Sickle Cell Task Force
Meeting Minutes
November 20, 2020
1:00 p.m.

Microsoft Teams Live Event

Table 1: Sickle Cell Task Force member attendance at the Friday, November 20, 2020 meeting.

MEMBER NAME	IN ATTENDANCE
Dr. Titilope Fasipe	Yes
Dr. Melissa Frei-Jones	Yes
Dr. Michelle Mackey	Yes
Dr. Alecia Nero	Yes
Ms. Tonya Prince	Yes
Ms. Marqué Reed-Shackelford	Yes
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 1:07 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 Ms. Sallie Allen, HHSC, Policy & Rules, Advisory Committee Coordination Office. Ms. Allen reviewed logistical announcements, conducted a roll call, ask members to introduce themselves, and announced the presence of a quorum.

Agenda Item 3: Review and Approval of Meeting Minutes from August 31, 2020

Dr. Mackey requested a motion to approve the August 31, 2020 meeting minutes.

MOTION: Dr. Melissa Frei-Jones motioned to approve the August 31, 2020 meeting minutes. Ms. Marqué Reed-Shackelford seconded the motion. Ms. Allen conducted a roll call vote, and the motion carried with no objections and no abstentions.

Agenda Item 4: Newborn Screening program’s follow up process for children identified with sickle cell

Dr. Mackey introduced Ms. Karen Hess, Genetics Branch Manager, DSHS, Newborn Screening Unit, and she referenced the handout presentation, *Newborn Screening Clinical Care Coordination.*

Members discussed:

- Appreciation for the presentation of information
- Overview of screening processes and notification process to parents and providers for each of the two screens
    - 1st, 2nd and 3rd tier Lab testing
    - Short term, long term follow-up
    - Sickle Cell trait notification
        - Sickle Cell trait notification has been in place for approximately 10 years
    - ACT and FACT sheets
- The Newborn Screening (NBS) Program has access to Vital Statistics' database of birth and death records as a resource but not for aggregate information
- The move to digital from paper forms was accelerated with the COVID-19 pandemic and will continue as systems to share information improve
- The NBS Program has protocols for children with abnormal screens
- Sickle Cell cases are followed up through age 18 and records are retained for 3 years – up to 21 years

Agenda Item 5: Texas Syndromic Surveillance (TxS2) System

Dr. Mackey introduced, Mr. Linc Allen, Texas Syndromic Surveillance Coordinator, DSHS, and he referenced the handout presentation, *Texas Syndromic Surveillance (TxS2) System.*

Members discussed:

- Acute chest syndrome was offered as an additional query for the surveillance team to investigate
- Clarification that the International Classification of Diseases, Tenth Revision (ICD-10) code-based queries identified the physician discharge diagnosis regardless of the chief complaint
- County level data reflects that there are some counties with no hospitals or free-standing Emergency Rooms
- The usefulness of the information and its representation of the state data
- 80% of facilities report into the system
- It may be helpful to query additional ICD-10 codes for describing sickle cell-related complications such as Acute Chest Syndrome and Splenic Sequestration
- Reviewing a broader sickle cell surveillance query and further analysis based on complications and regional trends

Agenda Item 6: Community Health Workers

Dr. Mackey introduced, Mr. Brett Spencer, Community Health and Wellness Branch Manager, DSHS, and he referenced the handout presentation, *Community Health Workers.*

Members discussed:

- Acknowledgement that the Community Health Workers (CHW) Training and Certification Program does not have a specific Sickle Cell education component, but there is sickle cell education for healthcare providers module in the Texas Health Steps education catalogue that is a a CME accredited course for CHWs
- Referenced other states efforts to reimburse CHW efforts with Medicaid and current reimbursement limitations with CHW services
- Process for getting curriculum approved for CHW use and possible additional curriculums available in the community
- Provide suggestion of how to engage CHWs to highlight awareness month

Agenda Item 7: Medicaid Medical Home

Dr. Mackey introduced, Ms. Laura Jourdan, Senior Policy Analyst, HHSC, Medicaid and CHIP Services, Policy and Program Development, to provide an update.

Members discussed:

- Community Health Worker services are not a payable benefit in the Medicaid state plan
- Clarification of the terms Medical Home, Health Home and Center of Excellence, including their use in the field
- Clarification on whether Sickle Cell diagnosis alone would qualify a person for Health Home services
- If there is a list of qualified Health Homes and how many providers are designated Health Homes in Texas
- Various performance measures that the Managed Care Organizations (MCO) develop for providers to qualify as Health Home participants, including per member per month (PMPM) participation
- Opioid exemption for Sickle Cell
- Including the patient’s medical specialists in the medical home model and identifying examples of need
- Issues with referrals needing to go through a patient’s primary care provider, and how it delays care. May be helpful to contact the provider hotline for the member’s MCO to request service coordination or service management for sickle cell to see if the MCO can assist in facilitating the referrals
- MCO limitations and benefit differences in various state Medicaid programs

ACTION ITEM: Ms. Jourdan will provide a list of the components of health home services and follow up if there is a list of providers qualified as Health Homes. Ms. Jourdan will also share the opioid exemption policy and address for the Vendor Drug Program mailbox for questions on denials and prior authorizations.

Agenda Item 8: Medicaid Contracts Subcommittee Reporting

Dr. Mackey introduced, Dr. Titilope Fasipe, Subcommittee member, to provide update.

Highlights included:

- Subcommittee presented at the quarterly MCO meeting on October 15, 2020
- Two health plans (Cook and Amerigroup) had processes and protocols for sickle cell interventions and subcommittee is following up for more information
- Discussion included Health Plan availability by region and acceptance of those plans by providers
- Committee looking to invite organizations to continue discussion on Medical Home services and examples from other states

Agenda Item 9: Public Awareness Campaigns Subcommittee Reporting
Dr. Mackey introduced, Ms. Marqué Reed-Shackelford**,** Subcommittee member, to provide update.

Highlights included:

- Clarification that a request for funding from pharmaceutical companies is not within the scope of the Task Force
- Discussed a no-cost opportunity to work with the University of Texas Human Dimensions of Organization Program
- Discussed findings of other state Public Awareness efforts and additional contacts to research

Agenda Item 10: Sickle Cell Disease Transactional Stress and Coping Model
Dr. Mackey introduced, Ms. Cierra King and she referenced the handout power point presentation, *Sickle Cell Disease Transactional Stress and Coping Model.*

Members discussed:

- Appreciation for the thoughtful presentation and advocacy efforts
- Improvement of care model needed to decrease hospitalization and readmission rates and combat Sickle Cell crises, mental health, prescription access and 20th century system need to keep up with 21st century
- Considering aspects from the presentation when defining adult and pediatric sickle cell centers and to include as criteria in those established centers

Agenda Item 11: Public Comment
Ms. Allen read the public comment logistical announcements and called on those registered for public comment.

Written public comment was received from:
Ms. Allen read aloud the written comment provided by Caroline Grossman and Joel de Jesus with Mirepoix, LLC. Members were provided a copy of the written document for reference. The commenters requested the Task Force recommend that red cell antigen testing for newborn sickle cell screening should be a covered benefit without preauthorization for the lifetime improvement in health outcomes and patience experience.

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 was scheduled for February 19, 2021.

Members discussed:

- 2020 Legislative Report is under review, is expected to be submitted on time and can be discussed at the next meeting
- Subcommittee reports will be included in the agenda for the next meeting
- Dr. Mackey called for the establishment of the Sickle Cell Surveillance Data Subcommittee to include Dr. Frei-Jones, Ms. Prince, and Ms. Thomas
- Dr. Frei-Jones will chair the Surveillance Data committee and be included in the next meeting – Task Force Chair does not need to take part in new Subcommittee
- Legislative Mandated Report Subcommittee will continue as a standing Subcommittee
- Next meeting will include Task Force milestone review
- Developing recommendations for the 2021 Legislative Report
- Deadline of January 4, 2021 to submit additional agenda items for the next meeting
- Referring Public Comment from Mirepoix, LLC, to Medicaid Contracts Subcommittee for additional discussion

Dr. Mackey adjourned the meeting at 4:38 p.m.

To listen to the archived recording of the November 20, 2020 meeting, go to:

http://texashhsc.swagit.com/play/11202020-945