Sickle Cell Task Force
FINAL APPROVED Meeting Minutes August 20, 2021
12:00 p.m.

Microsoft Teams Live Event

Table 1: Sickle Cell Task Force member attendance at the Friday, August 20, 2021 meeting.

MEMBER NAME	IN ATTENDANCE
Dr. Titilope Fasipe	Yes
Dr. Melissa Frei-Jones	Yes
Dr. Michelle Mackey	Yes
Dr. Alecia Nero	Yes (Joined at Agenda Item 3)
Ms. Marqué Reed-Shackelford	Yes
Ms. Alysian Thomas, J.D.	Yes

Agenda Item 1: Welcome & Introductions and logistical announcements

Dr. Michelle Mackey, Chair of the Sickle Cell Task Force (SCTF), called the meeting to order at 12:00 p.m. and welcomed everyone in attendance.

Dr. Mackey provided opening remarks and asked agency staff to introduce themselves. David R. Martinez, Director, Department of State Health Services (DSHS) Newborn Screening Unit, introduced himself and called on DSHS staff members Dr. Debra Freedenberg, Karen Hess, Laura Arellano, Aimee Millangue, and Christy Ryman to provide brief introductions.

Dr. Mackey introduced and turned the floor over to Eric Owens, Health and Human Services Commission (HHSC), Policy & Rules, Advisory Committee Coordination Office (ACCO). Mr. Owens reviewed logistical announcements, conducted a roll call, asked members to introduce themselves, and announced the presence of a quorum.

Agenda Item 2: Consideration of June 10,2021 meeting minutes

Dr. Mackey reminded members that the June 10, 2021 draft meeting minutes were sent to members via email for review and asked if they had any edits or changes. Dr. Mackey requested a motion to approve the June 10, 2021 meeting minutes.

MOTION: Dr. Melissa Frei-Jones motioned to approve the June 10, 2021 meeting minutes. Ms. Marqué Reed-Shackelford seconded the motion. Mr. Owens conducted a roll call vote, and the motion was majorly carried with five “for” votes, no objections, and no abstentions.

Agenda Item 3: Sickle Cell Data Collection (SCDC)

Dr. Mackey introduced Ms. Susan Paulukonis, Program Director, Tracking California and Principal Investigator, California Sickle Cell Data Collection (SCDC) Program, Dr. Angie Snyder, Research Associate Professor, Department of Public Management and Policy, and Director, Health Policy and Financing, Georgia Health Policy Center, Andrew Young School of Policy Studies, Georgia State University and Principal Investigator, Georgia SCDC Program, and Dr. Sarah Reeves, Assistant Professor, Department of Pediatrics, Susan B Meister Child Health Evaluation and Research Center and Principal Investigator, Michigan SCDC Program. Ms. Paulukonis, Dr. Snyder, and Dr. Reeves referenced and reviewed the PowerPoint and handout, *Sickle Cell Disease Surveillance: Challenges and Opportunities.*

Highlights of the presentation included:

- The sickle cell surveillance program has been around in some form since 2010 with California and Georgia leading the way in understanding how to conduct surveillance effectively and accurately
- The importance of having a team ready, having legal agreements figured out, and taking advantage of the resources from the Centers for Disease Control and Prevention (CDC) and the other states conducting surveillance
- Overall purpose of surveillance is to inform the management of public health programs and direction of public health policy
- Guiding principle: Accurate identification and longitudinal follow up is essential to improve health of those with SCD
- History of need for SCD surveillance systems in the US
    - Registry and Surveillance System for Hemoglobinopathies (2010-2012)
    - Public Health Research, Epidemiology, and Surveillance for Hemoglobinopathies (2012-2014)
    - SCDC Program (2015–ongoing)
- Necessity of multi-source data for SCD surveillance
- Methods and practices for SCDC surveillance systems
    - SCDC case definitions
    - Core and supplemental dataset requests by state
    - Data linkage and deduplication
    - Data gathering from Medicaid and discharge databases to pick up additional SCD cases
    - Lessons learned and potential challenges
- Use cases for SCDC data
    - Publications, data briefs, contributions to reports
    - Health education materials
    - Maps, prevalence data
    - Stakeholder uses

Members discussed:

- Who the coordinating centers are for each of the states
- How each state was able to get buy in from various clinical partners

- If there is a good representation of the clinical partners in each state or if any of the states have areas where they lack clinical data
- What Texas needs to put in place before including other partners
- What steps Texas can take to be in a good position for applying for a CDC grant in a future round of expansion of the SCDC program

Agenda Item 4: Texas Syndromic Surveillance (TxS2) Annual Report

Dr. Mackey introduced and turned the floor over to Linc Allen, Texas Syndromic Surveillance (TxS2) Coordinator, DSHS, Division for Regional and Local Health Operations. Mr. Allen referenced and gave an overview of the handout, *Sickle Cell Disease in Texas Syndromic Surveillance Systems in 2020.*

Highlights of the presentation included:

- Background information
- Sickle cell disease in Texas Syndromic Surveillance Systems overview
    - Data on number of visits per sickle cell patient in 2019 and 2020
    - Data on length of stay for sickle cell-related visits in 2019 and 2020
- Number of visits for sickle cell disease compared to similar conditions
- Demographic Breakdown for sickle cell-related visits
- International Classification of Diseases, 10th Edition (ICD-10) Codes used in discharge of sickle cell-related visits
- Counties with highest per capita sickle cell-related visits to facilities

Members discussed:

- The system includes some pediatric facilities such as children's hospitals and specialty hospitals, but not primary care physicians since the system is made of different types of emergency care
- Clarifying that syndromic surveillance data may include inpatient admissions, but only those that have emergency centers somewhere on the record
- Possibility of clustering diagnoses such as those for pain crisis or similar codes, so when they are added together, they should be the majority of diagnoses
- Ability to distinguish between the admitting diagnosis and discharge diagnosis
- Deep East Texas has a greater African-American population and a more concentrated number of cases
- Syndromic surveillance was not really designed to track a condition like sickle cell, but to identify emerging threats infectious diseases
- Ability to identify emerging threats, not necessarily track them
- Records are from the electronic health record systems from hospitals and emergency rooms, so syndromic surveillance cannot track a patient across time very well or non-crisis diagnosis as well as another system

Agenda Item 5: 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 handouts, *Sickle Cell Surveillance Subcommittee Meeting Minutes and Texas Sickle Cell mortality tables and maps*.

Highlights of the presentation included:

- Subcommittee worked with Mr. Allen and team to get syndromic surveillance data
- When looking at what is data available and how to best use that data, considering the quote “Perfection is sometimes the enemy of the good” and that you have to start somewhere
- Syndromic surveillance data is a helpful tool even if it wasn’t designed as a longitudinal registry
- Texas probably has more data than the Task Force thinks, but the challenge is how to link it and develop it into something that has longevity and can be followed over time
- The Syndromic Surveillance report is at least a first kind of report to capture data the Task Force didn’t have before, such as a percentage of sickle cell patients who are seen in the emergency room in Texas, which is a start
- Subcommittee has been working with Vital Statistics to develop a report on mortality data for sickle cell patients
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  - Identified cases of total sickle cell disorder-related deaths and average age by age Group, Texas residents, 2009 to 2019 aggregate data using diagnosis codes
  - Data limitations
    - Not having actual counts for certain counties with fewer than 10 deaths since that might lead to being able to identify individuals
    - Unsure if there is delineation between primary and secondary cause of death
    - Not all sickle cell-related ICD codes are included in the death certificate data, such as acute chest syndrome codes
  - Tables have been included in the appendices of the draft of the legislative report
  - Sickle cell trait cases were not included
  - Maps were color-coded for numbers of deaths by region and is consistent with where the largest sickle cell populations are known reside in the state
  - Wanted a visual representation to share with the legislature to help them understand the need and the burden of sickle cell disease in the state and why help is needed to figure out a way to do better surveillance
- Subcommittee is also working with Medicaid and the Children’s Health Insurance Plan (CHIP) to generate Texas data similar what was included in the national sickle cell report from the Centers for Medicare & Medicaid Services

Members discussed:

- If breaking up data into five-year clusters would be helpful
- Unsure how deaths are reported for other diseases, such as if they are reported on an annual basis

- Not knowing if diagnoses were applied appropriately to death certificates

ACTION ITEMS:

- For the legislative report, include the syndromic surveillance report and with only the last five years of mortality maps and aggregate data
- Share Medicaid and CHIP data with the full committee when the data request is completed
- Add an additional member to the subcommittee when the Task Force's vacancies are filled

Agenda Item 6: Public Awareness Campaigns Subcommittee Reporting

Dr Mackey introduced Marqué Reed-Shackelford, subcommittee member. Ms. Reed-Shackelford referenced the handout, *Public Awareness Campaigns Subcommittee Meeting Minutes*.

Highlights of the presentation included:

- Increased mortality of sickle cell patients with COVID-19 and high risk for patients with sickle cell trait and raising awareness of the COVID-19 vaccine and requesting the Program develop a vaccination guide
- Subcommittee reviewed recommendations proposed for the legislative report
- Activities planned for September 2021 Sickle Cell Awareness Month

Members discussed:

- Addressing vaccine hesitancy and other patient concerns in the COVID-19 vaccination guide
- Patients value the opinion of other patients, so sharing voices of sickle cell patients on why they got vaccinated and the benefit may even be stronger than just sharing the science in a COVID-19 vaccination guide
- Adding to the proposed recommendation for the legislative report for a COVID-19-specific public awareness campaign information about treatments
- Program project for Sickle Cell Awareness Month

ACTION ITEMS:

- Program will seek feedback on the draft of the one-page COVID-19 vaccination flyer that has been developed before sharing and posting on the DSHS website
- Laura Arellano, Unit Coordinator, DSHS Newborn Screening Unit, will email Dr. Titilope Fasipe the link to the video she filmed for Sickle Cell Awareness month so it can be finalized

Agenda Item 7: Medicaid Contracts Subcommittee Reporting

Dr Mackey introduced Dr. Titilope Fasipe, subcommittee member. Dr. Fasipe referenced the handout, *Medicaid Contracts Subcommittee Meeting Minutes.*

Highlights of the presentation included:

- Subcommittee was able to meet with several staff from the Office of the Medical Director, HHSC Medicaid & CHIP Services - Dr. Ryan D. Van Ramshorst, Chief Medical Director and Emily Rocha, Senior Nurse Policy Advisor - to address education, opioids, and the medical home
- Update on the approval for the Texas Medicaid preferred drug list (PDL) all the medications for sickle cell disease
- One sickle cell treatment is not on the PDL but is a clinician-administered drug infused in an outpatient setting that is also covered by Texas Medicaid
- Subcommittee reviewed recommendations on care packages and alternative therapies proposed for the legislative report

Members did not have a discussion.

ACTION ITEMS

- Dr. Van Ramshorst and Ms. Rocha will check the Medical Benefits team to review which services might already be covered by Medicaid
- Subcommittee will explore use of Federal Financial Participation Program and Value-Added Services to maximize use of alternative therapies
- Subcommittee will present at the next Medicaid Medical Directors' meeting

Agenda Item 8: Legislatively Mandated Report

Dr. Mackey led the discussion over the draft of the Legislatively Mandated Report (LMR). Dr. Mackey reminded members they received a draft copy of the Legislatively Mandated Report by email for their review and that they were asked to submit proposed edits and comments to Ms. Aimee Millangue, Task Force Liaison, DSHS Newborn Screening Unit. Dr. Mackey then turned the floor over to Ms. Millangue.

Ms. Millangue reviewed the draft of the Legislative Report developed by the Legislatively Mandated Report Subcommittee with the Task Force and led the discussion over the members' proposed edits and comments.

Members discussed:

- The order and wording of the recommendations
- Making sure the wording of the recommendations is consistent throughout the report
- Removing the graphic of the timeline of Federal Drug Administration Approved therapies in the appendices since it is redundant
- Including a table in the appendices comparing the number of visits to the DSHS Newborn Screening website in August, September and October 2020 to show if numbers increased during Sickle Cell Awareness month in September 2020

MOTION: Dr. Mackey requested a motion for approval of the report. Dr. Melissa

Frei-Jones motioned that the report be approved with the edits as discussed during the meeting or as presented, and that Dr. Mackey will furthermore grant authority to a member of the LMR subcommittee (or new Chair of the LMR subcommittee that is to be determined at a future date) in order to finalize edits and/or corrections to the report made during the meeting and non-substantive items such as grammar, formatting, spelling for the routing process to DSHS and HHSC Commissioners by December 1, 2021Dr. Titilope Fasipe seconded the motion. Mr. Owens conducted a roll call vote, and the motion was unanimously carried with six "for" votes with no objections and no abstentions.

Agenda Item 9: Review of Bylaws

Dr. Mackey reminded members that they received a copy of the Sickle Cell Task Force Bylaws by email to review. Dr. Mackey stated that the program will be reviewing the bylaws for compliance with the updated required template and will provide the updated bylaws for review and a vote approval at the next meeting and asked members if they had any changes or edits to discuss.

Members had no changes or edits to discuss.

Agenda Item 10: Public Comment

No public comment was received for this meeting.

Agenda Item 11: 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 November 10, 2021. Dr. Mackey turned the floor over to Ms. Millangue to recap action items and topics for a future meeting. Ms. Aimee Millangue stated that before proceeding, she wanted to thank Dr. Mackey for her service as Chair on behalf of the DSHS Newborn Screening Program.

Ms. Millangue stated:

- Arranging to have a presenter from John Hopkins University speak at the next SCTF meeting
- Subcommittee reports
    - Medicaid Contracts Subcommittee
    - Sickle Cell Surveillance Subcommittee
    - Public Awareness Campaigns Subcommittee
- Bylaws
- Chair Election

Ms. Millangue also provided the status of the solicitation process for the vacant positions on the Task Force.

Dr. Mackey thanked everyone and adjourned the meeting at 4:53 p.m.

Below is the link to the archived video of the August 20, 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://texashhsc.swagit.com/play/08232021-959/2/