

**Sickle Cell Task Force
APPROVED Meeting Minutes
April 08, 2021
1:00 p.m.**

Microsoft Teams Live Event

Table 1: Sickle Cell Task Force member attendance at the Thursday, April 8, 2021 meeting.

MEMBER NAME	IN ATTENDANCE
Dr. Titilope Fasipe	No
Dr. Melissa Frei-Jones	Yes
Dr. Michelle Mackey	Yes
Dr. Alecia Nero	Yes
Ms. Tonya Prince	Yes
Ms. Marqué Reed-Shackelford	Yes (Arrived at Agenda Item #4)
Ms. Alysian Thomas, J.D.	Yes

Agenda Item 1: Welcome and Introductions

Dr. Michelle Mackey, Chair of the Sickle Cell Task Force (SCTF), called the meeting to order at 1:02 p.m. and welcomed everyone in attendance. Dr. Mackey provided opening remarks and asked the agency staff to introduce themselves.

Agenda Item 2: Task Force Logistical Announcements, Roll Call

Dr. Mackey introduced and turned the floor over to Ms. Sallie Allen, HHSC, Policy & Rules, Advisory Committee Coordination Office (ACCO). Ms. Allen introduced and announced that Eric Owens, a new ACCO staff member, will assume the role of facilitator at the next meeting. Ms. Allen reviewed logistical announcements, conducted a roll call, asked members to introduce themselves, and announced the presence of a quorum.

Agenda Item 3: Review and Approval of Meeting Minutes from November 20, 2020

Dr. Mackey requested a motion to approve the November 20, 2020 meeting minutes.

MOTION: Ms. Tonya Prince motioned to approve the November 20, 2020 meeting minutes. Dr. Melissa Frei-Jones seconded the motion. Ms. Allen conducted a roll call vote, and the motion carried with no objections and no abstentions.

Agenda Item 4: Review of 2020 Sickle Cell Task Force Annual Report

Dr. Mackey stated the task force members will have the opportunity to review the handout, *2020 Sickle Cell Task Force Annual Report*, and opened the floor for discussion.

Dr. Frei-Jones inquired about the status of the report, and Mr. David R. Martinez, Director, DSHS Newborn Screening (NBS) Unit, responded that the 2020 annual report was finalized in December 2020, submitted to HHSC and then to the Legislature. Mr. Martinez reminded everyone that the final version of the report was to be shared at the February meeting, which had to be rescheduled to April.

Members discussed:

- How well the report was written and put together
- How pleased they were with the level of detail and effort put into the report and the appendix
- The ability of the Task Force to come together on behalf of all Texans who live with sickle cell disease and for putting together a comprehensive report before the Legislature
- Thanked members for their work
- The recommendation that a subcommittee begin work on producing recommendations for and writing the next report, so a draft is ready for review at the summer meeting

Agenda Item 5: Review of Medicaid and CHIP Sickle Cell Disease Report T-MSIS Analytic Files 2017

Dr. Mackey referenced the handout, *Medicaid and CHIP Sickle Cell Disease Report T-MSIS Analytic Files 2017* and opened the floor for discussion.

Members discussed:

- The report was discussed at the last Sickle Cell Surveillance Subcommittee meeting and was presented by Medicare & Medicaid Services (CMS) staff at a recent Sickle Cell Coalition meeting attended by Dr. Frei-Jones
- Data from 2017, the first year for which the information on the CHIP and Medicaid recipients was able to be obtained.
- Hope for additional data as each year goes by
- The development of a one-page summary in addition to the report
- Data on the number of persons with sickle cell
- Data on the performance of transcranial doppler ultrasound (TCD) screenings to identify children at risk for stroke between the ages of 2-16
 - Supports the idea that a low number of these screenings are being done in practice
 - This is despite the fact sickle cell doctors agree this is a known way to benefit patients and availability of treatments
- Data suggests only a third of patients use hydroxyurea, despite the 2014 guidelines that it be used as a treatment
- Contents of report is a good stepping stone, in terms of data, to address what individual programs need to do to improve care among children with

sickle cell disease, such as how to increase stroke screening, improve hydroxyurea use, and penicillin/vaccination use.

- Data for the report was pulled from national Medicaid and CHIP data, not just specifically from Texas.
- Availability of a state-by-state breakdown of the report data
- National estimates for sickle cell disease

Agenda Item 6: Medicaid Contracts Subcommittee Reporting

Ms. Allen announced that Dr. Titilope Fasipe, subcommittee member, was not present to give the subcommittee report. Ms. Allen introduced and turned the floor over to Dr. Alecia Nero, subcommittee member. Dr. Nero referenced the handout, *Medicaid Contracts Subcommittee Meeting Minutes, February 3, 2021*.

Members discussed:

- Representatives from the different Managed Care Organization (MCO) health plans presented to the subcommittee on how they identify and serve members who have sickle cell disease and some of the services they provide to them
- Impressing upon the MCOs the unique needs of the sickle cell population and how care is delivered to them
- Variability in the guidelines among the different MCOs, so there is no standardization across organizations
- Prior grant opportunities that facilitated a partnership with medical teams in the Houston area to develop a unique care model for individuals with sickle cell disease
- Focusing on care coordination, population needs, definition of the medical home, barriers to care, how to share lessons learned across organizations, and the transitional age group
- Sharing summary and guideline information with the health plans
- Gaining an understanding of both sides of care delivery and the issues, barriers to providing timely care, and processes in place when developing ideas moving forward
- Appropriateness of recommending the inclusion of TCD screening as a component of services provided by Medicaid
- Highlighting what one of the Medicaid health plans is doing
 - Sending providers reminders about necessary services for sickle cell patients, such as using hydroxyurea and having a TCD done
 - Suggested working with other Medicaid plans to put these services into standard practice
- STAR Medicaid plans and polices are designed for patients with special needs, and may have more developed protocols than the health plans in other Medicaid and CHIP programs that serve a more general population.
- A Managed Care Service Areas map shows the various health plans that serve different regions of Texas depending on the Texas Medicaid and CHIP Program they fall under.

Agenda Item 7: Sickle Cell Surveillance Subcommittee Reporting

Dr. Mackey introduced and turned the floor over to Dr. Melissa Frei-Jones, subcommittee member. Dr. Frei-Jones referenced the handout, *Sickle Cell Surveillance Subcommittee Meeting Minutes, February 2, 2021*.

Members discussed:

- Mr. Linc Allen, Texas Syndromic Surveillance Coordinator, DSHS, presented to the subcommittee a PowerPoint, *The Texas Syndromic Surveillance System (TxS2)*. The presentation included the results of the updated data queries requested at the November 20, 2020 meeting. He also highlighted the limitations of the data available.
- The subcommittee developing a recommendation to have an annual report on the state of sickle cell disease based on Texas Syndromic Surveillance data. This report could be added to the Task Force's annual report moving forward.
- Mr. Allen put together a draft of a report that has been distributed to the subcommittee for their review and feedback. The formalized report will be shared with the full task force at the next meeting.
- There are limitations to working with administrative data but being able to share objective data with the Legislature would be helpful.
- Possibility of including information based on claims data about patients who are visiting the Emergency Room and knowing if they are coming in randomly or for sickle cell-related reasons, if they have a hematologist, or if they are not being seen by a primary care provider or a hematologist
- Enjoying working with the TxS2 program in trying to explore every opportunity to pull data, such as around lab codes, diagnosis codes, type of field, or medical record number
- Surprises in the regional per capita data that was captured in the draft of Mr. Allen's report

Agenda Item 8: Public Awareness Campaigns Subcommittee Reporting

Ms. Allen announced that Ms. Marqué Reed-Shackelford, subcommittee member, was not present to give the subcommittee report. Dr. Mackey and Dr. Alecia Nero, subcommittee members, referenced the handout, *Public Awareness Campaigns Subcommittee Meeting Minutes, February 5, 2021*.

Members discussed:

- Updates on efforts to reach out to other states regarding public awareness campaigns to use as a model for Texas for funding structures, outreach, education, and resources such as transition of care
- Developing a broader recommendation that utilizes existing programs as a framework for funding and improving access and outreach for sickle cell and tying in recommendations from the *2018 Sickle Cell Advisory Committee Annual Report*
- Including in a recommendation consideration of what areas of the state a public awareness campaign might focus on

ACTION ITEM: Utilize or include in a recommendation the University of Texas Human Dimensions of Organizations (HDO) program as a resource

Agenda Item 9: Review of Task Force Milestones

Dr. Mackey referenced the handout, *2020 Sickle Cell Task Force Annual Report*, and opened discussion to the Task Force for any updates to the milestones they previously developed and listed in their 2020 report.

Members discussed:

- Milestones for Public Awareness Campaigns
 - Tying COVID-19 into a campaign
 - Identifying champions or ambassadors
 - Utilizing online platforms to increase public awareness
- Milestones for studying Sickle Cell Surveillance
 - Communicating estimated sickle cell population in Texas
 - Working with Syndromic Surveillance
- Milestones for partnering with Medicaid/Medicare, Managed Care and Accountable Care Organizations
- Milestones for working with Community Health Workers (CHWs)
 - Address fee schedules and training modules
 - Working with CHWs during Sickle Cell Awareness month in September

ACTION ITEM: Program to work on ideas for September 2021 Sickle Cell Awareness month, a public awareness campaign, and recommend this work be ongoing for future Sickle Cell Awareness months.

Agenda Item 10: Development of Recommendations for the 2021 Sickle Cell Task Force Annual Report

Dr. Mackey opened the floor for discussion of the development of recommendations for the *2021 Sickle Cell Task Force Annual Report*.

Members discussed:

- Requirements for the legislative report
- How the subcommittees' work is leading to next steps
- Discussion during the meeting has identified some points that can be addressed and prioritized for making of the recommendations in the upcoming report.
- Meetings are not transcribed but are captured through high-level minutes. Copies of the presentations/handouts are also made available and not described in the meeting minutes.
- Records retention schedule for committee meeting recordings and the process for the public to have access and review

Agenda Item 11: Public Comment

No public comment was received for this meeting.

Agenda Item 12: Future Agenda Items/Next Meeting Date/Adjournment

Dr. Mackey opened the floor for discussion of future agenda items and stated the next meeting is scheduled for June 10, 2021.

Members discussed:

- Inviting Brett Spencer from the Community Health Workers program to present and have a discussion on the SCTF milestone objective.
- Subcommittees will continue to develop recommendations and present at next meeting.
- Subcommittees continuing to review Sickle Cell surveillance, public awareness campaigns and Medicaid contracts.
- The Legislatively Mandated Report Subcommittee (Drs. Frei- Jones, Fasipe, Mackey) that worked on the 2020 annual report will resume to meet and work on the 2021 annual report. If Dr. Fasipe is not available, Dr. Nero will assist in her place.

Dr. Mackey thanked everyone and adjourned the meeting at 2:43 p.m.

Below is the link to the archived video of the April 8, 2021 Sickle Cell Task Force (SCTF) 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://texashsc.swagit.com/play/04082021-1083>