

Sickle Cell Task Force

Bylaws

1. Name and Legal Authority

The Sickle Cell Task Force (Task Force) is established in accordance with House Bill 3405, 86th Legislature, 2019, and amended under the Texas Health and Safety Code Chapter 50. The Task Force is governed by Texas Government Code Chapter 2110 (State Agency Advisory Committees).

2. Purpose and Role

The purpose of the Task Force is to study and advise the Texas Department of State Health Services (DSHS) on implementing the recommendations made in the 2018 Sickle Cell Advisory Committee Report published by the Sickle Cell Advisory Committee or any other report the Texas Health and Human Services Commission (HHS) Executive Commissioner determines is appropriate.

The Task Force shall file an annual report with the HHS Executive Commissioner to submit to the Governor and the Legislature by December 1 each year, starting December 1, 2020. The report summarizes the Task Force's work and includes any recommended actions or policy changes endorsed by the Task Force.

3. Definitions

ACCO: Advisory Committee Coordination Office

Agency staff: Staff from various areas across the Health and Human Services system, such as the ACCO and Office of Legal Counsel.

DSHS: Texas Department of State Health Services

HHS: Texas Health and Human Services

HHS System: Texas HHS System includes DSHS and the Texas Health and Human Services Commission

HHSC: Texas Health and Human Services Commission

High Level of Integrity: For purposes of these bylaws, this means that the member is honest and behaves in a morally upright way, at a level above a normal or average level, such that the public's trust in the member is warranted. A high level of integrity includes disclosing conflicts of interest as required by HHS policy and these bylaws.

NBS: Newborn Screening Program

SCD: Sickle Cell Disease

SCT: Sickle Cell Trait

4. Task Force Composition

The Task Force is composed of seven voting members appointed by the HHS Executive Commissioner as described in Texas Health and Safety Code § 50.003.

This membership includes:

- A. Two members from community-based organizations with experience addressing the needs of individuals with SCD;
- B. Two physicians specializing in hematology;
- C. Two members of the public, each of whom either has SCD or is a parent of a person with SCD or SCT; and
- D. One representative of a health-related institution.

To the greatest extent possible, the HHS Executive Commissioner appoints members who reflect the diversity of Texas.

5. Member Terms

All members will serve a term of two years, except when appointed to complete the remaining unexpired term of an outgoing member. Individuals may apply to be reappointed to serve a second term. A member may serve these terms consecutively. With the adoption of these bylaws, initial terms will be staggered over several years to ensure the continuity of Task Force work so the terms of half of the members will expire on August 31st of each year starting in 2021. Regardless of the term limit, a member serves until his or her replacement has been appointed. This ensures sufficient, appropriate representation.

6. Resignations and Vacancies

If any member of the Task Force wishes to resign, the member will contact, in writing, the current Chair and designated DSHS Task Force Liaison requesting the appointment of a successor member.

In the event of a vacancy for any reason, agency staff will work with the HHS Executive Commissioner to solicit applications as appropriate to fill the vacancy with a representative of the same membership category to serve the unexpired portion of the term of the vacant position. People who submitted applications within the previous year through HHSC may be reconsidered for membership.

7. Presiding Chair

The Task Force shall elect a Chair from among its membership who shall preside over each Task Force meeting. The Chair will serve one term of two years. If the Chair is unable to complete his or her term for any reason, a new chair will be determined by election from among the Task Force's membership. Regardless of the expiration of the term, the Chair will serve until the Task Force elects a successor; however, a presiding officer may not remain in office past his or her membership term.

The role of the Chair is to:

- A. Report to DSHS and HHSC;
- B. Participate in agenda planning and preparation for Task Force meetings;
- C. Provide leadership in conducting Task Force meetings;

- D. Promote, maintain, and encourage a participatory environment;
- E. Identify the need for, and work with the designated DSHS Task Force Liaison, to call meetings to accomplish the work of the Task Force;
- F. Ensure the Task Force adheres to its charge;
- G. Call for the establishment of subcommittees (if applicable and with approval of agency staff); and
- H. Confer with agency staff to acquire the support needed for Task Force operations.

8. Task Force Operations and Meetings

A. Meetings

1. The Task Force meets during regular business hours at the call of the Chair, DSHS Commissioner, or HHS Executive Commissioner, but no less than three times a calendar year
2. The Task Force shall comply with Texas Government Code Chapter 551 (the Texas Open Meetings Act) as if it were a governmental body.

B. Quorum

Four voting members constitutes a quorum for the purpose of transacting official business. If less than a quorum of the Task Force is present, members may not vote upon action items but may take testimony and public comments so long as the meeting is being conducted in accordance with the Texas Open Meetings Act.

C. Voting

1. Members have the right to vote on any subject that is listed on the agenda. However, members must abstain from deliberating or voting on issues that would provide monetary or other gain to the member, or the member's family, or that could present, or reasonably appear to present, a conflict of interest.
2. The Task Force may determine procedural matters by majority vote of the members attending the meeting or may use Robert's Rules of Order as a guide to its operations and proceedings.
3. A member may participate and vote by telephone conference as deemed necessary by agency staff.
4. A member may not authorize another individual to represent the member by proxy.

5. For all business except adopting or amending bylaws, a simple majority is needed on a motion duly made and seconded. (A simple majority is defined as more than half of the votes cast by persons entitled to vote who are in attendance with a quorum, excluding abstentions.)

D. Adoption and Revision to Bylaws

1. Bylaws will be adopted and amended pursuant to a two-thirds vote (of members attending the meeting) on a motion duly made and seconded.
2. Task Force members or agency staff may propose changes to these bylaws. All proposed changes from Task Force members, along with the rationale for the changes, should be submitted in writing to the designated DSHS Task Force Liaison at least 30 days before the next Task Force meeting for inclusion in the publication of the agenda in the *Texas Register* and distribution to the members for their consideration.
3. The Task Force will review the Bylaws by December 31 of every even-numbered year. Task Force-proposed amendments that occur as a result of the biennial review will be considered in a meeting and will be passed and become effective based on a two-thirds vote of members attending the meeting, pending review and approval by DSHS and HHSC staff.
4. All proposed changes are subject to review and approval by DSHS and HHSC staff.
5. The Bylaws will become effective as of the date they are adopted by the Task Force. The Task Force will make note of the date of the adoption of the Bylaws in its minutes. Members will sign a Statement by Members when bylaws are amended (see attached Statement).

9. Responsibilities of Members

A. Attendance

Members are expected to attend all meetings in person or by telephone conference. A member unable to attend a meeting should notify the designated DSHS Task Force Liaison in advance. The Task Force Liaison will notify the Chair and appropriate program staff. Members may not send a substitute to attend a meeting in their place.

Any member missing three meetings within a one-year period with or without notice to the designated DSHS Task Force Liaison, may be removed from the Task Force.

B. Member expectations:

1. Attend meetings in person or by telephone conference;
2. Participate in subcommittees as assigned;
3. Review agendas and other information sent by staff prior to each meeting;
4. Participate in discussions at meetings;
5. Abstain from deliberating or voting on issues that would provide monetary or other gain to the member, or the member's family, or that could present, or reasonably appear to present, a conflict of interest;
6. Attend/participate in an orientation session for the Task Force;
7. Complete the Texas Open Meetings Act Training and Public Information Act Training within 90 days of appointment and submit the Certificates of Completion to the designated DSHS Task Force Liaison. If a member has taken the trainings within the last five years, a copy of the Certificates of Completion may be submitted to the Task Force Liaison in lieu of taking the trainings;
8. Sign and submit to the Task Force Liaison the Statement by Members document (attached) within 30 days after appointment. This document includes a Conflict of Interest Statement and a Nondisclosure Agreement to which Task Force members must agree;
9. Notify the Task Force Chair and Task Force Liaison if a change of status alters the category of membership that the member was filling or if any circumstance occurs that prevents the member from being able to discharge his or her duties;
10. Maintain a high level of integrity that warrants public trust, including complying with all applicable ethics guidance provided by HHS Ethics Officers and all aspects of the Texas Open Meetings Act and Public Information Act; and
11. Hold and maintain in strictest confidence all confidential information and all agency-generated information, including information in draft form, until such time as the information or document is released and made public, the HHS Executive

Commissioner has approved the release in writing, or the HHS Ethics Policy permits release. This requirement survives the member's tenure on the Task Force. In addition, the member must confirm that he or she will require the member's interpreters, attendants, or other support persons if any, to comply with this requirement. For purposes of these bylaws and the Nondisclosure Agreement, the term "confidential information" includes all information protected by the Health Insurance Portability and Accountability Act (HIPAA), information that has commercial value or use, such as trade secrets, and information communicated in confidence by the HHS System.

Failure to comply with member expectations numbers 6-11 above by a voting member is grounds for dismissal and may result in removal from the Task Force.

C. A Task Force member may not:

1. Claim or appear to represent DSHS, HHSC or the Task Force in any legislative or advocacy activity without written approval from the Task Force Chair and the HHS Ethics Office in coordination with the HHSC Government and Stakeholder Relations Office and the Task Force Liaison. A member is not prohibited from discussing a report that has been formally adopted by this Task Force, so long as he or she does not purport to represent DSHS or HHSC. A member is not prohibited from representing him- or herself or another entity in the legislative or advocacy process.
2. Accept payment for any services offered to the member because of his or her position on the Task Force.
3. Disclose confidential information or draft information (from any source including grants, requests for proposals, and contracts) acquired through his or her participation on the Task Force until such time as that information or document is released and made public, the HHS Executive Commissioner has approved the release in writing, or the HHS Ethics Policy permits release. This includes all forms of communication including written, verbal, and social media;

4. Fail to require the member's interpreters, attendants or support persons, if any, to keep confidential information or draft information (from any source including grants, requests for proposals, and contracts) acquired through the member's participation on the Task Force until such time as that information or document is released and made public, the HHS Executive Commissioner has approved the release in writing, or the HHS Ethics Policy permits release. This includes all forms of communication including written, verbal, and social media.

A violation of any of these items are grounds for dismissal and may result in removal from the Task Force.

10. Removal from the Task Force

The HHS Executive Commissioner may remove a voting member from the Task Force for the following reasons:

- A. A member votes or deliberates on an issue that would provide monetary or other gain or that presents a conflict of interest to the member, the member's family, or an entity with which the member is closely affiliated.
- B. A member refuses to sign or violates the Statement by Members, which includes the Conflict of Interest statement and Nondisclosure Agreement, or another Nondisclosure Agreement.
- C. A member does not maintain a high level of integrity that warrants public trust, including complying with all applicable ethics guidance provided by HHS Ethics Officers and all aspects of the Texas Open Meetings Act and Public Information Act.
- D. A member changes status that alters the category of membership that the member was filling.
- E. A member claims or appears to represent DSHS, HHSC or the Task Force in a legislative or advocacy activity without approval from the Task Force Chair and the HHS Ethics Office in coordination with the HHSC Government and Stakeholder Relations Office and designated DSHS Task Force Liaison. (A member is not prohibited from discussing a report that has been formally adopted by this Task Force, so long as he or she does not purport to represent DSHS or HHSC. A member is not prohibited from representing him- or herself or another entity in the legislative or advocacy process.)

- F. A member receives payment for any services requested because he or she holds a position on the Task Force.
- G. A member discloses confidential or draft information acquired through his or her participation on the Task Force not in accordance with the Bylaws.
- H. A member fails to require his or her interpreter, attendant or support person, if any, to keep confidential any information or draft information acquired through the member's participation on the Task Force as required by the Bylaws.
- I. A member, in a 12-month period, misses three meetings with or without notice to the designated DSHS Task Force Liaison.
- J. The HHS Executive Commissioner may remove a member who has violated the conflict of interest provisions or made a statement in violation of the Statements by Members form. Decisions to remove a member of the Task Force due to violations of this nature will require input from HHS legal counsel.

11. Subcommittees

Unless otherwise noted in statute, the Chair, with the approval of agency staff, may establish subcommittees that meet at other times for purposes of studying and making recommendations on issues the Task Force determines appropriate to the charge of the Task Force. A subcommittee may be created for a limited period of time and will cease to exist when the assigned tasks are completed or upon determination of the Chair or HHS Executive Commissioner or it may be a standing subcommittee. The Chair and agency staff will evaluate the need for all existing subcommittees annually.

Subcommittee Operations and Meetings

- A. Unless otherwise noted in statute or required by a grant document, members of subcommittees are required to be members of the Task Force.
- B. Except as set out in #D below, subcommittee(s) will follow the general rules of the Task Force as applicable.
- C. Subcommittee(s) must keep minutes of the meetings and report back to the full body.

- D. The presence of a quorum of the full Task Force at a subcommittee meeting:
 - 1. Constitutes a full Task Force meeting that requires posting appropriate notice of the meeting as a full Task Force meeting in accordance with the Texas Open Meetings Act; and
 - 2. Requires the subcommittee meeting to be held in compliance with the Texas Open Meetings Act to include posting appropriate notice of the subcommittee meeting.

12. Subject Matter Experts

DSHS and HHSC recognize the value of subject matter experts (SMEs) to provide information to the Task Force as it develops recommendations and initiatives relative to its charge(s). The primary role of a SME is to provide objective, independent information and analysis to be considered by the Task Force. SME participation will be subject to the request of voting Task Force members and will fall within the following guidelines:

- A. A SME may be invited to provide information on specific subjects and topics at the discretion of voting Task Force members, the Chair and agency staff;
- B. An invited SME may be recognized by staff, the Task Force Chair to provide information or analysis during allotted time periods at a specified Task Force or subcommittee meeting;
- C. SMEs will participate in questions and answers at the direction of the staff or Task Force Chair;
- D. All SMEs will participate and serve at the pleasure of the Task Force;
- E. SMEs do not hold any official capacity on the Task Force or subcommittees and do not have rights of deliberation or the right to vote on any Task Force activities or decisions;
- F. SMEs should disclose any conflicts of interest they may have prior to providing information to the Task Force; and
- G. None of the information or guidance contained in this section shall prevent any individual from participating in or providing comments to the Task Force as allowed under the Texas Open Meetings Act.

13. Responsibilities of Support Staff

The DSHS Newborn Screening Program and the DSHS Maternal and Child Health Section will provide reasonable administrative and technical support and coordination for all Task Force and subcommittee activities. DSHS will coordinate as needed to provide the accommodations and supports needed by a Task Force member requiring accommodations to enable him or her to fully participate in Task Force and subcommittee meetings and activities.

Staff is expected to perform the following tasks:

- A. Develop effective working relationships with Task Force members;
- B. Solicit nominations for membership in accordance with the appropriate HHS procedures;
- C. Provide information, including data, and technical resources, in the write-up and submission of the annual report to the HHS Executive Commissioner;
- D. Serve as liaison between members and operating agencies' staff; and
- E. Plan, coordinate, and organize Task Force and subcommittee meetings and activities, including:
 - 1. Schedule meeting dates and ensure meeting sites are set up;
 - 2. Notify members of upcoming meeting dates, times, and locations;
 - 3. Develop agenda and support materials for each meeting;
 - 4. Prepare and oversee that the agenda is posted in the *Texas Register* in a timely manner and on the HHS website;
 - 5. Serve as point of contact for the public, including ensuring that contact information, agendas, and meeting support materials are easily accessible on the HHS website;
 - 6. Prepare and distribute information and materials for member review; and
 - 7. Prepare and maintain Task Force records and documentation in accordance with the DSHS and HHS records retention policy.
- F. Coordinate as needed to provide any accommodations and supports required for a Task Force member who has a disability to enable the member to fully participate in Task Force meetings and activities; and
- G. Staff may perform other duties within staff discretion provided the necessary resources are available.

14. Travel Reimbursement

A member of the Sickle Cell Task Force is not entitled to any compensation (stipend) or reimbursement of expenses.

Bylaws approved on February 27, 2020 by a two-thirds vote of members attending the meeting.

Michelle N. Mackey, PhD
Chairperson
Printed Name

Michelle A. Mackey, PhD
Signature

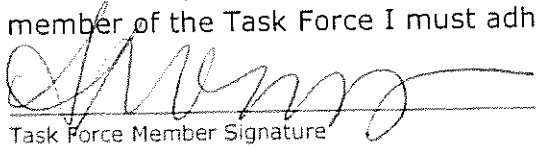
David R. Mantz
DSHS
Printed Name

David R. Mantz
Signature

Statement by Members

- The Texas Department of State Health Services (DSHS), Texas Health and Human Services Commission (HHSC), and the Sickle Cell Task Force (Task Force) are not bound in any way by any statement or action on the part of any Task Force member except when a statement or action is in pursuit of specific instructions from HHSC or the Task Force.
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I have been provided a copy of the Sickle Cell Task Force bylaws. I understand that as a member of the Task Force I must adhere to the bylaws.


Task Force Member Signature

02/27/2020
Date

Alysian Thomas
Printed Name

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Task Force Member Signature


3/27/20
Date

Marquis Reed-Shackelford
Printed Name

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Task Force Member Signature

2/27/2020
Date

Melissa Fred Jones
Printed Name

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Michelle N. Mackey
Task Force Member Signature

2-27-2020
Date

Michelle N. Mackey
Printed Name

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Tanya Prince
Task Force Member Signature

2-27-2020
Date

Tanya Prince
Printed Name

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- Conflict of Interest Statement. I agree to disclose any personal or private interest that myself or my family have in a measure, proposal, or decision pending before DSHS or HHSC. ("Personal or private interest" does not include the member's engagement in a profession, trade, or occupation when the member's interest is the same as all others similarly engaged in the profession, trade, or occupation, or if the member merely provides a personal experience, with no personal or private financial interest, in giving feedback on the subject matter.) If there is a direct personal or financial interest in a motion under consideration, I further agree to disclose that fact in a public meeting and will recuse myself from any Task Force deliberations or decisions on that matter.

I have been provided a copy of the Sickle Cell Task Force bylaws. I understand that as a member of the Task Force I must adhere to the bylaws.



Task Force Member Signature

2/27/2020

Date

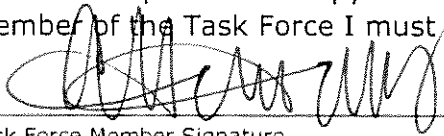
Titilope Fasipe

Printed Name

Statement by Members

- The Texas Department of State Health Services (DSHS), Texas Health and Human Services Commission (HHSC), and the Sickle Cell Task Force (Task Force) are not bound in any way by any statement or action on the part of any Task Force member except when a statement or action is in pursuit of specific instructions from HHSC or the Task Force.
- The Task Force and its members may not claim or appear to represent Texas Health and Human Services (HHS) or the Task Force in any legislative or advocacy activity without approval from the Task Force Chair and the HHS Ethics Office in coordination with the HHSC Government and Stakeholder Relations Office. Task Force members are not prohibited from discussing a report that has been formally adopted by this Task Force, so long as members do not purport to represent DSHS or HHSC. Task Force members are not prohibited from representing themselves or another entity in the legislative or advocacy process.
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Task Force Member Signature

2/27/2020

Date

Alecia Nerymas

Printed Name

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Revisions Tracking Page

Document Version #	Revision Date	Revisions / Purpose	Author
Initial/New	02/27/2020	Drafted document in compliance with agency policy.	Aimee Millangue

