Advisory Committee on Infant and Maternal Mortality

Meeting Minutes of March 20-21, 2023

Virtual Meeting

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DAY ONE: Monday, March 20, 2023

Welcome

Vanessa Lee, M.P.H., Designated Federal Official (DFO), ACIMM Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair

Ms. Vanessa Lee (DFO) called the Advisory Committee on Infant and Maternal Mortality (ACIMM) to order and welcomed attendees. She introduced newly appointed ACIMM Chair, Ms. Belinda Pettiford, who has more than 30 years of experience in public health and currently serves as the Chief of the Women, Infant, and Community Wellness Section within the North Carolina Department of Health and Human Services.

The Chair expressed her gratitude for the support she had received for this appointment, and that she looked forward to working with the Committee and ex-officio members going forward. She emphasized the importance of listening to community voices, especially those from underserved populations, to ensure their perspectives were incorporated into the Committee's recommendations to the Secretary of the Department of Health and Human Services (the Secretary). She highlighted the need to move from recommendations to action and to align the Committee's work with national maternal and child health (MCH) partners in order to have support for their recommendations from the grassroots level.

Introductions

Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair ACIMM Members Ex-Officio Members

The Chair invited Committee and ex-officio members to introduce themselves and highlight an inspirational or influential woman in their lives as a tribute to Women's History Month. Members spoke about their mothers, grandmothers, great-grandmothers, and daughters and the significant impact these women had on their personal and professional lives.

Review and Approve Minutes

Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair

The Committee unanimously passed a motion to approve the minutes of the December 7, 2022 meeting.

Federal Updates

Maternal and Child Health Bureau (MCHB)

Michael Warren, M.D., M.P.H., FAAP, Associate Administrator, MCHB, HRSA

Dr. Michael Warren provided an update of the MCHB budget for Fiscal Year 2023, which included a \$127 million increase from the previous year. Specifically, the budget included \$823 million for the MCH Block Grant and a five-year reauthorization of the Maternal, Infant, and Early Child Home Visiting (MIECHV) program. Notably, the tribal set-aside budget for

MIECHV doubled from 3% to 6%, which was aligned with the Committee's recent recommendations to HHS on improving American Indian/Alaska Native (AI/AN) birth outcomes. MCHB also received \$145 million towards reducing disparities in MCH outcomes.

Several <u>funding opportunities were highlighted</u>, including increased funding for the Alliance for Innovation on Maternal Health (AIM) and the maternal mental health hotline. New funding was available to address sudden infant death syndrome (SIDS); create research networks and a coordinating center for minority serving institutions; provide screening and treatment for maternal mental health and substance use disorders; develop state-focused demonstration projects; and focus on projects addressing disparities and social determinants of health. Dr. M. Warren noted that MCHB planned to award all funding by September 30, 2023.

Programmatic updates were shared, including that the Healthy Start program was going to be recompeted in 2024, and MCHB had published a request for information to get input on its future iteration. MCHB received more than 100 responses from various stakeholders, highlighting the need to increase the focus on addressing social and structural determinants of health, racism and bias in health care, and expressing the needs of rural and border communities. Additionally, MCHB released updates to the Women's Preventive Services Initiative (WPSI) Guidelines and the Bright Futures Periodicity Schedule at the end of last year. Once the guidelines were accepted by the HRSA Administrator, insurance companies would be required to provide coverage for specific preventive services without cost-sharing, which would help improve access and equitable care.

National Institute of Child Health and Human Development (NICHD) Alison Cernich, Ph.D., ABPP-Cn, Deputy Director, NICHD

Dr. Alison Cernich discussed the Implementing a Maternal health and PRegnancy Outcomes Vision for Everyone (IMPROVE) initiative, which aimed to reduce preventable causes of maternal deaths and improve the health of women before, during, and after delivery. This effort included a focus on communities of color and those in maternity care deserts. In Fiscal Year 2022, IMPROVE received a new appropriation to establish Centers of Excellence, data coordinating hubs, and data methodology hubs to support evidence-based practices for maternal health. IMPROVE also supported collaborations between academic centers and community organizations to bring evidence-based health care into communities, an effort to create standards for the electronic health records, and two challenges to drive point-of-care and in-home technologies in maternity care deserts.

IMPROVE supported the Connecting the Community for Maternal Health Challenge, an effort to build a research infrastructure within <u>15 organizations</u> in order to increase representation in research and to leverage community knowledge. The <u>Rapid Acceleration of Diagnostics</u> <u>Technology (RADx® Tech) for Maternal Health Challenge</u> supported 15 organizations in an effort to promote viability assessments into the commercialization and usability of diagnostic technologies.

The <u>Stillbirth Working Group of Council</u> was established to produce recommendations for the federal government to address stillbirth. The Working Group had held four meetings and put out

a request for information, resulting in recommendations to improve the quality of vital statistics, surveillance, and epidemiologic data on stillbirth; identify prevention opportunities; conduct implementation research; and develop culturally sensitive interventions to support families that have experienced stillbirth.

The Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC), established in 2016 to address knowledge gaps regarding safe and effective therapies and vaccines for pregnant and lactating people, provides recommendations to the Secretary to promote the inclusion of pregnant and lactating people in clinical trials. NICHD has continued these efforts through its Maternal and Pediatric Precision In Therapeutics (MPRINT) Hub, established to implement PRGLAC's recommendations. The MPRINT Hub focused on conducting and fostering therapeutics-focused research in obstetrics and pediatrics, addressing the underrepresentation of women and children in clinical trials, and using real-world data for neonatal opioid withdrawal syndrome and other research areas. Additionally, NICHD created an advisory committee to monitor implementation of recommendations from PRGLAC.

The NICHD Global Network for Women's and Children's Health Research had collaborated with the Bill and Melinda Gates Foundation to conduct a <u>study</u> on post-partum sepsis and death in seven low and middle-income countries (LMICs). The study found that a single dose of azithromycin could reduce postpartum sepsis and death by one-third, although it did not reduce stillbirth or newborn sepsis or death. NICHD also had two major networks in maternal and neonatal research: the <u>Maternal-Fetal Medicine Units</u> and the <u>Neonatal Research Network</u>. These networks were being restructured to broaden and diversify the investigators who could propose projects to use the network.

Discussion

A Committee member asked whether the scope of PRGLAC extended to fetal surgery. Dr. Cernich answered that PRGLAC was focused on pharmacotherapies, but that surgical therapies were under the purview of other NICHD funding mechanisms, such as the Maternal-Fetal Medicine Units or the Neonatal Research Network.

A Committee member asked for clarification on what pharmacotherapies encompassed. Dr. Cernich answered that it referred to medications, such as those to treat depression, epilepsy, or other conditions that are common going into pregnancy. Many medications used during pregnancy had never been studied in pregnant people and there was a need to understand the effects on both the mother and fetus. PRGLAC looked at areas such as safety, dosing, physical changes during pregnancy, or education for providers about risks of using or not using a medication. PRGLAC also considered how much of a drug was passed through breast milk. For instance, there was a study underway looking at samples of breast milk, maternal blood, and infant blood to determine transmission of multiple medications.

ACIMM Charter Renewal and Bylaws

Vanessa Lee, M.P.H., Designated Federal Official, ACIMM Sarah Hueneke Meyerholz, M.P.H., Program Lead, MCHB

The ACIMM charter must be renewed every two years and the current charter is set to expire on September 30, 2023. MCHB planned to submit a renewal package to HRSA in June and requested that Committee members provide feedback for changes or additions by April 20, 2023.

A review of both the 2019 - 2021 and the 2021 - 2023 charters was provided to highlight the previous changes, including a revision in the 2019 - 2021 charter to focus on maternal morbidity and mortality. The 2021 - 2023 charter further highlighted this focus area with the Committee name change and also broadened its scope to include examining structural and social determinants of health. The 2021 - 2023 charter also added a representative from the Substance Abuse and Mental Health Services Administration (SAMHSA) and provided an opportunity to expand the number of meetings per year.

Discussion

A Committee member asked whether the move from two to four meetings per year had resulted in a positive outcome. The Chair responded that the Committee had decided to include that revision because it felt like twice a year was not sufficient time to address the many critical issues that needed attention. The DFO added that the Committee had submitted three sets of recommendations to the Secretary over the last two years, whereas the last set of recommendations prior to the increased number of meetings was in 2013.

Follow-Up: Recommendations to Improve American Indian/Alaska Native (AI/AN) Birth Outcomes

Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair Vanessa Lee, M.P.H., Designated Federal Official, ACIMM ACIMM Members Ex-Officio Members

The Chair talked about the efforts that former Committee members who had departed in December had engaged in to disseminate the Committee's December 2022 report of recommendations on improving AI/AN birth outcomes. Committee members then discussed activities or plans for dissemination.

A Committee member shared the report with the New Hampshire Endowment for Health and the American Academy of Family Physicians (AAFP). The Committee member would also be working on a collaboration about the fourth trimester, in which they planned to discuss cultural sensitivity, and was engaged in discussion with Indigenous members of the AAFP about value-based care in Indian Health Services.

A Committee member shared the report with several organizations including Zero to Three, a national nonprofit, the Council on Early Childhood within the American Academy of Pediatrics, the Council on Healthy Mental and Emotional Development, the Oregon MCH Division, and the Alliance for the Advancement of Infant Mental Health.

A Committee member had referenced the report in multiple conversations with state and federal legislators to make them aware of its influence on mothers and babies within Indigenous populations.

A Committee member had several nursing organizations and leaders that would be good groups to reach out to. The member asked whether anyone had used a template or introductory email with appropriate language when doing outreach/dissemination. The Chair responded that she could share a template.

The Chair added that she had shared the report with the North Carolina Commission on Indian Affairs, the Office of Health Equity, the state Title V program, the Board of the National Healthy Start Association, and the Board of the Association of Maternal and Child Health Programs (AMCHP). She planned to distribute it more widely across North Carolina through presentations with their provider support network.

A Committee member had been moving the report through a rural health network and rural agencies. The Committee member had also worked with tribes in Wyoming to translate the recommendations into action and advocacy to help them govern their own health services.

The Chair asked Committee members to consider what accountability measures the Committee would like to see from the Secretary and HHS. The feedback included:

- Accountability from the Secretary's office should be concrete and actionable.
- HHS should consider the agencies that were already working on some aspect of the recommendations. There could be point people to provide updates on those activities in terms of action items or appropriations.

A Committee member wondered about the parameters or challenges that HRSA might face in implementing recommendations and whether there were influences outside of HRSA that could impact those parameters. MCHB responded that there were a few challenges including recommendations applied to other agencies and offices outside of HHS, and legislative authorities to consider. For instance, there were eligibility parameters for grants and set aside funds and an agency might not have the ability to change the way their grants were funded based on how that legislation was written.

The DFO shared that HRSA had convened a meeting with ex-officio members to exchange updates on implementation and adoption of the AI/AN recommendations. They planned to continue these update meetings and to look for opportunities to collaborate or synergize between agencies to move the recommendations into action. Ex-officio members then shared updates on their implementation and adoption of the recommendations.

Indian Health Service (IHS): Dr. Tina Pattara Lau shared that FY 2023 was the first year in which IHS had received advanced appropriations for health care provision. In January, IHS leadership began implementing an agency workplan that outlined critical priorities to guide agency improvement over the next year, including providing regular updates on their website and launching an MCH-specific webpage. In terms of the AI/AN recommendations to expand and diversify the IHS workforce, the agency had prioritized employment, workforce development, mentorships, and partnerships with academic centers. IHS was also focusing on maternity care deserts and addressing the barriers to care by working on provider training, telehealth, and home

visitation programs to supplement the work done in clinics and hospitals. These efforts would be in collaboration with their public health nurses and community health workers.

Centers for Disease Control and Prevention (CDC): Dr. Charlan Kroelinger shared that the CDC was disaggregating data by race and ethnicity, with a recent focus on the categorization for AI/AN populations. CDC recently published a brief on pregnancy-related deaths among AI/AN persons from 36 maternal mortality review committees (MMRCs), and had also implemented methods for classification of AI/AN based on the advice from tribal organizations. The Division of Reproductive Health (CDC-DRH) was continuing to develop a tribally-led MMRC with expanded funding later this year to support those activities. CDC also planned to provide funding to MMRCs for key informant interviews with surviving families and friends. CDC planned to partner with NICHD to update materials for their Healthy Native Babies project with engagement from tribal leaders and organizations. The CDC-DRH continued to support the Hear Her campaign, sharing personal stories from American Indian people who experienced pregnancy-related complications. The CDC Division of Population Health maintained a Healthy Tribes Program to prevent disease and promote wellness in tribes and planned to launch a new funding cycle for health and wellness in Indian country. The CDC National Center on Birth Defects and Developmental Disabilities planned to engage with tribal epicenters in surveillance efforts to protect mothers and infants from infectious disease threats. Finally, the Center for State, Tribal, Local, and Territorial Support published a new funding cycle to strengthen public health systems and services in Indian country. Dr. Danielle Ely, CDC-National Center for Health Statistics, added that she was developing a report on AI/AN pregnancy events, linkages between infant birth and death files, and a category to capture AI/AN who identify as multiracial.

Administration for Children and Families (ACF): Dr. Wendy DeCourcey is working with the Administration for Native Americans to provide an update on their various activities related to the recommendations and would provide this to the Committee at a later date.

MCHB: Dr. Michael Warren shared that MCHB reviewed the AI/AN recommendations and identified 29 that directly applied to MCHB, 19 of which MCHB or its grantees were either currently supporting or could support in the near future. He reiterated that the budget reauthorization doubled the MIECHV funds for tribes and MCHB had already begun transferring those funds. In addition, MCHB aimed to be more inclusive with language and funding eligibility. They also had been working to increase consultation with tribes at the HHS level with the Secretary's Tribal Advisory Committee and through HRSA's Tribal Advisory Committee. HRSA recognized the value of meeting on tribal lands and looked forward to holding future advisory committee meetings in communities that could provide similar lived experience and feedback. Finally, MCHB planned to increase the number of tribal entities receiving Healthy Start funding; invest in training for AI/AN doulas and traditional birth workers; encourage the inclusion of universal screening and referral for intimate partner violence, substance use disorder, depression, and anxiety; and facilitate access to maternal mental health services.

Discussion

A Committee member asked whether there was precedent for bidirectionality in reporting, allowing Committee members to share diverse perspectives of the Committee's work with stakeholders across different departments. The DFO noted that the communication has

historically been more in the direction of inviting other bureaus within HRSA to speak to the Committee, and Dr. Michael Warren suggested that this could be part of Committee members' roles. He emphasized the need for partnerships across all levels to identify solutions.

An Ex-officio member asked whether there was a PowerPoint presentation that all Committee and Ex-officio members could use to disseminate the recommendations across multiple channels with consistency. Some of the partners might want to use those slides to disseminate through their own channels. The Chair agreed that a standard presentation or templates could help with consistency going forward.

A Committee member discussed the development of metrics for a strategic plan within another advisory committee and proposed the possibility of similar metrics for the implementation of the recommendations. This may include the number of Indigenous women who were reached in programs after an increase in grant funds or program expansion.

A Committee member asked whether there was any guidance available on what Committee members could or could not present, on behalf of the Committee. Dr. Michael Warren answered that there were two instances to consider: (1) media inquiries should be directed back to HRSA staff and the Committee Chair, and (2) Committee members should always be mindful of conflicts of interest. Committee members may consider working with the DFO and the Chair to develop a package of standard materials that all members could share with their stakeholders.

Discussion on Framing/Language Matters Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair ACIMM Members

The Chair opened a discussion on framing conversations about maternal and infant health, especially in relation to equity, in order to engage stakeholders at all levels. She asked whether Committee members had heard messages within their own communities that suggested any controversies or challenges implementing MCH initiatives. She shared her experience working with the Frameworks Institute to develop effective messaging strategies around tobacco use in North Carolina and suggested that the Committee might explore similar approaches for their work on maternal and infant health. Committee members shared:

- skepticism was being heard about the accuracy of maternal mortality data, as it was focused on preventability, which some providers perceived as an indictment on their practice. Rather than broadening their understanding of maternal mortality to the overall safety of their patients, providers might feel defensive. Education or outreach efforts with organizations, such as the American College of Obstetricians and Gynecologists (ACOG), might help providers better understand the data and updated perspectives of maternal mortality.
- providers needed to recognize the importance of the fourth trimester and the continuum of pregnancy into post-partum care. The AAFP was working on this messaging to ensure that it becomes foundational knowledge for primary care providers.
- different states were in different places for these conversations, highlighting a need for baseline education to accompany the recommendations and to strategically frame

- information for a target audience. Working within a framework would be helpful if that framework provided flexibility to adapt to individual states.
- consider framing in terms of recent legislation on abortion and contraception, newer data on Black maternal health, and historical influences on health outcomes.
- policymakers had an important role in implementation and that there was a need to move the recommendations into the hands of those who could write the legislation needed to improve outcomes.
- any entity the Committee engaged with should be genuinely bipartisan.

Data Refresher on Infant Mortality, Maternal Mortality, Severe Maternal Morbidity, and Pregnancy-Related Mortality

Fetal, Perinatal, and Infant Mortality *Danielle Ely, Ph.D.*, Statistician, Division of Vital Statistics, Reproductive Statistics Branch, CDC

Dr. Ely discussed the availability of data on births, fetal deaths, and infant mortality. Final data for 2021 were available, as were provisional estimates for births and infant mortality through the third quarter of 2022. The provisional birth report for 2022 data was expected in May 2023, and final data was expected in August 2023. CDC was developing a new provisional linked file report for 2022 data and recently released the 2021 fetal death file, which included both demographic and cause of death information for the first time.

Dr. Ely reviewed declining rates in fetal, infant, and prenatal mortality over the last two decades, noting that mortality rates remained highest for infants of Black, AI/AN, and Native Hawaiian or other Pacific Islander women. Black infants had mortality rates that were nearly twice as high as those of white, Hispanic, or Asian infants. Black, AI/AN, and Native Hawaiian or other Pacific Islander women had the highest percentages of preterm births, and their infants also had the highest preterm mortality rates.

Dr. Ely presented data indicating that infants of Black and Hispanic women who received WIC had lower mortality rates than those who did not, while the opposite was true for infants of white women. Additionally, infants of women who received Medicaid had higher mortality rates than those of women with private health insurance, which was true across all maternal race and Hispanic origin groups. Infants of women who received late or no prenatal care also had higher mortality rates than those of women receiving care in the first trimester, which was true for all race and Hispanic origin groups. Dr. Ely highlighted the five leading causes of infant mortality, which had remained largely consistent since 2006. Overall, infant mortality rates were higher in non-metro counties than in metro counties, which held true across maternal race and Hispanic origin groups.

Dr. Ely emphasized the need to continue working on the timeliness of period and cohort file data releases. To that end, CDC was developing a publication based on provisional linked birth and death data that they aimed to release six months earlier than their final data.

National Vital Statistics System Maternal Mortality Donna Hoyert, Ph.D., Division of Vital Statistics, NCHS, CDC Dr. Donna Hoyert presented a summary of maternal mortality data trends from the National Vital Statistics System (NVSS). The data were collected from death certificates and cause of death statements, and NCHS used the World Health Organization's International Classification of Diseases (ICD) to define maternal mortality, which focused on deaths occurring while pregnant or within 42 days of the end of the pregnancy. Maternal mortality rates were calculated as the number of maternal deaths per 100,000 live births, with statistics dating back to the early 1900s, with periodic disjuncture coinciding with the adoption of ICD revisions.

In 2003, CDC added a checkbox to death certificates to improve maternal death data accuracy. However, it took a long time for all states to implement this. They also found that the checkbox was being marked more often than appropriate. NCHS resumed publishing maternal mortality data in 2018 after all states added the checkbox. The first fully processed dataset from the new reporting system, which included changes to improve data quality, was released in a 2021 Health E-Stat report.

Dr. Hoyert reviewed the 2021 Health E-Stat data, which showed disparities in maternal mortality rates by age and race and ethnicity. The highest maternal mortality rate was for women over 40 years old. Non-Hispanic Black women had a maternal mortality rate 2.6 times higher than non-Hispanic white women. Maternal mortality also varied by urbanization level, with lower rates in large metropolitan counties. Maternal mortality rates rose during the COVID-19 pandemic, but 2022 data showed a trend back to pre-pandemic levels.

Dr. Hoyert announced that CDC recently released a new data visualization tool that presented the numbers of provisional maternal deaths through October 2022. This tool provided a series of counts for twelve-month periods and showed overall data, as well as data by age, race, and Hispanic origin. NCHS also provided provisional data, but Dr. Hoyert emphasized that these data were subject to change after multiple reviews.

Pregnancy-Related Deaths: Data from Maternal Mortality Review Committees in 34 U.S. States, 2017-2019

Ashley Busacker, Ph.D., Epidemiologist, Division of Reproductive Health, CDC

Dr. Ashley Busacker presented data on pregnancy-related deaths from 36 U.S. states from 2017 to 2019, based on reports from MMRCs. MMRCs were multidisciplinary committees that used standardized data collection to determine the causes of pregnancy-related deaths. These data focused on deaths that occurred during pregnancy, or within one year after its end, and that were related to or aggravated by pregnancy.

Among the 1,018 pregnancy-related deaths reviewed, over 70% occurred among individuals aged 25-39. Over half of the individuals who died had a high school education or less. Over 50% of the pregnancy-related deaths occurred one week to one year after the end of pregnancy. Mental health conditions, including suicide and substance abuse, were the most frequent cause of pregnancy-related death, followed by hemorrhage and cardiac conditions.

Dr. Busacker also presented data on pregnancy-related deaths by race and ethnicity. Among non-Hispanic Black individuals, cardiac and coronary conditions and cardiomyopathy were the most frequent underlying causes of death. Mental health conditions were the most frequent cause of pregnancy-related death among Hispanic individuals. Hemorrhage was the most frequent underlying cause of pregnancy-related death among non-Hispanic Asian individuals, while mental health conditions were the most frequent underlying cause of death among non-Hispanic white individuals.

There were 17 reported pregnancy-related deaths among AI/AN. Mental health conditions were the most frequent cause of pregnancy-related death, and 93% of all deaths were determined to be preventable. Dr. Busacker noted that methodological decisions about racial classification can impact the size and characteristics of the population used in an analysis.

Severe Maternal Morbidity (SMM): Trends and Disparities Ashley Hirai, PhD, Senior Scientist, Office of Epidemiology and Research, MCHB, HRSA

Dr. Ashley Hirai presented data collected through the Healthcare Cost and Utilization Project (HCUP) and the Title V MCH Block Grant Program. She began by highlighting that reported maternal and pregnancy-related deaths were only the tip of the iceberg, as there were 50-100 cases of SMM for every maternal death. HRSA collaborated with the Agency for Healthcare Research and Quality (AHRQ), which acted as a data purveyor, and with CDC, which acted as a measure developer to populate national and state estimates for monitoring and surveillance. The HCUP data came from the Healthcare Cost and Utilization Project, an all-paired database of hospital discharge records from non-federal acute care hospitals in nearly all U.S. states.

Dr. Hirai discussed the definition of SMM, which involved unexpected outcomes of labor and delivery that resolved in significant short or long-term consequences to a woman's health. SMM data came from hospital discharge record codes, using 21 different indicators based on 16 diagnosis codes and five procedure codes. However, there could be measurement issues with SMM, because some indicators required greater clinical judgment and examination of signs and symptoms to determine severity.

Dr. Hirai presented data that showed that there was a 26% increase in SMM in the last decade, with the largest single-year change in 2020 as a result of the COVID-19 pandemic. The reasons for these trends were unclear, but they could be related to increases in chronic conditions and maternal age. However, a study in California showed that maternal characteristics and comorbidities could not explain the rise in SMM in that state.

The data also showed racial and ethnic disparities in SMM, with Black women having the highest rates of SMM—twice that of white women, who had the lowest rates. Black, Hispanic, and Asian Pacific Islander women had the largest increases in SMM between 2019 to 2020. However, data from HCUP and hospital discharge records might not always be accurate and not all states had adequate reporting. In addition, although AI/AN populations had higher SMM rates, these data might not be complete because IHS facilities did not participate in HCUP. There were also differences by expected payer. SMM was higher for Medicaid or Medicare-billed

delivery hospitalizations compared to those who were privately billed, billed to people who did not have health insurance, or covered by other public insurance such as military benefits.

Contrary to other perinatal indicators, SMM was higher among those in large metropolitan counties than in small-medium metro counties or non-metro counties. Dr. Hirai noted that there may be measurement problems for these data due to potential coding variation or indicator-level issues. She emphasized the importance of recognizing that most studies only capture SMM at delivery and that mental health conditions and hospitalizations had not been included in SMM definitions. She summarized that there was still much work to do toward refining and advancing SMM measures and that CDC had been collaborating with federal partners to improve surveillance and prevention efforts.

Discussion

A Committee member said that it was important to have data from every state to truly understand the disparities across the country. The Committee member asked how it might be possible to obtain data from the other states that were not currently reporting MMRC data. Dr. Busacker said that each data call resulted in an increased number of reporting states. There were approximately 45 states and jurisdictions that were currently reporting in the Maternal Mortality Review Information Application (MMRIA), and that number continued to increase over time. The CDC hoped that their 2022 data call would include even more states.

The Committee member noted that the NVSS data only represented a broad view and asked what plans there were for a deeper dive into the data. The Committee member expressed particular interest in receiving Pregnancy Mortality Surveillance System (PMSS) data from more recent years to better understand the impact of COVID-19. Dr. Busacker responded that the CDC hoped to release 2019 PMSS data soon, and that they were still receiving data from 2020. She added that their team provided training and tools to jurisdictions to help with data reporting standardization.

The Chair clarified that MMRCs had multiple steps to complete prior to reporting to the MMRIA. Different state legislation could require providers to send health records, which could be a box of paper that needed to be abstracted and formatted. The MMRC must then review those data before making a determination, and the CDC helped to keep reporting as standardized as possible, but there were variations in state processes for moving data forward.

A Committee member asked whether the system was prepared to collect health-related social needs and if there were barriers to collecting those data. Dr. Busacker answered that the CDC had recently introduced the Community Vital Signs Dashboard that provided community context indicators based on where the individual last lived. In addition, next-of-kin and informant interviews could also provide social information. MMRCs had the potential to incorporate social determinants of health data that could not be obtained by vital records.

A Committee member asked whether any of the inequity gaps were closing, even as a trend if not statistical significance. Dr. Ely answered that the data showed some disparities that were closing and others that were widening.

A Committee member asked whether there was systematic tracking of pregnancy-related deaths as a result of intentional injury. Dr. Busacker answered that MMRC did collect data on intentional death, whether by suicide or homicide.

Where Does the Committee Go from Here?

Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair ACIMM Members

The Chair asked Committee members whether there was any unfinished work from the last iteration of the Committee, specific areas they might want to focus on next, and specific resources the Committee might need to move forward. The following was shared:

- maternal mortality was higher among those who received state benefits than those who had private insurance. Since those benefits were intended to help rather than hurt, it would be important to better understand why.
- the Committee's intense focus on AI/AN and emphasized the importance of community engagement in the process. She wondered whether there were other communities that would benefit from a similar approach.
- there was value in engaging communities and suggested that there might be a community within the 13 states most impacted by infant and maternal mortality that would benefit most from the Committee's focus. The Committee could conduct deeper research into the needs of the community, the best practices needed, and implementation of those practices in order to develop recommendations for other struggling communities.
- mental health should be a priority focus area because of its deep association with maternal mortality. There was also interest in whether the data was adequate for understanding how mental health was related to maternal mortality.
- balance conversations about magnitude of impact with attention to the smaller regions that do not have big numbers, but that could be greatly impacted by equity efforts.
- reaching and communicating with communities was important and suggested that there could be best practices in this field that were worth exploring.
- integrating recommendations into professional education and training across the health care spectrum would be an important part of messaging.
- opportunity to share lessons learned and challenges from communities to inform grant-making entities. Dr. Cernich suggested involving communities already supported by NIH challenge grants. Dr. M. Warren said that MCHB was also considering simple grant-making revisions to better support awardees and encourage more entities to apply.
- The Chair said that capacity-building grants were another opportunity for communities to develop their research resources.

DAY TWO: Tuesday, March 21, 2023 Call to Order and Review of Day One

Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair

The Chair welcomed Committee members and provided an overview of Day One. She emphasized the importance of ensuring lived experience was reflected in the Committee's work, as context for the presentations on Day Two.

Community Voices

Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair ShaRhonda Thompson, ACIMM Member

To help the Committee focus its work on the individuals who were impacted by its recommendations, The Chair invited ACIMM member, Ms. ShaRhonda Thompson, to share her pregnancy and birth stories.

Ms. Thompson talked about the contrast between her two birth experiences, and how those experiences influenced her work as an advocate. Her first child was born when she was very young and uninsured. As she did not have access to someone who could help her navigate the health care system, she read through lengthy Medicaid materials to learn about what was covered and self-advocated to receive services. Despite these efforts, she was still unaware of all of her birthing options. Ms. Thompson's second pregnancy was several years later, when she was considered high-risk because of her age. This time, however, she had access to a social worker who helped her navigate through the system. The social worker introduced her to the Healthy Start program and helped her understand her rights in the medical system. Although access to a social worker made her second birth experience much easier than her first, Ms. Thompson still experienced insensitive communication from the medical staff.

During her second birth experience, Ms. Thompson learned that the nation's infant mortality rate was similar to that of third-world countries. She could not understand how a country with some of the best medical systems in the world could have such a high infant mortality rate. She became involved with patient advocacy, supporting the inclusion of social workers, programs such as Healthy Start, and ensuring respectful and accessible health education and communications.

Discussion

A Committee member asked whether Ms. Thompson, or anyone in her community, had any experiences with or thoughts on midwives as a care model. Ms. Thompson said she had met with midwives and doulas and felt that their one-on-one services with mothers were more personal and positive. However, she was less sure about the information they could offer on assistive programs in the area.

A Committee member expressed appreciation for the reminder that care navigation and peer support were such important components of pregnancy from the very beginning.

MCHB asked Ms. Thompson to share more about her experience with Healthy Start and any takeaways she could offer. Ms. Thompson said that her experience with Healthy Start was wonderful. Her home visitor was non-judgmental and helped her feel comfortable asking any questions. She believed that her outcome would not have been as positive without Healthy Start and has since become a strong advocate for Healthy Start in her community.

The Chair asked Ms. Thompson if there were any specific lessons learned that the Committee should consider going forward. Ms. Thompson reiterated that social workers were very important because they helped people navigate through the system and ensured they had everything they needed. In addition, she had been working with medical students to help them understand how to talk and listen to their patients.

Dr. M. Warren expressed appreciation for her work with the future workforce. He highlighted a <u>funding opportunity</u> that supported integrated maternal health services as an innovative model of care.

A Committee member echoed the importance of integrated, co-located social services within obstetric practices, and the need for well-paid social workers who provide high-value services as a standard of care.

Partnership Panel of National Organizations (Part One)

Moderator: Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair

National Institute for Children's Health Quality (NICHQ)

Scott Berns, M.D., M.P.H., FAAP, President and Chief Executive Officer

NICHQ's mission is to improve the health and well-being of children and their families through an emphasis on health equity. A central project is a collaboration with the CDC-funded National Network of Perinatal Quality Collaborative (NNPQC). Since 2017, NICHQ has been the coordinating center for the NNPQC to provide resources and expertise to 27 state-based Perinatal Quality Collaboratives (PQCs) to enhance their ability to make measurable improvements in maternal and infant health outcomes. NICHQ's support had increased the number of PCQs from 14 to 27 over the previous five-year cycle. NICHQ also worked with the HRSA-funded Healthy Start Technical Assistance and Support Center (TASC) to support 101 Healthy Start grantees to enhance and strengthen their capacity to improve health outcomes before, during, and after pregnancy and to reduce racial and ethnic disparities in infant death and maternal health outcomes in their communities.

In addition, NICHQ hosted collaboratives with hospitals and clinics to better understand the supports needed for healthy pregnancy and birth outcomes, and with Healthy Start community members to identify population-based recommendations to improve outcomes and achieve equity. Findings from these collaboratives highlighted the need for better synergy and alignment between hospital-focused and community-based initiatives to integrate population health, social determinants of health, and clinical care. PQCs needed to partner with birthing hospitals and facilities to ensure providers delivered safe, equitable, and respectful care. It was also critical to engage patients in hospital quality improvement initiatives and to collect patient-reported measures within hospitals and clinics to obtain perspectives from those with lived experience. They also found a need for more holistic thinking about equity and upstream approaches to address institutional racism. The promotion of racially- and culturally-concordant care could help break down social, racial, and clinical patriarchy and hierarchy.

Potential federal solutions to improve maternal and infant health outcomes per findings from NICHQ included providing comprehensive, gender-specific primary care and perinatal mental health; building and diversifying the maternal care workforce; promoting midwifery and similar models of care; improving quality of health care, including data improvements; extending Medicaid to twelve months postpartum; and conducting clinical research to identify preventive and treatment strategies.

National Healthy Start Association (NHSA) Deborah Frazier, R.N., Chief Executive Officer

The National Healthy Start Association (NHSA) represents 101 Healthy Start programs across the country—approximately 25% located in rural areas, including two in tribal regions and one in Appalachia. Healthy Start is a community-based program that provided home visiting and care coordination for pregnant and postpartum people and their children. The program also provides services such as fatherhood engagement, doula services, and screening and referral for interpersonal violence and depression.

In recent NHSA focus group findings, grantees discussed the disproportionate impact of COVID-19 on pregnant, postpartum, and breastfeeding people, as well as their concern about vaccine hesitancy in their communities. To address these issues, NHSA developed a webinar with pediatric immunologists and obstetricians to dispel myths, as well as infographics and brochures for mothers and public health practitioners. NHSA also heard from fathers, who indicated that they did not feel thoroughly engaged or valued as partners in obstetrics visits, and wanted to be more involved in decision-making, highlighting that more work was needed in engaging fathers as valuable partners in obstetrics and public health efforts.

NHSA also partnered with HRSA's Division of Healthy Start and Perinatal Services through the <u>AIM Community Care Initiative</u> (AIM-CCI) to address maternal morbidity and mortality. In this effort, NHSA focused on implementing non-hospital based maternal safety bundles in community-based organizations and outpatient clinical settings. They conducted focus groups with women who gave birth 18 months to two years pre-bundle implementation to understand thoughts about the care they received. Feedback indicated the need for women to feel more respected and valued during their pregnancy and in the labor and delivery room.

Association of Maternal & Child Health Programs (AMCHP) Terrance Moore, M.A., Chief Executive Officer

AMCHP's focus on <u>racial equity</u> is central to their work in reproductive, perinatal, and infant health efforts. They are guided by principles centered around improving health during sensitive timeframes, while acknowledging and confronting racism as the primary oppressor that impedes progress. AMCHP is committed to co-creating community-led solutions rooted in reproductive justice and anti-racist health equity frameworks, and constructively facing racism while accepting that mistakes would be made. This includes partnering and sharing power with Black and Brown scholars, providers, healers, nurturers, creatives, community-based and community-rooted organizations. AMCHP aims to be an asset in anti-racism work and to hold space for the

organizations that already held justice solutions, serving as the conduit for co-creating community-led solutions in MCH.

In 2020, AMCHP convened a national meeting of public health, health care, and community thought leaders and institutional partners with a role in preterm birth prevention. The goal of the meeting was to develop joint strategic action to improve outcomes for the mother-infant dyad, specifically related to preventing preterm birth. The effort was a significant step towards reducing preterm birth rates, which was a crucial indicator of MCH in the U.S. that disproportionately affected marginalized communities. Five strategies were identified: 1) refining funding structures to support community-based organizations and transdisciplinary perinatal providers using a reproductive justice framework; 2) ensuring perinatal and social determinants data were inclusive, relevant, and accessible; 3) investing in comprehensive perinatal data systems for states and community-based organizations; 4) covering the costs of necessary supports to prevent preterm birth with public and private funds; and 5) standardizing the accountability of health systems to the patient experience.

AMCHP's <u>Innovation Hub</u> serves as an online searchable repository for these community-driven best practices in MCH. Community-based organizations were encouraged to respond to a recent call for applications and to attend the 2023 <u>conference</u> in New Orleans.

CityMatCH Denise Pecha, LCSW, Deputy Executive Director

CityMatCH, a membership organization that supports local urban MCH programs, including those run by community-based organizations and hospitals, provided updates on their activities since previously participating in a Committee meeting. They connect health departments, Healthy Start programs, tribal entities, and partner organizations to ensure national alignment of efforts and strategies.

One of CityMatCH's key projects was capacity building, training, and TA for programmatic and data-related issues, or bridging the gap in epidemiology and data support at the local level, as many MCH programs lacked the necessary staff to manage and analyze data. CityMatCH also hosted an annual conference and provided training courses for epidemiologists in partnership with MCHB and CDC. Additionally, they had an emerging leadership program called CityLeaders to address the shortage of MCH workers and workforce challenges, such as burnout. CityMatCH also worked to reduce perinatal HIV, which included efforts to address the rising rates of HIV and syphilis in AI/AN communities.

During the December 7, 2022 meeting, CityMatCH members had asked the Committee to address certain priority areas and questions including social determinants of health, such as housing and economic stability, access to quality health care and paid family leave. They also asked the Committee to address extended telehealth options for birthing families and increased postpartum support and mental health services to families during the "fourth trimester. CityMatCH noted that challenges to reproductive rights were also impacting local MCH programs and CityMatCH's members.

Discussion

The Chair asked the panelists to follow-up with an email to identify at least one critical component of their work that could be addressed by the Committee.

A Committee member asked the panelists whether they had data or research that could help the Committee support inclusion of social workers and community health workers, particularly in the fourth trimester and in high-risk communities.

NHSA responded that the integration of social workers was not a new idea. When Healthy Start began, it was community-driven and focused on addressing social determinants of health. Most of the programs had embedded social workers and nurses. Although there may have been a shift from this focus, it was important to return to a holistic approach to addressing social determinants of health and racism.

AMCHP added that a strong dataset was available from Commonsense Childbirth and Easy Access Prenatal Clinics and Perinatal Safe Spots, both of which were part of AMCHP's Innovation Hub. These clinics and safe spots provided community members with perinatal care and support in their communities, which has been shown to close racial disparities in perinatal health. AMCHP pointed out that there were also data available from California and other states demonstrating that certain services reduced disparities in communities. AMCHP also emphasized the importance of qualitative data from lived experience in addition to quantitative data.

NICHQ said there was a comprehensive document, "Why Kids and Why Community Health Workers?" created by a group led by Charles Bruner. Although the focus of the document was on health care transformation and primary care, there was a section specifically dedicated to the effectiveness and impact of community health workers.

A Committee member asked if there were any available data on how the needs of individuals experiencing housing insecurity were being met. CityMatCH said that community health workers worked with those individuals' families and friends to find temporary housing until they could find a more permanent solution. NHSA added that housing was a priority in the Healthy Start program. There were other examples of housing support—for instance, some cities extended housing for pregnant people and United Health Group invested in housing programs.

A Committee member expressed interest in a future presentation on the evidence of the impact of social determinants of health on the mother-infant dyad and the developing fetus. She had recently learned that there was robust data on the influence of environmental experiences, such as vicarious racism.

Partnership Panel of National Organizations (Part Two)

Moderator: Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair

March of Dimes

Elizabeth Cherot, M.D., M.B.A., FACOG, Chief Medical and Health Officer

The March of Dimes' mission to end preventable maternal morbidity and mortality, preterm birth, and infant death has an 85-year history, beginning with Franklin Delano Roosevelt's request that everyone contribute a dime to end polio, which later pivoted to preventing preterm birth and disabilities. Today, March of Dimes is focused on leading the way for healthy moms and strong babies through a health equity lens.

The March of Dimes' national equity framework of priorities was identified in collaboration with over 600 partners, subject matter experts, and convening members, included maternal morbidity and mortality around cardiovascular health, mental health, chronic stress, and preterm birth and birth defects. March of Dimes aims to address these priorities through advocacy, research, education, and partnerships.

The March of Dimes' portfolio also included work on the Momnibus Act, the PREEMIE Act, expanded protections for pregnant workers, paid medical and family leave, and the fourth trimester. March of Dimes also conducted research, including their Maternity Care Deserts Report, and provided education for families and providers through programs such as the NICU Family Support® program. March of Dimes advocated for health equity through the Mom and Baby Action Network, a national consortium of 400 partners, as well as through local initiatives, such as their support for doulas.

National Association of County and City Health Officials (NACCHO) Lori Freeman, M.B.A., Chief Executive Officer

NACCHO's mission is to advocate for the nearly 3,000 health departments across the country and to strengthen their ability to promote optimal health, equity, and security for all communities. Services provided by local health departments played a significant role in delivering MCH services, particularly in rural areas where health departments were often the only provider of clinical services. NACCHO emphasized their importance in providing touchpoints to communicate important health information to families, such as well-child and home visits.

NACCHO's TA and training to local health departments, includes the <u>Continuity of Care for Breastfeeding Blueprint</u>, which supports communities with system-level approaches to support chest/breastfeeding. NACCHO's also increased the capacity of local health departments to address maternal and child health during <u>emergency preparedness and response efforts</u>, including support for disease mitigation and vaccination during the COVID-19 pandemic.

Pressing concerns identified by NACCHO's MCH workgroup included prenatal and postpartum care, maternal and infant mortality, substance abuse, mental health concerns, safe sleep-related deaths, and congenital syphilis. The MCH workgroup also focused on health equity and the ability of local health departments to address disparities by building coalitions to support communities affected by structural racism, medical racism, low income, behavioral health issues, or documentation barriers.

NACCHO's extensive <u>policy</u> and <u>education</u> work, in partnership with local health department officials, included the development of approximately 130 policy statements advocating for action

and sustained funding for efforts that supported infant and maternal mortality, such as home visiting and fatherhood programs.

Association of State and Territorial Health Officials (ASTHO) Christi Mackie, M.P.H., Vice President, Community Health and Prevention

ASTHO is a nonpartisan member organization comprised of State Health Officials and their leadership teams. They work to formulate, influence, and implement internal and external policies. ASTHO's current priority areas are racial and health equity, workforce development, and sustainable infrastructure improvement data, modernization, and evidence-based practices. Their operational model includes leadership development, technical assistance, capacity building, government affairs, and advocacy.

ASTHO supported two portfolios of work related to MCH: 1) family and child health and 2) maternal and infant health. ASTHO worked with the CDC's Pregnancy Risk Assessment Monitoring System (PRAMS) to support states with data linkages so they could identify and understand the complex needs of maternal populations. They also worked with the Data Roadmap for Racial Equity Advancement in Maternal and Child Health (DREAM), which focused on advancing racial equity through data collection, recording, and intervention. ASTHO led a Community, which aimed to improve access to telehealth, delivery of contraceptive care, and billing and coding systems for Title X clinics.

ASTHO supported the <u>Promoting Innovation in State and Territorial MCH Policymaking</u> (PRISM), which aimed to build capacity for policymaking, specifically to address substance use and co-occurring mental health conditions. They also supported a <u>Breastfeeding State Learning Community</u>, which aimed to improve breastfeeding disparities. Their CDC-funded <u>Risk-Appropriate Care Learning Community</u> provided data-driven best practices via cross-agency collaboration to analyze pooled data on maternal risk conditions.

ASTHO conducted <u>environmental scans</u> with state health officials twice a year to identify public health trends and issues across the US. Their latest environmental scan revealed three key priority areas: 1) youth mental health and social well-being, 2) maternal and infant mortality and morbidity, 3) and racial and socioeconomic inequities in perinatal outcomes. ASTHO's priorities included the Zero to Three Nutrition Security initiative, severe maternal morbidity and mortality, understanding their role in supporting communities, and addressing polysubstance use among pregnant people. ASTHO actively supported health agencies in these areas by providing technical assistance to help state health officials with workforce development, data equity, and funding streams to sustain their work.

National Birth Equity Collaborative (NBEC) Inas-Khalidah Mahdi, M.P.H., Dr.Ph.(c), Vice President of Equity-Centered Capacity Building

National Birth Equity Collaborative (NBEC) discussed the NBEC's history and current focus areas. NBEC originally centered its work on Black infant health with the goal of reducing black infant mortality across the U.S. by 25% within 10 years. Early efforts included the <u>Campaign for</u>

<u>Black Babies</u>, which was centered on racial inequality and Black infant mortality. Its <u>mission</u> has since expanded to also include <u>transnational solutions</u> for infant health, Black maternal health, and sexual and reproductive well-being. NBEC has conducts capacity building work focused on organizational equity assessment, training, technical assistance, as well as community-oriented work focused on shifting power to community research and policy advocates.

The Birth Equity Index, which was developed to identify community-level characteristics associated with an increased risk of Black infant mortality across 100 U.S. metropolitan cities, drew data from multiple public sources, such as education, unemployment, residential segregation, adult smoking, poor mental health, poor physical health, adult obesity, limited access to healthy foods, homicide rate, crime, air pollution, and structural racism. This approach highlighted the impact of environmental racism, redlining, state-sanctioned violence, and structural factors—marking an important shift from placing blame entirely on Black families. The Birth Equity Index provides actionable direction for NBEC partners seeking to understand how to best use their limited resources to make the greatest impact in their communities. NBEC discussed how the Birth Equity Index centered on reproductive justice—the right to bodily autonomy, the right to have a child or not have a child, and the right to parent children in a safe and sustainable environment. This approach allowed NBEC to look beyond whether the mother and child survived.

NBEC emphasized the importance of listening to Black birthing people and incorporating their lived experiences in community and care settings. NBEC had continuously expanded their research and programming to include patient experience and was also working on a patient-recorded experience measure in hospital discharge surveys in collaboration with Johns Hopkins University.

Public Comment

Sarah Meyerholz, M.P.H., Program Lead, MCHB

Jester Jersey

Mr. Jester Jersey was a member of several community-based service organizations, such as Kiwanis and Vaccinate Your Family, leading efforts to ensure that women of childbearing age were vaccinated against preventable diseases. Although the recent "tripledemic" of COVID-19, the flu, and respiratory syncytial virus (RSV) resulted in increased rates of vaccination, it also marked an increase in maternal mortality and morbidity. He urged the Committee and other HHS agencies to reach out to community-based service organizations to collaborate on future vaccine campaigns. As trusted voices of the community, community-based service organizations could reach underserved community and develop a foundation of trust to promote vaccine messaging.

Discussion

A Committee member agreed with the recommendation to address vaccine access and equity and said that the Committee would keep this request in mind going forward.

Next Steps and Assignments

Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair

ACIMM Members

The Chair asked Committee members to share high priority areas, specifically those that could be identified as future Workgroups. She restated topics that were raised during Day One including maternal mental health and well-being, community engagement and the inclusion of lived experience, workforce challenges, patient communication, and elevating lessons learned into measurable improvement in communities. MCHB encouraged Committee members to consider the role of ACIMM as an advisory body for the Secretary and to view their priorities through the lens of what they believed the Secretary should be hearing as a recommendation.

Priority areas from Committee members included:

- evidence-based best practices, particularly around community engagement.
- integrated maternal health models; bringing into alignment social supports and clinical health, including behavioral health.
- aligning public health entities with clinical health. The inclusion of the community voice had worked well in public health, but that language of inclusiveness had yet to reach the clinics.
- elevating solutions, strengths, and positive outcomes; rather than a sole focus on fixing problems. There were positive birth outcomes, even in vulnerable communities, and more voice should be given to those stories.
- addressing sustainable and equitable funding. Funding was not distributed to everyone
 and there was a need to identify the gaps and potential solutions to expand funding to
 those areas.
- focusing on the barriers related to payment, particularly for midwifery and doula support as integrated components of the medical system.
- center discussions on the Black and Brown experiences within maternal and infant care, focusing on practical applications of interventions to improve birth outcomes and birth experiences across the continuum of care.
- addressing the lack of standardization in data collection across states, which was needed to better understand the full picture of maternal and infant mortality.
- addressing workforce issues across health care as a destabilizing force in maternal health.
- consider best practices in states that had implemented the Medicaid expansion so that non-expansion states could address how those practices and lessons learned might fit within their reality for implementation.
- international efforts to reduce stillbirth that could be translated nationally and the need to balance parameters between reducing stillbirth and reducing pre-term delivery.
 - Wellcome Trust was conducting a large global study on stillbirth and a Committee member thought it would be important to address stillbirth at a future meeting.
- best practices related to NICU infants and maternal opioid use.
- social determinants of health data, particularly in states with Medicaid waivers.

Adjourn

Belinda D. Pettiford, M.P.H., B.S., B.A., ACIMM Chair

The Chair adjourned the meeting at 3:00 p.m. ET.