

**Sickle Cell Task Force
Meeting Minutes**

May 27, 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 called the meeting to order at 12:05 p.m. and welcomed everyone in attendance.

Dr. Fasipe introduced and turned the floor over to Mr. John Chacón, Texas Health and Human Services Commission (HHSC), Policy & Rules, Advisory Committee Coordination Office (ACCO). Mr. Chacón reviewed logistical announcements, conducted a roll call, and announced the presence of a quorum.

Dr. Fasipe welcomed Karen Hess, Director, Texas Department of State Health Services (DSHS), Newborn Screening (NBS) Unit, asked her to introduce herself, and that as she called on program staff members, Dr. Debra Freedenberg, Aimee Millangue, Laura Arellano, Gwen Hanley, and Julianna Ybarbo they would provide a brief introduction.

Dr. Fasipe also welcomed Ms. Tessa Buck-Ragland with ACCO and stated she will provide facilitation for the meetings going forward.

Dr. Fasipe then offered opening remarks. She requested a moment of silence to honor the tragedy in Uvalde and a period of reflection for the work that everyone in attendance does for sickle cell disease and the community that is affected in Texas.

Table 1. Sickle Cell Task Force member attendance at the Friday, May 27, 2022 meeting.

Member Name	In Attendance
Dr. Titilope Fasipe	Yes
Dr. Melissa Frei-Jones	Yes
Ms. Priscilla Hill-Ardoin	Yes
Dr. Dawn Johnson	Yes
Dr. Alecia Nero	No
Mrs. Marqué Reed-Shackelford	Yes
Ms. Alysian Thomas, J.D.	Yes

Yes: Indicates attended the meeting

No: Indicates did not attend the meeting

Agenda Item 2: Consideration of April 1, 2022 draft meeting minutes

Dr. Fasipe reminded members that the April 1, 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 April 1, 2022 meeting minutes.

MOTION: Mrs. Marqué Reed-Shackelford motioned to approve the April 1, 2022 meeting minutes as presented. Ms. Priscilla Hill-Ardoin seconded the motion. Mr. Chacón conducted a roll call vote, and the motion carried unanimously with no objections or abstentions.

Agenda Item 3: University of Texas College of Pharmacy presentation

Dr. Fasipe introduced and turned the floor over to Dr. Jaime Barner, Klinck Centennial Professor and Division Head, Health Outcomes Division, University of Texas at Austin and Co-Director, Texas Center for Health Outcomes Research and Education (TxCORE) and Dr. Hyeun Ah Kang, Assistant Professor, Health Outcomes Division, University of Texas at Austin, College of Pharmacy, and member of TxCORE. Dr. Barner and Dr. Kang referenced the PowerPoint and handout, Sickle Cell Disease (SCD) Research.

Highlights of the presentation included:

- List of their sickle cell disease-related publications and podium/poster presentations
- Use of Texas Medicaid data and retrospective secondary data analysis
- General study methodology
- Overview of sickle cell disease-related studies, objectives, results, and conclusions
 - ▶ Age-related medication and healthcare utilization
 - ▶ Hydroxyurea adherence and relationship to outcomes
 - ▶ Opioid use and relationship to outcomes
 - ▶ Sickle cell disease-related healthcare utilization and costs
 - ▶ Unintended consequences of Centers for Disease Control and Prevention (CDC) opioid guidelines
- Current and future studies
 - ▶ What factors are associated with adult patients' willingness to go to the emergency department (ED) when in pain? (Working with the Sickle Cell Association of Texas Marc Thomas Foundation)
 - ▶ What is the prevalence of sickle cell disease (SCD) complications by age group?
 - ▶ Examine differences during transition periods
 - ▶ What are the relative impacts of the CDC 2016 guidelines on patients with SCD compared to those in other populations?
 - ▶ Do the revised CDC guidelines change the trends in opioid prescribing and pain-related health outcomes among SCD population?
 - ▶ Do patients who live close to a comprehensive sickle cell center receive better care and have better health outcomes than those who do not?
 - ▶ How the new pharmaceutical therapy options for treatment of SCD have been used?
 - ▶ What is the comparative effectiveness of the new pharmaceutical therapy options for the treatment of SCD?
 - ▶ Telemedicine use among patients with SCD during COVID pandemic
 - ▶ How transfusion is being used in the ED setting to treat vascular occlusive crisis among patients with SCD? Is the use of transfusion in ED settings associated with decreased opioid use?

Members discussed:

- Definition of “index therapy”
- Definition of “non-opioid”
- Whether data could be drilled down further, such as by institution, region/location, or prescriber
- If studies included all formulations of hydroxyurea
- If there is a way to delineate hydroxyurea use based on *International Classification of Diseases, 10th revision* (ICD-10) diagnosis codes
- When looking at hospital-dependent data, if it is possible to drill down to indication for a visit, such as fever
- Data only includes outpatient claims only
- Whether data on age-related SCD complications goes up only to age 63 due to transition at that age to Medicare
- If there are significant changes between pre-death and post-death data
- If there is interest in conducting research on why people choose not to take hydroxyurea
- If there is any difference demographically in patients’ adherence to hydroxyurea
- Using data from the studies to set some targets and goals for the state of Texas in terms of quality improvement
- Appreciation to Dr. Barner and Dr. Kang for their research

ACTION ITEM: Dr. Kang will share the research paper that is pending publication once it is available.

Agenda Item 4: Medicaid Contracts Subcommittee Reporting

Dr. Fasipe reviewed the handout, *Medicaid Contracts Subcommittee Report* and led discussion with members.

Highlights of the presentation included:

- Membership now includes Dr. Fasipe, Dr. Dawn Johnson, and Dr. Alecia Nero
- Subcommittee met on May 2 and discussed:
 - Where they wanted to take the subcommittee next
 - Their activities over the past year, such as meeting with the Medicaid Medical Directors and getting bidirectional education. Members provided education about SCD and received education on Medicaid processes.
 - During COVID, Texas children could receive Medicaid coverage up to age 21 instead of at the age of 18
 - Targeting what benefits each of the Medicaid payors could offer to address the drop in the percentage of individuals with SCD getting Medicaid coverage when they reach 18 or 21 years old
 - The pediatric population going through transition to adult care is at high risk, and it makes sense that prescriptions dropped off in the transition age, even from the healthcare access
 - Concept of medical home and Dr. Johnson’s experience through the pediatric lens, and continuing to look at the idea of a comprehensive care model for SCD to improve outcomes and reduce disparities
 - Next steps

Members did not have a discussion for this agenda item.

Agenda Item 5: Public Awareness Campaigns Subcommittee Reporting

Dr. Fasipe introduced and turned the floor over to Ms. Priscilla Hill-Ardoin, Subcommittee Chair. Ms. Hill-Ardoin reviewed the handout, *Public Awareness Campaigns Subcommittee Report*.

Highlights of the presentation included:

- Subcommittee includes Ms. Hill-Ardoin, Dr. Nero, and Mrs. Reed-Shackelford
- Subcommittee met and discussed:
 - ▶ The status of the University of Texas Human Dimensions of Organizations Program (HDO) project, pending a response from Dr. Amy Nathan-Wright
 - ▶ Mrs. Marqué Reed-Shackelford and the Newborn Screening staff briefly recapped the task force's and subcommittee's work with HDO for new subcommittee member, Ms. Hill-Ardoin
 - ▶ Defining a specific ask for the HDO program to engage them on what exactly does it take to create an effective well-rounded statewide sickle cell awareness campaign
 - ▶ Selection of a subcommittee chair. Subcommittee members asked Ms. Hill-Ardoin to serve as Chair and for Mrs. Reed-Shackelford to serve as back up.
 - ▶ How the subcommittee operates with a \$0 budget
 - ▶ Needs of public awareness education and requirements of developing a state plan
 - ▶ Any recommendations to the task force should include an estimate of the resources and budget requirements, and members agreed
 - ▶ How to promote Sickle Cell Awareness Month, such as using the angle of the provision of National Collegiate Athletic Association (NCAA) requirements, featuring the video Dr. Fasipe recorded for Sickle Cell Awareness Month in 2021, and issuing press releases that spotlight some of the statewide data available
 - ▶ Not having enough time to promote Sickle Cell Awareness Day in June 2022, but requesting an effort to recognize the date in 2023
 - ▶ Action items include DSHS staff following up with Texas Health and Human Services Communications for World Sickle Cell Day 2023 and Dr. Nathan-Wright with the HDO program for the Fall 2022 semester
 - ▶ Recommendations for the 2022 Sickle Cell Task Force annual report:
 - ◇ Increasing the membership of the task force to facilitate the efficient work of subcommittees, since it could be difficult for the subcommittees to meet with fewer than a quorum of seven members
 - ◇ Developing future recommendations specifically related to Community Health Workers
 - ◇ Promote funded projects in rural areas to connect doctors to sickle cell specialists

Aimee Millangue, Advisory Committee Liaison, DSHS, NBS Unit, added that the subcommittee had also discussed that members could present at one of the Community Health Workers stakeholder group meetings and the idea of promoting sickle cell awareness through a Grand Rounds.

Public Comment: Dr. Kang asked if the task force has a subcommittee working on the topic of increasing awareness in Emergency Departments.

Members discussed:

- In response to Dr. Kang's public comment, the subcommittee being willing to engage with various consultant and stakeholder groups on targeted messages
- If the NCAA requirements are related to sickle cell trait testing
 - ▶ Ms. Aimee Millangue, Advisory Committee Liaison, DSHS, NBS Unit, replied that the NCAA requirements is related to the provision of sickle cell trait testing results upon participation.
- If the subcommittee has concerns for barriers to the plan for a press release spotlighting state-specific data

- ▶ Ms. Millangue replied that the role of the subcommittees is to provide recommendations, so it would be something to think about including in a recommendation
- Possible Grand Rounds topics that target specific groups such as emergency medicine or family medicine
- Various healthcare institutions also have Grand Rounds that the task force could explore as a means of spreading awareness
- The possibility of making a new video for Sickle Cell Awareness month
 - ▶ Ms. Laura Arellano, Unit Coordinator, DSHS, NBS unit, stated that the DSHS NBS program is working with Communications, so members should feel free to bring up anything they would like to put forward
- Ms. Alysian Thomas asked if DSHS could coordinate a Facebook or Instagram Live event with a doctor answering questions from the public

ACTION ITEM: Ms. Arellano will reach out to Communications to see if a Facebook or Instagram Live could be a possibility.

Agenda Item 6: Sickle Cell Surveillance Subcommittee Reporting

Dr. Fasipe introduced and turned the floor over to Dr. Melissa Frei-Jones, subcommittee member. Dr. Frei-Jones reviewed the handout, *Sickle Cell Surveillance Subcommittee Report*.

Highlights of the presentation included:

- Dr. Johnson and Dr. Frei-Jones met on May 10 and discussed that, due to not having full attendance, that they table selection of a subcommittee chair until their next meeting
- Subcommittee goals are to identify pieces of data and information that are available in Texas that DSHS could use to produce a sickle cell surveillance report and explore the feasibility of Texas participating in the larger CDC sickle cell surveillance program.
- The Center for Health Care Data (CHCD), University of Texas in Houston, School of Public Health, presented at the May 10 subcommittee meeting, and the subcommittee learned more about data that could be used in surveillance based on the data CHCD has access to
- Legislation established an all-payor claims database (APCD) that will collect both private insurance, Medicaid, CHIP, and Medicare data all in one place and assigned the development of the APCD to CHCD
- CHCD also presented their work on a sickle cell project looking at prevalence, utilization, and cost, which is available on their public website, healthoftexas.org
- Subcommittee also learned about CHCD's capabilities, experience with data use agreements and applying for grants, and how they could collaborate with DSHS to be part of the CDC sickle cell surveillance program
- A review of the data the subcommittee had identified was available the last year – Texas Medicaid and CHIP data, Syndromic Surveillance data, and Vital Statistics data
- Next steps

Public Comments: Dr. Barner stated that as Co-Coordinator of TxCORE, she works with Trudy Krause of CHCD, but did not know that they had done work in sickle cell. She will look at their website. Dr. Barner also offered that if the subcommittee wants to reach out, she and Dr. Kang could discuss with the subcommittee further how they could collaborate on sickle cell surveillance.

Dr. Kang stated that she received market data through CHCD and experienced submitting a grant with CHCD. Dr. Kang also stated that the task force should look at Medicare data as well. She added that Health and Human Services can be the one who links the data without violating privacy or confidentiality and would love to be involved in conversation about it.

Members discussed:

- Inviting Dr. Barner and Dr. Kang to a sickle cell surveillance subcommittee meeting
- Some of the background on what subcommittee is trying to decide on – recommending that Texas does their own surveillance system or figure out a way for Texas to participate in the CDC surveillance program
- The task force is trying to find away so clinical providers are not competing for a grant by trying to identify if there is a center, or university-based or academic program that could serve as a primary coordinating center
- Dr. Fasipe said that the work of the surveillance subcommittee energizes her the most because it gives them a way to provide data which allows for accountability to those who have the disease and their families
- Recapping the four areas of data that the subcommittee has uncovered and if Vital Statistics was included
- Dr. Fasipe had a question for DSHS staff about the recommendation from the Public Awareness Campaigns Subcommittee about increasing the task force’s size and whether individuals can participate at advisory committee meetings and subcommittee meetings even if they are not official members
- If the task force was able to have an increase the total number of members, if each subcommittee could then have more members

Public Comment: Dr. Kang stated that anytime she looked at data, it was always California and Georgia and asked where is Texas? She added that they are happy to be involved in the process and to try to find the best solution.

Agenda Item 7: Legislatively Mandated Report

Dr. Fasipe reviewed the handout, *2022 Legislative Mandated Report Subcommittee Report*, and led a discussion with members.

a. Subcommittee reporting

- Part of the task force’s charge is of submitting a Legislatively Mandated Report every year
- The first report in 2020 set up milestones for the task force
- In 2021, the task force had recommendations
- In 2022, the task force will decide on new recommendations or on modifications to former recommendations
- DSHS staff had a preliminary kick off meeting to make sure the task force received correct guidance regarding how they draft their report
- The task force is charged with focusing on recommendations
- The task force could focus on how to spotlight the information they value and want people to know and use the recommendations to elevate the spotlight
- Dr. Fasipe, Dr. Frei-Jones, and Mrs. Reed-Shackelford met on May 17 and divided parts of the report among themselves
- The subcommittee needs help of all the members and found it effective in 2021 when each of the subcommittees gave at least one recommendation to the whole task force

b. Planning

- If members would like to take the time during the meeting to discuss possible recommendations
- If members would like a period of reflection and the deadline by when they should submit recommendations to the Legislatively Mandated Report Subcommittee before they develop their first draft
- How the subcommittees could provide recommendations to Legislatively Mandated Report Subcommittee or the full task force without violating the Open Meetings Act
 - ▶ Mr. Chacón stated that for other advisory committees, members submit any information to a dedicated email address for the task force and the liaison puts that information out back to them via blind carbon copy
- Making the meeting a working meeting as much as possible, but using the blind copy format for edits later
- For members to keep in mind that the 2021 Sickle Cell Task Force Annual Report recommendations have not yet been presented to the HHSC Executive Council but will be at a meeting later this summer
- Framing recommendations as things for DSHS to do
- Emphasizing continuation of recommendations and new recommendations
- Sickle Cell Surveillance Subcommittee Recommendations
 - ▶ Continue to recommend that DSHS publish an annual Texas sickle cell report based on data from the DSHS NBS Unit, DSHS Texas Syndromic Surveillance System, and DSHS Center for Statistics and expand the recommendation to include Medicaid data
 - ◇ Makes sense to be broad
 - ◇ A press release can be issued about the availability of the data
 - ▶ Continue to recommend the establishment of a sickle cell data collection system but specify that DSHS begin the steps to establish sickle cell surveillance in state of Texas
 - ▶ Recommend that DSHS explore how Texas can participate in the CDC grant program for Sickle Cell Data Collection
- Public Awareness Campaigns Subcommittee Recommendations
 - ▶ Continue to include two recommendations on public awareness campaigns from 2021, but modify the recommendations so that the public awareness campaigns have funding
 - ◇ Include issuing press releases for Sickle Cell Awareness Day in June and Sickle Cell Awareness month in September
 - ▶ Increase the number of members on the task force
 - ▶ Make a goal for 2023 to develop recommendations on funding projects in rural areas and Community Health Workers
- Medicaid Contracts Subcommittee Recommendations
 - ▶ Continue to recommend facilitating collaboration HHSC Medicaid and CHIP Services to study current sickle cell care guidelines and studying feasibility of integrating non-pharmacological alternatives into care packages of bundled services for patients with SCD
 - ▶ Recommend that Medicaid and CHIP programs extend the age of eligibility for their services for patients with sickle cell disease from age 18 to 26
 - ▶ Work on future recommendations regarding medication coverage, providing access to therapies, and medical homes
 - ▶ Recommend that DSHS partner with Medicaid or Managed Care Organizations to develop SCD quality metrics for SCD based on national guidelines for SCD care

- Emphasizing in the conclusion of the report the task force's top-line recommendations

PUBLIC COMMENT: Dr. Barner stated that their data goes from ages 18 to 25, so 26 would be a good recommendation.

Agenda Item 8: Sickle Cell Task Force Rules

Dr. Fasipe introduced and turned the floor over to Ms. Arellano, and she provided an update to the members and responded to questions.

Highlights included:

- A brief background - HHSC and DSHS are in the process of repealing Texas Administrative Code Title 25, Chapter 37, Subchapter R for the Sickle Cell Advisory Committee, 37.420. The rule will be replaced with a new 37.420 governing the Sickle Cell Task Force
- The reason for the strike and repeal is that that the Sickle Cell Advisory Committee rules are no longer needed, so DSHS is complying with state legislation.
- The proposed new rule establishes the task force composition, roles, responsibilities, and abolishment date
- DSHS is still making changes to the draft, and the latest version is under review with the Governor's office
- After review by the Governor's office, the rules will go back to the HHSC Executive Commissioner
- DSHS will work on finalizing the packet and on July 22, NBS program staff expect that the rules will go to the Texas Register for publication; at that point, DSHS can receive public comment
- NBS program staff will let the task force know when the rules are published, and Ms. Millangue or Ms. Arellano will send an email to the task force members, who can make public comment as individuals
- Public comment will go through August 22; the rule packet will be presented at the Executive Council meeting on August 18, when it is expected to be finalized and effective.
- DSHS has November 21 as the rule effective date as of May 27.

Members did not have a discussion for this agenda item.

Agenda Item 9: Public Comment

No public comment was received for this meeting.

Agenda Item 10: Future agenda items, next meeting date, and adjournment

Dr. Fasipe stated the next meeting is scheduled August 19, 2022 and opened the floor for discussion of future agenda items. Dr. Fasipe added that they will have the standing items of their subcommittee reports and turned the floor over to Ms. Millangue to recap action items and topics for a future meeting.

Members and NBS program staff discussed:

- If the task force is interested in inviting Linc Allen to present an updated Syndromic Surveillance report for 2021
- Address public awareness and outreach to rural areas by inviting someone to present to the Public Awareness Campaigns Subcommittee or the full task force from Project ECHO (Extension for Community Healthcare Outcomes)/Heartland Southwest or the United States Health Resources & Services Administration

ACTION ITEMS:

- Dr. Fasipe will provide presenter contact information to NBS program staff

- The task force subcommittees will work on detailing recommendations discussed during the meeting and members can email thoughts directly to the task force liaison, Aimee Millangue, who will send out the information back out via blind copy
- NBS program staff will continue looking into how data left out of the 2021 Sickle Cell Task Force Annual report can be shared or published
- Invite a representative from the HDO program to get input on developing a concrete ask and to get a timeline on when a concrete ask is needed
- The Public Awareness Campaigns Subcommittee will complete a survey for HDO that includes details about the ask, and the subcommittee will review the survey with the full task force at the August meeting
- Members will brainstorm some tangible asks of the Community Health Workers program
- NBS Program staff will invite staff from DSHS Government Affairs to present or be available at the Legislatively Mandated Report Subcommittee meeting to answer questions about the 2022 report
- Invite Dr. Barner and Dr. Kang to the Sickle Cell Surveillance Subcommittee to discuss collaboration on sickle cell surveillance

Dr. Fasipe thanked everyone and adjourned the meeting at 3:49 p.m.

Below is the link to the archived video of the May 27, 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:

<https://texashhsc.new.swagit.com/videos/174682>