

New York State Department of Health

Health Equity Council

June 13, 2025 - Meeting Minutes

Attendees	Council Members: Virtual: Mario R. Ortiz, Helen Arteaga, Earlando Thomas Virtually: Ngozi Moses, Sara Boerenko, Virginia Sack, John R. Pamplin II, Tandra LaGrone Partial Attendance/Logged in late: Council Members with an excused absence: Luis (Freddy) Molano, LaRay Brown, Guillermo Chacón, Alberto J.F. Cardelle Council Members without excused absence: Mill Etienne, Raul Vazquez New York State Department of Health Office of Health Equity and Human Rights Staff: Tina Kim, Mary McCormick, Kacey Griffin, Alice Spina, New York State Department of Health Staff: Kristina Usack, Barbara D. Sykes, Stephanie Gagnon, Carolyn Perry, Virginia Sack, Jamie Spina
Topics	
Call to Order: Mario Ortiz: <i>Presiding Chair</i>	The meeting was convened at 10:30 A.M. Chair, Mario Ortiz, RN, NP; PhD; FNAP, FAAN, introduced himself and welcomed fellow council members. Dr. Ortiz calls meeting to order.
Council Business	Mario Ortiz, Chair: - Provided overview of the agenda - Advised that council voting on meeting minutes for December 6, 2024, meeting and March 7, 2024, meeting would take place at a future meeting when quorum is achieved. Conversation ensued around quorum. Clarification was given by Jamie Spina, Division of Legal Affairs, – the language was that at no time should a quorum consist of less than three active members when group membership is low. The majority has always been the standard. The majority of the 14 members is 6 active members. New Member introduction: Dr. Earlando Thomas introduced himself and gave brief overview of his experience.
Updates from the New York State Department of Health:	Office of Health Equity and Human Rights (OHEHR)/Tina Kim – since the Health Equity Council (HEC) met last quarterly, many changes have been made – grants were terminated, staff were let go and brought back. Tina will provide updates about departmental changes in writing. Tina reassured the council that the charge of this group is of utmost importance and advised that since the last council meeting: - New York State has joined 22 states to sue the Federal Government and was granted a preliminary injunction to continue the work through the duration of the court case - The Office of Minority Health and Health Disparities Prevention was consolidated into the Executive team of the Office of Health Equity and Human Rights – this does not impact the priorities of this team or eliminate funds. The Office continues to do the work of the American Indian Health Program, focus on advancing health equity and Diversity, Equity,

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	and Inclusion initiatives of the Department, support the Health Equity Council as it has been since its inception, and continue other operations. In the interest of time, other updates will be shared in writing. • Tina is working very closely with the Commissioner's Office to ensure that we are having conversations with the Governor's office, and we will not lose sight of equity and the issues that our communities continue to experience. Health Equity and Diversity, Equity, and Inclusion are critical to the mission of the Department of Health. We do not operate Diversity, Equity, and Inclusion programs that violate the Federal or State anti-discrimination laws. Conversation about roles of the council – Sickle Cell, Women's Health and AI – who will take the lead on these topics? The Council identified the following: Artificial Intelligence (AI) Lead - Sara Boerenko (Montgomery County). Comments: • No matter the topic we need to speak the Federal Language –shift language to align with the language coming out of the Federal Government • www.madeofsomethingstronger.com Woman's Health – Co-leads Earlando Thomas, Ngozi Moses Sickle Cell Disease – Co-leads Mario Ortiz, Helen Arteaga Further Comments regarding the priority areas: John Pamplin II advised that he has a background in mental health, brings experience to the council in racial and health equity, the overdose crisis Ngozi Moses requested a list of council members circulated and areas of expertise – perhaps we can ask each of the council members to provide us with a short bio? The Department of Health agreed to circulate that request. Tina Kim - Roadmap for Health Equity Council Priorities
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Sickle Cell Legislation

Presentation from Danielle Ongondo, PhD, RN – Sickle Cell Disease Screening – (slides on file)

Dr. Ongondo delivered presentation titled “Advancing Health Equity through Sickle Cell Disease Screening and Education: Recommendations for Education and Outreach.” This presentation illustrated health disparities experienced by sickle cell patients and the gaps that persist in current screening and diagnosis pathways. She identified opportunities for education in prenatal, academic/career, and symptomatic or risk-based pathways. She also described the benefits of surveillance to ensure early identification of sickle cell disease and meaningful follow up with primary care providers.

Question:

- Mario inquired about funding for [National Instructional Materials Access Center](#) (NIMAC)
 - o They are not funded but they do have infrastructure already in place across the East Coast from New York to Maryland regarding genetic treatment. Telehealth is also included in this infrastructure.
 - o This brought up further discussion about how to make recommendation to the Commissioner about the provision of grants to organizations that support the sickle cell community.
 - o Sickle Cell Disease Association of America has a few subchapters in different states that could possibly offer guidance or resources on the promotion and development of a registry.
- Mario asked - do you imagine in looking at structural resilience that as we move through your screening and detection education and then counseling and referral that the grants and the data are sort of like the structure of your structure.
 - o Yes - it's an arm of the structure because finances are needed to support housing, transportation, and health care.
 - o There's a bill out to establish five centers of sickle cell disease excellence – approved in the Senate and is now in the House
- Ngozi emphasized that as a council, we need to consider that 90 percent of the population with sickle cell disease is black and we don't know the status of many people, particularly people not born in the United States. These individuals, therefore, not could not be in the birth registry. The Council should consider how partnerships and collaboration with community-based organizations with boots on the ground can really influence and promote education and awareness. These organizations already have infrastructure in the community to reach clients. Clients come to them, particularly the newer immigrants who do not know the system or are fearful. There is a huge opportunity for the New York State Department of Health to make a deliberate decision to leverage the resources of community-based organizations for partnerships with the education, promotion of awareness, and other priorities.
 - o Earlando stated that education and dissemination of information through these community-based organizations is going to be crucial. Remembering also that sickle cell disease through gene therapy is now curable, we need to emphasize infrastructure for screening. The problem is connecting the communities to the resources, educating not just the community but also the healthcare providers too.
- Mario asked Dr. Ongondo if in her research, is there any data that identified trends in how common or to what intensity it's covered in healthcare programs?

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	- o reauthorizes funds for Health Resources and Services Administration is up for this next fiscal year, there was \$25 million federally allocated with some money that's allocated for workforce development, specifically for sickle cell disease. Medicaid could also be a potential pathway for that type of education. • Sara - If we were to do point of care testing as a local department of health, through a mobile unit with a mobile van, would that point of testing be covered under our Clinical Laboratory Improvement Amendment (CLIA) waiver? - o Tina - I would say that this certainly should be one of the final recommendations that the sickle cell work group or subgroup could develop. We will take that question back just so that we have an answer and that could be the baseline for then how the recommend the final recommendation should be informed. Update: Community Listening Sessions Ms. Alice Spina, Public Health Fellow III, OHEHR Alice provided a recap of the community listening session discussion that took place at the March 7, 2025, Council meeting. She summarized the Council members preferences based on surveys that were distributed prior to the meeting regarding if and how they would like to use community listening sessions to fulfil requirements of the legislation. She then deferred to the Chair to continue the discussion. Department of Health Staff and Council members provided the following feedback: DOH Staff: consideration of feedback determined by/on age (Carolyn Perry) Mario – timing of the sessions may be problematic at this time, there are other ways to garner information, which could include distributing surveys. Ngozi – the current environment creates anxiety among the communities, which should be considered. Dr. Ongondo –community listening sessions are good for the data piece of this, but also create an alternate means to educate the sickle cell community There are clinics in downstate that have support groups and they could potentially help out in the community listening sessions. Alice - virtual sessions are also an option. Tandra does not want the Council to lose sight of the role that mobile testing can play to the community, recommending a virtual option for folks related to the Community Listening Sessions AND using existing organizations with reach in the Sickle Cell community via a QR code or survey option. Lastly offered that there is a currently LGBTQ+ statewide survey being conducted by CUNY and TRX that we could try and piggy back onto as Tandra's team is helping to promote that in different spaces.
Council Next Steps	- Create a sickle cell disease timeline of investigation - Develop AI and women's health priorities - Vote on 12/06/24 and 03/7/2025 meeting minutes at a meeting with quorum - The Department will look into Mobile Unit testing with a CLIA waiver to inform a recommendation to the Commissioner in the final report - Consider September is Sickle Cell Awareness month and that is when the Council should send out the Sickle Cell Survey.

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	<u>Recommendations to Commissioner of Health (by 12/05/25)</u>
Meeting Recap, Feedback, Action Items and Next Steps	Dr. Ortiz thanked the Council for a great discussion. Next steps include creating a sickle cell disease timeline of investigation and recommendations to the Department of Health and the Commissioner of Health. The Council is in the planning a development stage, the goal is to provide recommendations by the end of 2025.
Public Comment and Adjournment	Tina Kim opened the floor to public. No comments or emails were made by the public. The meeting adjourned at 11:54 AM.

Next Meeting Date June 13, 2025	Time 10:30 a.m. – 1:00 p.m.	Location Virtual
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