

**Sickle Cell Task Force Meeting  
Minutes**

**August 19, 2022**

**12:00 p.m.**

**Hybrid Meeting:**

**Microsoft Teams Virtual Meeting**

Robert Bernstein Building, Room K-100  
1100 W. 49th St, Room K-100, Austin, Texas 78756

**Agenda Item 1: Welcome, introductions, and logistical announcements**

Dr. Titilope Fasipe, Chair of the Sickle Cell Task Force (Task Force), called the meeting to order at 12:01 p.m. and welcomed everyone in attendance. Dr. Fasipe recognized Ms. Sallie Allen, Advisory Coordination Committee Office (ACCO) staff, for her service to the Task Force and stated that she will be retiring on August 31, 2022.

Dr. Fasipe introduced and turned the floor over to Ms. Tessa Buck-Ragland, Texas Health and Human Services Commission (HHSC), Policy & Rules, ACCO. Ms. Ragland reviewed logistical announcements, conducted a roll call, and announced the presence of a quorum.

**Table 1. Sickle Cell Task Force member attendance at the Friday, August 19, 2022 meeting.**

<b>Member Name</b>	<b>In Attendance</b>
<b>Dr. Titilope Fasipe</b>	Yes
<b>Dr. Melissa Frei-Jones</b>	Yes
<b>Ms. Priscilla Hill-Ardoin</b>	Yes
<b>Dr. Dawn Johnson</b>	Yes
<b>Dr. Alecia Nero – joined at 2:32 pm</b>	Yes
<b>Mrs. Marqué Reed-Shackelford</b>	Yes
<b>Ms. Alysian Thomas, J.D.</b>	Yes

Yes: Indicates attended the meeting  
meeting

No: Indicates did not attend the meeting

Ms. Karen Hess, Director, Texas Department of State Health Services (DSHS), Newborn Screening (NBS) Unit, introduced herself, and as she called on program staff members, Dr. Debra Freedenberg, Aimee Millangue, Laura Arellano, Gwen Hanley, Julianna Ybarbo, and new manager, Giselda Rios, asked that they provide a brief introduction.

Dr. Fasipe then offered opening remarks. She requested a moment of reflection to honor the legacy of Doctor Mackey, one of the prior chairs, and give time of reflection to think about those that we have lost with sickle cell disease and those that are still living and thriving with the disease and the future of how to improve outcomes.

**Agenda Item 2: Consideration of May 27, 2022 draft meeting minutes**

Dr. Fasipe reminded members that the May 27, 2022 draft meeting minutes were sent to them via email and asked if there were any edits or changes. Hearing none, she requested a motion to approve the May 27, 2022 meeting minutes.

**MOTION:** Dr. Frei-Jones motioned to approve the May 27, 2022 meeting minutes as presented. Mrs. Marqué Reed-Shackelford seconded the motion. Ms. Buck-Ragland conducted a roll call vote, and the motion carried unanimously with no objections or abstentions.

### **Agenda Item 3: Sickle Cell Task Force Rules**

Dr. Fasipe introduced and turned the floor over to Ms. Laura Arellano to provide members an update on Sickle Cell Task Force Rules.

#### **Highlights of the presentation included:**

- Ms. Arellano provided a brief background that a repeal of Texas Administrative Code Title 25, Chapter 37, Subchapter R, Sickle Cell Advisory Committee, a subsection in 37.420, is currently in order, and the rule will be replaced in the same area.
- These new rules will be governing the sickle cell task force because per Texas Government Code, Section 2110.008; the Sickle Cell Advisory Committee was abolished effective September 1, 2018. The task force was established per the advisory committee's recommendation in accordance with House Bill 3405, 86th Legislature, 2019, and it was promulgated under the Texas Health and Safety Code Chapter 50. That was later redesignated as Health and Safety Code, Chapter 52, per House Bill 3607, 87th legislature.
- The new rule establishes the task force and describes task force composition, roles, responsibilities, and abolishment date.
- The rule was posted to the Texas Register for public comment from June 24th through July 25th of this year and did not receive comments.
- The Executive Council convened August 18th, rules were presented, there were no comments or concerns.
- The rule was later reviewed and approved by the Rules Coordination Office, as well as the senior executive policy advisor and will require a full review by legal.
- The final approval will go to the Executive Commissioner, and the final version of the rules is expected to be published in the Texas Register on October 21st and will go into effect on October 24, 2022.

#### **Members discussed:**

- Dr Fasipe asked for the abolishment date for the Task Force, and Ms. Arellano stated September 1, 2025 is the date.

### **Agenda Item 4: Heartland Southwest Sickle Cell Disease (SCD) Network**

Dr. Fasipe introduced Dr. Allison King, Director, Heartland Southwest Sickle Cell Disease Network and Assistant Professor of Occupational Therapy, Pediatrics, Surgery Education, at Washington University School of Medicine and Taniya Varughese, Regional Coordinator, Heartland Southwest Sickle Cell, Disease Network and Clinical Lab Supervisor, Child Health and Education Laboratory, Program in Occupational Therapy, Washington University School

of Medicine. Dr. King referenced the PowerPoint and handout, *Heartland Southwest Sickle Cell Disease Network*.

**Highlights of the presentation included:**

- The Heartland Southwest SCD Network is funded by a grant from Health Resources and Services Administration (HRSA) under the Sickle Cell Disease Treatment Demonstration Program (SCDTDP) for the purpose of increasing access for people with SCD to quality, coordinated, comprehensive care by increasing the number of clinicians or health professionals knowledgeable about the care of SCD, improving the quality of care provided to people with sickle cell disease, and improving the care coordination with other providers.
- SCDTDP has a regional approach and organization with five regions, which includes the Heartland Southwest SCD Network, which are coordinated by a national coordinating center and have a subcontract with the National Institute for Children’s Health Quality (NICHQ).
- The Heartland Southwest SCD Network has five objectives that will be evaluated at the end of their five-year award, which includes establishing partnerships with sister grantees from the Newborn Screening Follow Up Program, partner with organizations to increase access to SCD care in at least 7 states in the region, increase the number of providers in the region who are delivering care for people with SCD by 25 percent, increase by 35 percent the total number of people who are receiving disease modifying therapies, and increase by 25 percent the number of patients within the region who are able to receive care for SCD via telemedicine.
- They operate under a logic model that includes all the resources or organizations supporting the work, activities, outputs, interim outcomes, and final measures they’d like to see by 2026, which are coordinated to enhance the lives of people with SCD and in ways, improve the quality of care and access of care for those families.
- The Heartland Southwest SCD Network includes eight states: Arkansas, Iowa, Kansas, Louisiana, Missouri, Nebraska, Oklahoma, and Texas.
- Within the eight-state region are seven partners at the state level led by Washington University: University of Nebraska Medical Center, University of Iowa, Truman Medical Center, University of Arkansas, Louisiana State University, Baylor, and Oklahoma University.
- Within the seven-state region that represents almost 16 percent of people within the United States who have SCD, Texas is largest and most populated state with the largest population of people lost to SCD.
- One of the larger activities they organize within their center to provide education, to try to enhance the number of people who feel comfortable and more educated about being able to provide care for someone SCD, is through Project ECHO.
- Project ECHO is a program for tele mentoring, with clinicians discussing challenging cases with another clinician who is a subject matter expert in the condition.

- The Heartland Network ECHO is set up to increase the amount of medical knowledge about SCD and share best practices to reduce disparities and case-based learning so that people can master the complexity of SCD.
- The Heartland Network also keeps a web-based database to monitor outcomes.
- Each of the five regions have ECHOs within their regions, and within each region, some states have set up sub-ECHOs.
- ECHOs have a hub and spoke model, with the experts within the hub and the clinics and clinicians are the spokes picking up knowledge through ECHO tele mentoring.
- The main goal is to enhance health care delivery, but as a secondary benefit, people have been able to demonstrate it reduced costs because of better quality care leading to fewer complications of prolonged hospitalizations.
- The Heartland Network started formally doing ECHOs in 2017, and in 2021, began offering Continuing Medical Education (CME) credits and maintenance of certification credits to providers.
- The ECHO program also has led to primary care practices being able to connect with sickle cell experts and launch relationships and partnerships for shared care and new satellite clinics, helping reduce the barrier for patients having to travel to reach an academic hematology center.
- The ECHO has also enhanced two forms of telemedicine, with the patient remote from home and the patient in a federally qualified health center or primary care with SCD expert in an academic center.

**Members discussed:**

- After CME was added to the ECHOs, if there was any change in attendance.
- How to learn about the existence of an ECHO and opportunities to participate.
- If Dr. Fasipe knows if the ECHO has reached out physicians in West Texas where there are smaller populations of sickle cell patients and whether they participate.
- If the Task Force could brainstorm how to make the ECHO program more well known in Texas so that doctors looking for information to help their patients get it and patients get access to improved care.
- Crossing over to the work of the Newborn Screening Advisory Committee and engaging hematology consultants through them.
- How the ECHO telemedicine visits when a patient is linked to a sickle cell expert are represented to the insurance companies - if they're counted as two appointments or if there is a different type of reimbursement model.
- Targeting efforts toward family medicine or internal medicine providers for improving adult care.

- Due to the gap in adult and the transition from pediatric to adult care, some pediatric providers end up learning how to take care of adults in some states.

**ACTION ITEM:**

- Program staff will reach out to the University of Missouri to inquire what reimbursement models for telemedicine look like for ECHO programs.

**Agenda Item 5: Texas Syndromic Surveillance (TxS2) annual report**

Dr. Fasipe introduced Yallu Sivaprakash, Texas Syndromic Surveillance (TxS2) Epidemiologist, Division for Regional and Local Health Operations (RLHO), DSHS. Ms. Sivaprakash reminded members that the full 2021 report is in their electronic meeting packet and referenced the PowerPoint and handout, *Texas Syndromic Surveillance System (TxS2)*.

**Highlights of the presentation included:**

- TxS2 has around 380 data providers going into their system, including the data going directly to DSHS and data that goes to DSHS through Tarrant County and the City of Houston, which accounts for about 85 percent of hospitals, hospital emergency rooms, and urgent care clinics.
- TxS2 has non-identifiable data but receives demographic information and wealth of health-related data as well as the patient discharge diagnosis.
- Their query included every D57 *International Classification of Diseases, Tenth Revision* code, which is the grouping for sickle cell diseases, and keywords "sickle" and "acute chest syndrome," resulting in 32,180 visits related to patients going to emergency rooms and urgent care clinics for sickle cell-related reasons in the system.
- As a percentage of overall visits, this represents only 0.2 percent, which is consistent with previous years.
- The demographic breakdown is like previous years, with more African Americans, more females, and more people between the ages of 18 to 65 visiting the emergency room for sickle cell-related issues.
- The age range is curious because many people in that age group are less likely to have insurance, and they are more likely to use the emergency room service as their primary means of medical care.
- They estimated about 1,264 patients re-presented at the emergency room within 72 hours of their last visit, which is the best practice indicator for quality of care and patient safety. They also estimated there were 2,884 visits within 72 hours of another visit. They could not get good data on hospital re-admissions within 30 days or tell if the same patient visited a different facility.

- They assume with the growth of the Texas population, there will also be a growth in the number of visits as well.

### **Members discussed:**

- It is striking that they do not know how many people in Texas have SCD because some estimates say 7,000, but they're discovering 15,000 individuals visited facilities in the TxS2 system for sickle cell disease-related issues in 2021. The number of people in Texas with SCD is either underestimated or there are a lot of duplicates in the 15,000, which raises questions about data quality.
- Aside from the duplicates and high utilization of some of the patients, what other things stood out to the TxS2 team in the data.
- The TxS2 team would want to know which facility patients are going to and getting care from, which was lacking from the data, and they were also curious to see where they are going, if they were able to get treated, and how early they are going into the hospital. For someone who only had two visits, did that mean they got the care they needed versus those who went 50 or 190 times? And how early is a person going to urgent care – are they not going soon enough or too late.
- If there is a way to link things to other data streams in the future so questions could be answered.
- One aspect the Sickle Cell Surveillance Subcommittee noticed about the 2021 report was the large number of visits or individuals where the ages were unknown, and if the TxS2 team had a chance to look at it.
- The distribution around counties that are less populated compared to population centers showed they had a significant number of individuals who utilized care, and if that speaks to maybe the individuals in those counties not having a primary care provider or someone managing their chronic health needs and are going to the emergency room, and the need to target those areas for the ECHO program or outreach.
- Clarifying what months made up a year for collecting the data.

### **Agenda Item 6: Sickle Cell Surveillance Subcommittee reporting**

Dr. Fasipe introduced Dr. Melissa Frei-Jones, Subcommittee Chair. Dr. Frei-Jones presented to the members the Sickle Cell Surveillance Subcommittee Report.

### **Highlights of the presentation included:**

- At the July 28 meeting, members selected Dr. Frei-Jones to be subcommittee chair.
- Linc Allen and Yallu Sivaprakash, TxS2, Division RLHO, DSHS, presented the TxS2 2021 annual report.

- The subcommittee noted sickle cell patients have far more emergency room visits than cystic fibrosis, another childhood onset genetic disease used often in comparison in terms of resources and limitations of the TxS2 data.

#### 2022 Legislatively Mandated Report Recommendations

- Dr. Frei-Jones lead discussion regarding recommendations from the surveillance subcommittee for the next report to the legislature.
- Dr. Frei-Jones highlighted the items identified that could be incorporated in a state surveillance program.
- Last year, the subcommittee recommended including various reports included as an addendum, but this was not consistent with recommended report format.
- Recommend DSHS publish a report about sickle cell disease using data from syndromic surveillance, vital statistics, and Medicaid data.
- Continue to recommend the establishment and maintenance of a universal sickle cell surveillance data collection system.
- State initiated surveillance versus participation in Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) program.
- Limitations of identifying a coordinating center and grant principal investigator within state versus public versus private versus university collaboration.
- Dr. Jamie Barner, University of Texas at Austin College of Pharmacy and Director of the Texas Center for Health Outcomes Research & Education (TxCORE) reported familiarity with grant participation and has collaborated with the Center for Health Care Data (CHCD).
- New recommendation: develop collaboration with or between CHCD and TxCORE.

#### Next steps

- Consider inviting the Michigan group back to have a combined meeting with TxCORE and CHCD and one of the other state CDC groups to explore how things were set up with other institutions.
- Attend the National Heart Lung and Blood Institute (NHLBI) sickle cell research meeting, which had a large section on surveillance.

#### **Members discussed:**

- Commending the subcommittee for their work, which shows how much work they must do and the progress they're making.
- Hesitancy about the right timing to go to the national level.
- The NHLBI has the meeting recordings on their website.

- CDC will announce the award in March 2023, and it would make sense for Texas to join as soon as they can but do it the right way.
- What the decision-making model is for determining whether Texas has reached the threshold of deciding to join the national CDC data collection effort, such as what the bare minimum list of items Texas needs.
- How to reach out to colleagues with the same goal to improve sickle cell disease care and maybe partner with them.

### **Agenda Item 7: Medicaid Contracts Subcommittee reporting**

Dr. Fasipe presented to the members the Medicaid contracts Subcommittee Report on behalf of Dr. Alecia Nero.

#### **Highlights of the presentation included:**

- The subcommittee has been trying to partner with the Medicaid medical directors and other key officials on two levels – on education to make sure each payer is aware of the sickle cell disease guidelines and how important it is for every person with SCD to get care based on those guidelines and on learning about resources within each payer model that may benefit people with SCD.
- Dr. Lisa B. Glenn, Senior Associate Medical Director, Office of the Medical Director, HHSC, Medicaid and Children’s Health Insurance Program (Medicaid & CHIP) Services and Dr. Ryan D. Van Ramshorst, Chief Medical Director, Office of the Medical Director, HHSC, Medicaid & CHIP Services were guests
- Members also asked how the 340B Drug Pricing Program could be applied to sickle cell therapeutics.
- Dr. Glenn stated this would require changes on a federal level and suggested talking to hospitals and medical providers who have worked with the 340B program.
- The Children’s Hospital Association of Texas may have thoughts or suggestions
- Members also inquired about Medicaid & CHIP Services eligibility for patients losing coverage between ages 18-21, and if they could qualify for extended coverage at least through the transition period
- Dr. Van Ramshorst explained how Medicaid eligibility works and that it would require legislation
- There is the concept of waivers and understanding how you can remain eligible with a disease like SCD by extending eligibility based on disease severity and other factors, not on the SCD diagnosis by itself.
- Dr. Van Ramshorst and Dr. Glenn recommended looking into options of waivers and thinking about products such as STAR Kids.

#### Next steps

- Get an introduction through the Medical Directors team to existing committees that may be able to advise on areas of optimization and waivers



- Including Community Health Workers in a discussion about value-based payments
- Get introductions with the Value-based Payment and Quality Improvement Advisory Committee
- Look into structure of value-based payments in oncology

#### 2022 Legislatively Mandated Report Recommendations

- Increase eligibility age of individuals with SCD throughout the lifespan

#### **Members discussed:**

- How Michigan was able to use surveillance data to improve insurance coverage, and how having appropriate surveillance information could help in Texas

#### **ACTION ITEMS:**

- Dr. Fasipe will present to the SMMCAC at their August 25 meeting.
- Dr. Van Ramshorst introduce them to the Children’s Hospital Association of Texas representatives to discuss the 340B program or something similar
- Dr. Glenn will send information for signing up for waiver interest lists.

#### **Agenda Item 8: Public Awareness Campaigns Subcommittee reporting**

Dr. Fasipe presented the Public Awareness Campaigns Subcommittee report on behalf of Ms. Priscilla Hill-Ardoin, as she was not able to attend the subcommittee meeting.

#### **Highlights of the presentation included:**

- Mrs. Reed-Shackelford met with NBS program staff and Dr. Amy Nathan-Wright on August 2, but no other subcommittee members were able to join.
- Program staff rescheduled the official subcommittee meeting for August 10, during which only Dr. Nero was able to attend, and they discussed how to move forward with the Human Dimensions of Organizations (HDO) project for the Fall 2022 semester.
- Ms. Millangue sent an email to Dr. Wright on the subcommittee’s behalf to commit to the Fall 2022 semester and worked with the subcommittee on completing an HDO survey with information about an ask and subcommittee member availability during the semester.
- Ms. Millangue sent an email to Task Force members for their survey feedback prior to the Task Force meeting.

#### **Members discussed:**

- Finalizing the survey responses, including sharing subcommittee member contact information, since they will represent the Task Force in meetings with the students, priorities, and expectations for deliverables.
- Clarifying if meetings will be in person or virtual.
- The project will focus on awareness among college students, which is one of the Task Force’s recommended actions.
- Deliverables may include a list of contacts at colleges and universities, recommendations on how to improve social media outreach, and identify opportunities to capture the college-age audience’s attention and maintain their engagement, especially as they think about their own future families.
- The final meeting with students in November may be in-person.
- Highlighting September Sickle Cell Awareness month, World Sickle Cell Day, importance of the bone marrow donor program, and women’s health and family planning or preconception counseling.

**ACTION ITEM:**

- Ms. Millangue will email the final survey due to Dr. Wright on August 22 after the meeting.

**Agenda Item 9a: Legislatively Mandated Report - Subcommittee reporting**

Dr. Fasipe reminded members they received a copy of the annual report and then presented the Legislative Mandated Report (LMR) Subcommittee report.

**Highlights of the presentation included:**

- Subcommittee members met August 9 and went through the draft report, which each of the members divided up.
- Some areas are similar year to year, such as the introduction and background.
- In the areas for actions for the past year and thoughts for the future, they wanted to make sure they reflected each subcommittee’s work appropriately, and the Task Force’s feedback is needed.

**Members discussed:**

- Members did not have a discussion for this agenda item.

**Agenda Item 9b: Legislatively Mandated Report – Consideration of draft legislatively mandated report for approval**

Dr. Fasipe called Ms. Aimee Millangue to go over proposed edits. Ms. Millangue then reviewed the draft LMR with the Task Force, led the discussion over the members’ proposed

edits and comments, and shared her screen to make additional edits live during the meeting based on member feedback.

**Highlights of the presentation included:**

- The table of contents will be updated as needed for each draft and the change was made in response to Dr. Fasipe's comment to include subheads for future activity and Task Force actions.
- Specific language that was added to the 2021 standing recommendations.
- The six recommended actions for the 2022 report.
- Minor corrections included spelling out acronyms and including acronyms where appropriate.
- Citations were updated to make sure web links were still accessible.
- Program staff made minor grammatical edits and added links to other parts of the report when appropriate.

**Members discussed:**

- How to express minor changes were made to the 2021 recommended actions for the 2022 report.
- Clarifying that the sunset date is September 1, 2025.
- The All-Payer Claims Database will include Medicaid, Medicare, Children's Health Insurance Program, and private insurance.
- Making the recommended action on increasing the number of members to a minimum of 15 versus maximum of 12 or 15 so that each subcommittee can have at least one additional person.
- Whether justification is needed for extending the sunset date and where to include it in the report.
- Whether wording of recommended actions should state "studying feasibility" or "develop" and "increase" or "study the feasibility of increasing."
- Using more powerful, direct language.
- Making sure the wording of the recommended actions is consistent throughout the report.
- Removing repeated words and adding language to and rephrasing some sections.
- Subcommittee members followed instructions to use the same language as last year's report in some sections and shortened others.
- Correcting references to the year.
- Adding additional links to other sections of the report where appropriate.

- Whether to include appendices that were removed in the editing process of the 2021 annual report.

**ACTION ITEMS:**

- Ms. Millangue will add some information on social media posts and website views missing from the draft and an Appendix D.
- Program staff will make non-substantiative edits for consistency and grammar.

Dr. Fasipe thanked everyone and requested a motion to approve the draft.

**MOTION:** Ms. Hill-Ardoin motioned to approve the draft 2022 LMR with the changes that were done. Dr. Dawn Johnson seconded the motion. Ms. Buck-Ragland conducted a roll call vote, and approve the draft report prevailed.

Dr. Fasipe called for a motion to allow for the Chair, Dr. Fasipe, to make any necessary non-substantiative final edits to the 2022 LMR prior to submission.

**MOTION:** Mrs. Reed-Shackelford motioned to authorize the Chair to make non-substantive changes or edits as necessary. Dr. Frei-Jones seconded the motion. Ms. Buck-Ragland conducted a roll call vote and authorizing the Chair to make non-substantiative final edits to the LMR prior to the routing process to DSHS and HHSC Commissioners by December 1, 2022 prevailed.

**Agenda Item 10: Public Comment**

No public comment was received for this meeting.

**Agenda Item 11: Future agenda items, next meeting date, and adjournment**

Dr. Fasipe stated the next meeting is scheduled for December 1, 2022 and opened the floor for discussion of future agenda items.

**Members discussed:**

- Subcommittee reports
- HDO report, if students can present
- If new members will be appointed by the December meeting and having an agenda item to welcome new members.

Dr. Fasipe then asked Ms. Aimee Millangue, DSHS NBS Unit, to recap any action items and topics for the next meeting that members may have missed.

**ACTION ITEMS:**

- Pause the Legislatively Mandated Report Subcommittee.

- Program will follow up with Dr. King’s contact at the University of Missouri at Columbia for more information about the Project ECHO reimbursement model.
- Program will follow up on duplication component of Syndromic Surveillance data.
- Subcommittee Reports
- Ms. Millangue will email webinar links.
- Invite staff from CHCD, UT College of Pharmacy and other states’ surveillance programs to attend the next Sickle Cell Surveillance Subcommittee meeting.
- Task Force members will submit agenda items by November 1.

Dr. Fasipe thanked everyone and adjourned the meeting at 4:47 p.m.

Below is the link to the archived video of the August 19, 2022 Sickle Cell Task Force meeting that will be available for viewing approximately two years from the date the meeting was posted on the website and based on the DSHS records retention schedule:

[Sickle Cell Task Force Meeting August 19, 2022](#)