could evaluate the report and prompt a regional surveyor to investigate and recommend appropriate corrective actions, if necessary.

Identify statewide awareness activities funding and develop partnerships with Texas colleges and universities to create sickle cell awareness campaigns

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
- Providing training for health professionals regarding SCD and SCT

Additionally, the Task Force recommends DSHS partner with Texas colleges and universities (including medical schools) in coordination with sickle cell CBOs 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, which is Sickle Cell Awareness Month, and June 19 as 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.

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 CHCD 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 new All-Payor Claims Database. Claims data reported by public and private payors includes information such as demographics, hospital utilization, prescriptions, and healthcare 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.

Publish an annual Texas sickle cell surveillance report to include information from a newly established statewide sickle cell data collection system

The Task Force recommends DSHS create and distribute an annual sickle cell report that incorporates available data from the DSHS Texas Syndromic Surveillance System, Medicaid reports, Center for Health Statistics, and DSHS Newborn Screening Unit. Data should include the number of babies born annually with SCD or SCT, as well as demographic characteristics, geographical distribution, hospital utilization data, social determinants 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, for example, the DSHS Texas Birth Defects Registry and Texas Cancer Registry. Information from the data collection system should be included within the surveillance report.

Collaborate with DSHS to meet the goals of the Centers for Disease Control and Prevention Sickle Cell Data Collection 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 Sickle Cell Data Collection 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.

Conclusion

During its fourth year, Task Force members worked with DSHS to cultivate and advance Task Force activities and recommended actions developed during the first three years. Through regular meetings, subject matter expert input, and Task Force subcommittee work, the Task Force recommends the next steps needed to raise public awareness of SCD and SCT in Texas, develop a state-level annual SCD surveillance report, and lay the foundation to participate in nationwide surveillance programs. The Task Force recommends actions and plans for future work in 2024 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.

Task Force recommended actions:

- Evaluate options to increase Medicaid and CHIP eligibility for individuals diagnosed with sickle cell disease until age 26
- Partner with Medicaid and CHIP Services to develop comprehensive medical home models
- Develop sickle cell quality care plans for Medicaid and private payors
- Establish a state-level healthcare facility sickle cell quality rating system
- Collaborate with HHSC to incorporate a reporting process for health care facility sickle cell care into an existing statewide system
- Identify statewide awareness activities funding and develop partnerships with Texas colleges and universities to create sickle cell awareness campaigns
- 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
- Publish an annual Texas sickle cell surveillance report to include information from a newly established statewide sickle cell data collection system
- Collaborate with DSHS to meet the goals of the CDC Sickle Cell Data Collection Program

List of Acronyms

Acronym	Full Name
CBO	Community-Based Organization
CDC	Centers for Disease Control and Prevention
CF	Cystic Fibrosis
CHCD	Center for Health Care Data
CHIP	Children's Health Insurance Program
CMS	Centers for Medicare and Medicaid Services
DSHS	Texas Department of State Health Services
HDO	University of Texas Human Dimensions of Organizations Program
HHS	Texas Health and Human Services
HHSC	Texas Health and Human Services Commission
NIH	National Institutes of Health
SCD	Sickle Cell Disease
SCT	Sickle Cell Trait
TCD	Transcranial Doppler Ultrasound
U.S.	United States

Appendix A. Sickle Cell Task Force Membership

Table 1. 2022-2023 Sickle Cell Task Force Members

Member Name	Member Position/Category
Dr. Titilope Fasipe, Chair	Representative of a health-related institution
Dr. Melissa Frei-Jones	Physician specializing in hematology
Mr. André Harris[21]	Member of the public who has SCD or is a parent of a person with SCD or SCT
Ms. Priscilla Hill-Ardoin[22]	Member of the public who has SCD or is a parent of a person with SCD or SCT
Dr. Dawn D. Johnson	Member from a CBO with experience addressing the needs of individuals with SCD
Dr. Alecia Nero	Physician specializing in hematology
Ms. Marqué Reed-Shackelford, Vice-Chair	Member of the public who has SCD or is a parent of a person with SCD or SCT
Ms. Alysian Thomas, J.D.[23]	Member from a CBO with experience addressing the needs of individuals with SCD
Ms. Linda Wade[24]	Member from a CBO with experience addressing the needs of individuals with SCD

[21] Appointed in March 2023 to fill position Ms. Priscilla Hill-Ardoin vacated.
[22] Resigned.
[23] Resigned.
[24] Appointed in March 2023 to fill position Ms. Alysian Thomas vacated.

Appendix B. Public Awareness Campaigns

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

Sickle Cell Awareness Month

DSHS worked with Texas Health and Human Services (HHS) to promote Sickle Cell Awareness Month in September 2020, 2021, 2022, and 2023. HHS and DSHS staff developed a Sickle Cell Awareness Month video featuring Task Force member, Dr. Titilope Fasipe, which DSHS posted on YouTube on September 3, 2021. As of August 15, 2023, the video has 1,098 total views with 589 views during fiscal year 2023. DSHS and HHS shared this video and other sickle cell information in social media messages and articles published on the respective DSHS and HHS websites and social media accounts.

HHS Communications shared the following social media posts in 2022:

- Texas DSHS Facebook
  - September 1, 2022 (Link)
- Texas DSHS Twitter/X
  - September 1, 2022 (Link)
  - September 21, 2022 (Link)
- Texas DSHS Instagram
  - September 1, 2022 (Link)

Articles and social media posts included information links to DSHS Sickle Cell Disease and Sickle Cell Resources webpages. These webpages received 2,192 unique pageviews in September 2022 compared to 2,056 unique pageviews in October 2022, according to Google Analytics statistics provided by the DSHS Web Office.

World Sickle Cell Day

DSHS also worked with HHS to promote World Sickle Cell Day on June 19, 2023, focusing on educating the public about knowing their sickle cell trait status.

HHS shared the following social media posts:

- Texas DSHS Facebook
  - June 16, 2023 (Link)

- Texas DSHS Twitter/X
  - June 16, 2023 (Link)
- Texas DSHS Instagram
  - June 16, 2023 (Link)