Secretary's Advisory Committee on Infant Mortality

Meeting Minutes of June 22-23, 2021

Virtual Meeting via Zoom

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DAY ONE: Tuesday, June 22, 2021

Welcome, Call to Order & Introductions

Lee Wilson,* Acting Designated Official, SACIM (on behalf of *David de la Cruz, Ph.D., M.P.H.)
***Edward Ehlinger, M.D., M.S.P.H.*, SACIM Acting Chair**
Mr. Lee Wilson called the meeting to order and welcomed participants to the virtual meeting. Dr. Edward Ehlinger reviewed the meeting objectives, which were to 1) finalize the recommendations to the Department of Health and Humans Services (HHS) Secretary (the Secretary), 2) review and discuss how SACIM can address current issues related to racism as a determinant of infant and maternal health, 3) increase SACIM's understanding of data and surveillance issues related to infant and maternal health, and 4) identify the issues and activities impacting infant and maternal health that SACIM will focus on over the next year.

Review and Approve Minutes

***Edward Ehlinger,* SACIM Acting Chair**
The Committee unanimously passed the motion to approve the Minutes of the April 2021 meeting.

Committee Member Introductions

***Edward Ehlinger,* SACIM Acting Chair**
Dr. Ehlinger stated that many of the current Committee members have 12 to 18 months left in their terms. As such, it would be a valuable exercise to review the unique perspectives and goals each member brings to the Committee and the key issues each member would like to see addressed over the next year. Dr. Ehlinger suggested that this current iteration of SACIM membership has brought a diverse set of skills, experiences, and expertise that has been particularly timely in addressing the present concerns affecting infant and maternal health. He mentioned that this Committee meeting falls during Pride Month, which represents a celebration of diversity and all its complexity. Juneteenth, which this month became a national holiday, is another celebration that acknowledges both positive and negative aspects of the nation's ancestry and history. Dr. Ehlinger also acknowledged Indigenous populations, especially in his home state of Minnesota and its Dakota and Ojibwe tribal populations. This history and ancestry laid the foundation for SACIM's work. Dr. Ehlinger invited each Committee member to provide an introduction and an overview of key issues each would like to see addressed.

Dr. Tara Sander Lee is a Senior Fellow and Director of Life Sciences at the Charlotte Lozier Institute. She has 20 years of experience in academic research and clinical medicine related to childhood disease. She has expertise in fetal development, congenital disease, and diagnostic testing. Her expertise ranges from prenatal to adult with a focus on fetal interventions to increase infant survival. Her focus area is protecting the life of every child and her experience includes intervention at the state and federal policy levels. Dr. Lee would like to see a focus on increasing access to medical treatment before and after birth for families at risk of poor prenatal outcomes. There are advanced, evidence-based interventions that treat birth defects and reduce infant deaths, but unfortunately not all families have access to these treatments. She would like to see increased awareness of the available therapies for these families and a focus on developing and expanding access to technologies for extremely premature births.

Dr. Steve Calvin is an OB/GYN specializing in maternal and fetal medicine. After spending three years serving Spanish-speaking and Indigenous mothers in Arizona, he brings knowledge about the needs of those diverse populations. In addition to his clinical practice, he is also a teacher, researcher, and advocate for system reform. Specifically, his reform efforts have integrated midwifery care with a strong perinatal "safety net" through independent, accredited birth centers. During his more than 40 years in maternity care, he has seen the emergence of medical advances that save lives—alongside a persistence or, in some cases, a worsening of endemic barriers to optimal care. The most dramatic of these are systemic racism and health disparities. Dr. Calvin would like to see an implementation of Medicaid payment reform for maternity and newborn care. Specifically, support for perinatal care and doula services have been neglected, with negative consequences to families. He would like to see an immediate implementation of a primary midwifery model of care with optional birth center care described within the Centers for Medicare and Medicaid Innovation Strong Start study. Including federal and state leadership towards this care model would encourage similar policy changes in the commercial market. The fee-for-service payment model is broken and should be evolved into a single comprehensive bundle of services for a single payment distributed over time.

Dr. Magda Peck was one of the first physician assistants working for National Health Service Corps at the U.S.-Mexico border, serving also as an advocate for women, children, and families. She moved from an individual-level perspective to a systems-level perspectives through her work as a public health scientist. Her expertise is in the strategic and effective use of data and translation of research to practice and policy. Taking a systems perspective towards the complex nature of infant and maternal mortality provides a broad view of the multiple perspectives and components of the challenges involved. She brings an ability to work with storytelling for social change, which helps bring forward the voices that inform and ignite SACIM's work. Dr. Peck would like to ensure that SACIM's work in racism and equity continue to be sustained and moved forward through the next year. She spoke about the power of data to ensure that SACIM's work is supported by evidence, the power of proxy to work together as a Committee, and the power of communication to help inform the narrative needed to effect change and better understand the mindsets of others. She would like to see a focus on women of reproductive age, specifically towards those experiencing homelessness and housing insecurity.

Dr. Jeanne Conry is a research scientist and a retired OB/GYN who worked at Kaiser Permanente for 30 years. Working in the largest health maintenance organization in the nation provided her with a solid foundation for her focus area of preventive healthcare. She has also served in leadership roles as Chair of Obstetrics and Gynecology in California and President of the American College of Obstetricians and Gynecologists (ACOG). She now acts as President Elect for the International Federation of Gynecology and Obstetrics (FIGO). She supports universal health coverage that covers preventive, emergency, and surgical healthcare as a right and not a privilege. She sees some movement towards this with the inclusion of well-woman healthcare in the Affordable Care Act. She believes that a woman's healthcare should be guided by her choice to make decisions. Dr. Conry spoke about ACOG's activities, including the National Maternal Health Initiative that proposed ten bundles of care for maternal morbidity and mortality, advocacy for well-woman healthcare, and their focus on the environmental exposures that impact infant health. She will continue to maintain these focus areas in her role with FIGO. The U.S. currently ranks at the same level as low-to-middle income countries in terms of

maternal morbidity and mortality, but a systemic approach to care can raise quality of care and outcomes to match other countries in the European Union.

Dr. Janelle Palacios is a nurse midwife, research scientist with expertise in maternal and infant health among women in tribal communities, and former president of the Native Research Network. As a nurse midwife, she has direct experience with the effects of a person's social determinants of health across the lifespan and how those manifest in the person's risk for disease and health outcomes. She also has lived experience. Growing up on a reservation, many of her family members had diabetes, not just as a result of genetic vulnerability to the disease, but rather as a result of the trauma and intergenerational pain related to having lands taken away and children sent away from their families, as well as consequent changes in lifestyle such as access to high fat foods from military assistance programs. She understands that the same impact of social environments on maternal and infant health outcomes also applies to Black communities. Her research challenges a long-held view that motherhood begins with the delivery of an infant, showing that it begins during childhood, when an individual begins to form ideas about motherhood. She brings the strength of storytelling to illustrate how historical effects manifest into maternal and infant health outcomes. Dr. Palacios would like to see SACIM move towards action, starting with a reconciliation of the nation's history and social consciousness.

Dr. Paul Wise is a pediatrician and professor at Stanford University Center for Health Policy. He has a long history working with SACIM members to address disparities in maternal, infant, and child health. He also has 45 years of experience working toward improving child health in areas of armed conflicts and political instability in the Guatemalan Highlands. Recently, he has represented the U.S. federal court system in overseeing the treatment of children in immigration custody, Border Patrol, Immigration and Customs Enforcement (ICE), and the Office of Refugee Resettlement (ORR). In this capacity, Dr. Wise spends a lot of time in detention facilities talking with families and unaccompanied children, as well as officials from different agencies about the opportunities that HHS has in providing leadership in the care and reunification of these children. He would like to see HHS work towards reforming the systems of care that affect these children and suggested that it is time for dramatic change in the humanitarian conditions that these children and their families face.

Dr. Colleen Malloy is a neonatologist and fervent supporter of women enduring difficult pregnancies and deliveries. Her experience with infant death has provided her the insight that there are not sufficient programs, such as perinatal hospice, to ensure support for families dealing with complex issues such as congenital birth defects. Social determinants of health are a driving factor for infant mortality. There are differences in standard of care between, for instance, the middle of Chicago and its rural areas, some which result in outcomes such as preeclampsia or chronic hypertension, leaving both mother and infant at high risk. Issues throughout pregnancy (e.g., nutrition) can exacerbate risk factors such as gestational hypertension and increase the risk of premature birth, which is a leading cause of infant mortality. There are other causes of infant mortality, such as violence, that should also receive more attention. Therefore, Dr. Malloy would like to see SACIM focus on premature birth and violence going forward.

Dr. Belinda Pettiford is the Head of the Women's Health Branch at the North Carolina Division of Public Health and has been involved in this work for over 30 years. Her focus is on health

equity, anti-racism, and community relationships. She would like to see SACIM continue to prioritize a diverse workforce that includes community service providers. The trust that is built from bridging the community to the programs that support individuals and families is critical.

Dr. Ehlinger is Acting Chair of SACIM and has worked at the local, state, and university level towards improving both clinical and public health care approaches in maternal and infant health. Through this work, he has determined that improving health comes from improving access to care and a focus on conditions within communities. One of SACIM's roles is to shift public sentiment towards understanding the importance of the health of mothers and infants in society. Many policies do not adequately address maternal and infant health, suggesting that the issue is not currently a high priority. His goal is to change this narrative by ensuring that all SACIM activities and recommendation focus directly on the health of mothers and infants.

Dr. Paul Jarris was not attendance at this time. Dr. Ehlinger invited the ex-officio members to introduce themselves.

Dr. Wanda Barfield is the Director the Division of Reproductive Health at the Centers for Disease Control and Prevention (CDC) and is a neonatologist by training. Through her lived experience as a mother of a premature child, she understands the critically important work that SACIM does to address the health of mothers and infants through the lifespan. As an ex-officio, her role is to make recommendations based on the work that she and her colleagues do at CDC, particularly from data surveillance efforts such as the Pregnancy Risk Assessment Monitoring System (PRAMS).

Dr. Alison Cernich is the Deputy Director of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, one of many Institutes at the National Institutes of Health (NIH) that works on issues related to maternal and infant health. NIH has a large portfolio of research dedicated to understanding birth defects, preterm birth, sudden infant death syndrome (SIDS), and sudden unexplained infant death (SUID) and is invested in transforming the evidence base for pre-pregnancy, pregnancy, and post-partum risk factors into care practices or safety bundles. NIH also engages with other agencies and the community to extend the lens of science towards health equity, including community stakeholders at different levels of the research process to help improve outcomes. SACIM provides different perspectives that she can then bring back to NIH.

Dr. Cheryl Broussard is the Associate Director for the Division of Congenital and Developmental Disorders at CDC and an epidemiologist. Her work focuses on the data needed to link maternal and infant health risk factors towards improving health outcomes.

Dr. Danielle Ely represents the Division of Vital Statistics at the National Center for Health Statistics at CDC. She manages the Linked Infant Mortality File, which links birth certificate and death certificate data for infants. In her role as ex-officio member, she provides SACIM with the data needed for the Committee to move forward with data-driven recommendations.

Dr. Joya Chowdry represents the Office of Minority Health (OMH), which is dedicated to improving the health of racial and ethnic minority populations through the development of health

policies and programs to eliminate health disparities. They have some exciting projects in collaboration with CDC to support Maternal Mortality Review Committee (MMRC) and to maintain the Hear Her campaign. OMH recently release the e-Maternal Health Planning program related to culturally and linguistically appropriate class services. OMH also encourages the use of disaggregated data towards improved maternal and infant health outcomes.

Dr. Karen Remley is the new Director of the Center on Birth Defects and Developmental Disabilities at CDC and currently partners with Dr. Broussard in the role of ex-officio. She is a pediatric ER doctor with experience providing end-of-life care for children with complex health problems and with SIDS and SUID. She had previously acted as a State Health Official in Virginia, working towards lowering the infant mortality rate and health disparities. Virginia had an infant mortality rate in Black communities three times that of White and Asian communities, and several previous Virginia governors had tried to reduce these disparities. She is proud that her term saw their March of Dimes grade increase from a D- in 2008 to a B+ in 2014.

Dr. Kristen Zycherman represents the Division of Quality and Health Outcomes at the Centers for Medicare & Medicaid Services (CMS). This division houses the Medicaid and CHIP core quality measures and improvement programs, including the Maternity Core Set and the CMS Maternity and Infant Health Initiative. Around 40 percent of children in the nation are born under Medicaid support. Therefore, this quality improvement data is critical towards understanding maternal and infant health in the nation.

Dr. Ehlinger asked SACIM staff to introduce themselves.

Ms. Vanessa Lee is a Senior Public Health Analyst with the Division of Healthy Start and Perinatal Services at HRSA MCHB. Prior to her work with SACIM, she led the Infant Mortality Collaborative Improvement and Innovation Network (COIIN) initiative towards quality improvement and innovative support for states and communities in their efforts to reduce their infant mortality rates.

Dr. Michael Warren is the Associate Administration of MCHB and a general pediatrician by training. Prior to his current position, he spent ten years supporting public health activities in Tennessee. He reviewed a 1916 report from the Chief of the Children's Bureau stating that maternal mortality was rising in the U.S. but was preventable. Though this report was written 105 years ago, the content still applies to today, and Dr. Warren would like to ensure that 105 years from now, the same could not be said by future Committee members. It is time to accelerate this work, particularly towards eliminating health inequity. Through his work in Tennessee, he realized that every community is different and therefore solutions are not uniform. The same is true at the federal level, and there is a need to meet states and jurisdictions where they are in their journey towards equity.

Update from the Maternal & Child Health Bureau

***Michael Warren, M.D., M.P.H., F.A.A.P.,* MCHB, HRSA**

Dr. Warren provided an update of Healthy Start funding opportunities, including funding for 20 grants to supplement support for community-based doulas and funding of approximately 30 grants towards the development of infant health equity plans. Both of these funding efforts

support SACIM priorities of expanding access to doula care and understanding social determinants of health. Both sets of funds will be awarded by September 30 of this year.

The fiscal year 2021 budget included increased funding for the Alliance for Innovation (AIM) on Maternal Health, which will support evaluation of the program and a supplement to ACOG. MCHB also anticipates 15 new awards to states to overcome challenges in collecting maternal health data. The new Infant Mortality Initiative is underway and will be supported by contracts for strategic planning, a literature review and environmental scan of interventions, and engagement with federal and private stakeholders. The Infant Mortality Initiative addresses differences across populations in meeting the Healthy People 2030 target for infant mortality.

Dr. Warren reviewed other MCHB activities such as the Title V MCH Block Grant program that funds public health services; Healthy Start, which supports 101 U.S. sites in improving infant and maternal health outcomes and health disparities; and the Maternal Infant and Early Childhood Home Visiting Program (MIECHV), which provides voluntary evidence-based visiting in high-risk communities. MCHB also supports Child Death Review and Fetal Infant Mortality Review work, provides technical assistance to states and communities, and supports the National Safe Sleep Partnership to prevent SIDS and SUID.

The President's fiscal year 2022 budget was recently released and proposed a budget of $1.5 billion to MCHB, including $822 million for the Title V MHC Block Grant program ($110 million increase), $377 million for MIECHV, and $128 million for Healthy Start. Specifically, there was a $4 million proposed increase for autism spectrum disorder (ASD) and other developmental disabilities and a $5.8 proposed increase for the Emergency Medical Services for Children program. Within the Title V MCH Block Grants, there was a proposed increase of $81 million for the Special Projects of Regional and National Significance (SPRANS). There was a proposed $30 million increase for the State Maternal Health Innovation program and $1 million for the Maternal Mental Health Hotline. New proposed budget items include $25 million for Pregnancy Medical Home Demonstration, $10 million for Early Childhood Development Expert grants, $5 million to establish training grants for health providers on implicit bias, and $1 million towards a National Academy of Medicine study for recognizing bias in medical schools. There is an additional $5 million proposed each for the Screening and Treatment of Maternal Depression program, the Rural Maternity and Obstetrics Management Strategies (RMOMS) program, and Maternity Care Target Area Implementation.

MCHB recently launched their updated Strategic Plan at the Association of Maternal & Child Health Programs (AMCHP) meeting. The new Strategic Plan outlines four goals, which are to 1) ensure access to high-quality and equitable health services; 2) achieve health equity for MCH populations; 3) strengthen public health capacity and workforce for MCH; and 4) maximize impact through leadership, partnership, and stewardship. MCHB will develop the strategies, activities, and measures needed to carry out the strategy across all MCHB programs over the next 10-15 years.

Discussion

Dr. Conry asked about the timeframe for the AIM evaluation. Dr. Warren answered that funding must be allocated by September 30, the end of the fiscal year. The contract will begin after that.

Mr. Wilson added that it is a year-long contract, and they expect the work will be completed within six to eight months, and a report will be released within four to six months after that.

Dr. Peck asked how MCHB uses language to include efforts outside of HHS, such as with the Environmental Protection Agency (EPA) for environment, the Department of Housing and Urban Development (HUD) for housing security, or the Department of Homeland Security (DHS) for immigration. Dr. Warren answered that their environmental scan is intended to understand where all issues related to maternal and child health occur across the government to help identify those federal partners that may already be working on related issues. He suggested that MCHB can share the outcomes of the scan with SACIM to help the Committee move forward in their priority areas. To focus on structural and social determinants of health, there is a need to engage with these external partners as well as non-governmental organizations across states and communities. Dr. Warren added that the feedback that SACIM provides to MCHB is highly valued and helps them understand what is going on outside of the government.

Dr. Wise asked what MCHB is doing specifically to address migrant children and families, particularly those with special health needs. Dr. Warren answered that one of the COIINs has focused on preconception and prenatal care in border states. A number of community-based grantees are also supporting communities with these needs and Title V MCH Block Grantees are also providing leadership to states that are addressing the needs of these families.

Discussion of SACIM Recommendations to HHS Secretary

***Edward Ehlinger,* SACIM Acting Chair**

Dr. Ehlinger introduced the most recent updates to the draft recommendations to the Secretary. These recommendations have evolved over the last few years and include information gathered from briefings and Committee members on a set of priority issues. In addition to the draft recommendations, Dr. Ehlinger developed background content to provide context and emphasize the importance and timeliness of the issues. Across all recommendations spans the theme that all levels and sectors of the government should consider the impact of their activities on infants, mothers, and women across their life course.

Committee members discussed consistency in language. Dr. Peck suggested that SACIM has the opportunity to generate a common language to describe issues related to infant and maternal health, especially towards health equity. Dr. Conry suggested using the word “pre-pregnancy” instead of “preconception.” Dr. Barfield suggested that language about race and ethnicity could come from the Commonwealth Fund. Dr. Palacios asked that recommendations include “linguistically appropriate” in addition to the recommendation language for “culturally appropriate” care.

Migrant and Border Health

Dr. Wise led the discussion about the Migrant and Border Health recommendations by reviewing the scope of the challenge. The recommendations drafted for this issue are directed not only to the challenges for the families and children who are currently being released into the U.S., but also to the expected increase of approximately 80 percent more people entering the country following relaxation of COVID-19 protocols. The recommendations address enhanced border community capabilities, access to services and programs, pregnant women and children with

special health care needs, integrated capabilities across agencies, the lasting effects of the separation of children from their families, COVID-19 vaccination, integration of medical records, and increased research on the immigration policies related to infant and maternal health.

Dr. Conry suggested that the recommendation related to COVID-19 vaccines include more assertive language such as "support" rather than "consider" and to highlight the opportunity for HHS to support the administration's reinstatement of ICE's Presumptive Release Policy applied to pregnancy detainees.

Care Systems and Financing of Care
Dr. Calvin led the discussion of the Care Systems and Financing of Care recommendations. These recommendations address inequities in infant and maternal health care that affect the approximately millions of people in the U.S. currently covered by Medicaid, calling for an expansion of Medicaid for postpartum coverage, increased support for alternative models of care and payment systems for perinatal care, access to and information about birthplace options and services, comprehensive support for community-based care teams, expansion of Healthy Start and home visiting programs, a prioritization of infant and maternal health in COVID-19 activities, and improved crisis communication strategies.

Dr. Calvin said that the current model of fee-for-service cannot adequately support maternal self-agency, can interfere with the positive impact of physiological birth, and may generate significant racial disparities. The current system is fragmented and results in relatively poor health outcomes. He suggested that SACIM include in their recommendation that CMS and state medical agencies implement bundled payment plans that covers pregnancy through the baby's first year of life. Dr. Conry said that she would need to see a deeper analysis of the economic basis of care to better understand the basis of Dr. Calvin's recommendation.

Dr. Conry asked for specific language for the data surveillance, evaluation, and research necessary to document the outcomes of these recommendations. Dr. Calvin said that he would be interested in feedback from the CDC ex-officio members because it is challenging to tease outcomes from billing data. Dr. Barfield said there are opportunities for evaluating utilization and programs at the state level. She added that the identification of risk-appropriate care is not well described but is important in terms of recommendations for quality care practices, particularly in higher-risk rural and tribal areas. Dr. Peck added that the recommendation should call out the need to strengthen existing data surveillance systems.

Dr. Calvin said that the Strong Study had infrastructure for measuring outcomes, and the challenge is ensuring that different data systems can work together. Dr. Ehlinger agreed and expressed concern that a request for evaluation prior to implementing a new recommendation might negate previous work. There is already research that supports many of these recommendations; accordingly, perhaps efforts should focus less on evaluating need and more on developing a mechanism for action. Dr. Barfield said that existing data systems can be leveraged, and invention of a new data system is not necessarily required. Dr. Peck agreed that the emphasis should be to sustain, strengthen, and harmonize existing systems for interoperability.

Dr. Conry asked if the recommendation for extended Medicaid coverage was for at least one year after delivery rather than one year after pregnancy. Dr. Ehlinger clarified that because not every pregnancy ends with a delivery, the language was adjusted to include all pregnancies. Dr. Conry asked if this meant that a person who miscarries at six weeks would have extended care. Dr. Lee said using "delivery" makes sense because they are not collecting data on all pregnancies.

Dr. Conry suggested that physicians be included in the recommendation to strengthen care teams. Dr. Palacios said that the Health Equity Workgroup discussed this suggestion and thought the recommendation was intended to be specific to public health, which would include community-based services such as home visits. Dr. Conry pointed out that the recommendation is to provide support for pregnancy, labor, delivery, and recovery. Dr. Ehlinger also thought the recommendation was specific to clinical care. Dr. Peck added that the preconception and interconception periods were not reflected in the recommendation. In the context of a life course approach, a narrow focus on the clinical services related to delivery would miss an opportunity to address upstream issues beyond environmental factors.

Dr. Palacios recommended "equitable reimbursement" for the same work done among different providers. Dr. Calvin added that this would be part of the concept for a bundled plan and incentivizes better care. A midwife, for instance, should be paid the same as a physician for the same service. Dr. Ehlinger said that the idea of reimbursement brings back the topic of the fee-for-service model. Therefore, the idea should be for equitable funding or resourcing of care.

Dr. Ehlinger proposed that the Committee hold on the development of an additional recommendation until after the presentation from the Data and Research to Action Workgroup. He suggested that an additional recommendation related to pre-pregnancy and interpregnancy may be needed. He also advised that the Committee does not currently have enough information supporting Dr. Calvin's proposed recommendation about financing to evaluate it carefully but suggested that it be addressed in the next year.

Workforce

Dr. Palacios reviewed the Workforce recommendations, which focused on expanding and diversifying the public health workforce. The Health Equity Workgroup discussed increased funding for the Indian Health Service (IHS), recognizing that they have been historically underfunded. There was a bipartisan Joint Commission report on civil rights specifically to increase IHS funding called *Broken Promises* that supported this suggestion. They also suggested using the term "structural racism" throughout the document. There is some concern that terms such as "vulnerable" and "minority" are negatively charged and may negate the thriving, positive aspects of race/ethnicity. Therefore, they decided to specifically name the different racial/ethnic groups and use those terms consistently.

The Workgroup determined that the recommendation to expand and diversify the workforce was specific to public health and therefore did not include certain clinical professionals. Towards the recommendation for professional liability protection to cover the evolving configuration of maternity care teams, Dr. Calvin commented that some service providers would have to close business because of their inability to obtain malpractice coverage and that this recommendation would provide protections.

Dr. Palacios talked about the addition of doula services as preventive care and her consultation with DONA, an international doula training organization, towards wording this recommendation. The recommendation to encourage the U.S. Preventive Services Task Force and the Women's Preventive Services Initiative (WPSI) to evaluate doula services was determined to be inappropriate at this time and was deleted. Dr. Ehlinger said that HRSA supports the Women's Preventive Services Guidelines, and it would be appropriate to make a recommendation to HRSA. The challenge was packaging this recommendation to provide a foundation of evidence for the impact of doula services on maternal and infant health outcomes.

Dr. Conry said that a recommendation for implementation of doula services would require evaluation from WPSI. SACIM should not do that, but any individual in the Committee can send a note to WPSI to request that it is considered. Dr. Ehlinger asked how to ensure that doulas are paid. Dr. Palacios reviewed an Oregon law to reimburse doula services that included a number of criteria. One route to ensure payment is to pass state laws that Medicaid funds doula services. It is also important to understand that not all doula services are the same.

Dr. Peck talked about the 2011 Institute of Medicine report, which recommended that covered services be updated based on evolving evidence. In this context, if SACIM focused on coverage of essential preventive services and the historical context of these services, then the mandate would allow for a recommendation to update. Dr. Peck suggested that the language in the recommendation specify *covered* preventive services. Mr. Wilson asked what category of doula services was being recommended and if doula services should be covered as social support or health support. Dr. Palacios answered that the language ensures a spectrum of services because there are different levels of doula services. Dr. Palacios asked if consensus was required for the recommendations, and Dr. Ehlinger answered that it is not required but that members should agree with the general concept. He suggested that the Committee does agree that doula services should be supported and that language to define doula services would help refine the recommendation. The Committee agreed that language also could be added to the background document towards the involvement of the U.S. Preventive Services Task Force.

Dr. Palacios pointed out that funding doula training would diversify the workforce because it is an accessible career path for Black, Indigenous, and People of Color (BIPOC). Dr. Warfield added that this was especially important given the high cost of nursing education. Dr. Peck said that care should be taken to ensure quality doula training without raising implicit bias about privilege related to an institutionalized training program. Dr. Palacios added that the doulas she consulted with advised not to consider doulas a panacea to maternal and infant outcomes but rather as a solution for expanding and diversifying the workforce.

Environmental Conditions

Dr. Conry reviewed the Environmental Conditions recommendations, which focus on the role of HHS in coordinating efforts to protect infants and pregnant women from toxic environmental exposure. The first recommendation calls for increased research, funding, and policies, specifically to ensure the protection of BIPOC, who are burdened with cumulative environmental impacts. Dr. Peck asked if there was context for the data recommendation to specify a collaboration between CDC and EPA. Dr. Conry added that the National Institute of

Environmental Health Science (NIEHS) was also specified in the recommendations. Dr. Cernich suggested broadening the recommendation to include all of HHS in collaboration with EPA.

Towards the recommendation to expand biomonitoring programs, Dr. Lee suggested that the recommendation include data monitoring for all racial/ethnic populations. Dr. Conry said that the emphasis on BIPOC was to target those at highest risk for exposure. Committee members discussed broadening this recommendation to include all federal biomonitoring programs and to highlight the need for interoperability of data and data collection across the life course. They added that there is an inter- and transgenerational component of environmental exposure that might be added to the recommendation language.

Dr. Conry reviewed the recommendation to eliminate all sources of lead in food and personal care products and said there is evidence of contamination even in prenatal vitamins. Using the word "elimination" therefore implies a zero-tolerance position. She had consulted with the EPA lead for children's health and used the CDC's zero-tolerance recommendations to support this language. Dr. Peck was curious how a nationwide strategy would be implemented in coordination with local, state, and tribal communities.

Committee members discussed the recommendation to prioritize equity in infrastructure projects. Dr. Ehlinger said that this recommendation was especially important considering the administration's attention on infrastructure funding. Dr. Peck asked if infrastructure should be defined because not all infrastructure investments meet the definition of "project."

Dr. Conry reviewed the recommendation for restorative justice and suggested that the language may need more definition. Dr. Palacios said there are a number of ongoing issues that would benefit from restorative justice and that this recommendation is both bold and important. Dr. Peck agreed that it is a powerful, essential recommendation but that it may lie beyond the scope of HHS. SACIM's leverage in this recommendation may be to encourage programs, policies, and collaboration across agencies.

Committee members discussed the final recommendation related to the climate crisis. Dr. Malloy suggested that taking a hardline perspective is good but wondered if a zero-tolerance policy is realistic suggesting that the cost of such policies should be considered. Dr. Conry replied that evidence for the elimination of lead and its cost and impact to population health are in the reference section of the background document. Dr. Conry suggested that the language specify an evaluation on the impact in women's health and birth outcomes in all environmental legislation. Dr. Ehlinger suggested that the objective is to raise awareness of the impact these issues have on infants and mothers because it is not well known. Dr. Lee asked if secondhand smoke exposure should be included in the recommendation. Dr. Conry answered that the issue is already well documented, but that there is a list of the toxic products. Dr. Ehlinger added that there is information in the background document and clarified that there is no language that limits what research can be conducted.

Data and Research for Action

Dr. Peck began the review of recommendations for Data and Research for Action by emphasizing the importance of data to inform programs and policies. The three major

recommendation areas are the strengthening of data and research specifically towards promoting equity, enhancing data systems and interoperability across agencies, and support for the morbidity and mortality sentinel event reviews.

Dr. Lee addressed the first recommendation by asking how to reconcile storytelling, which can be subject to recall bias, with the word "evidence." Dr. Peck said that the power of story enables qualitative data to accompany quantitative data to contextualize the issue. Lived experience should be as valued as numbers. When stories are included, data can be translated into actions. Dr. Peck also talked about adding language to encourage career development for researchers from diverse backgrounds towards enhancing data and research efforts.

Dr. Peck reviewed the recommendation to enhance interoperability of data systems, which allows for data sharing across sectors and agencies. The recommendation calls out data systems for specific high-risk populations that would help strengthen future recommendations. Dr. Peck reviewed added language towards including pre-pregnancy and maternity care.

Dr. Peck thanked Dr. Cernich for her assistance in the development of the recommendation to include women of reproductive age, pregnant and breastfeeding women, and infant in research efforts. This was a lesson learned as a result of the COVID-19 pandemic and vaccination program.

Dr. Palacios asked that any language referring to underrepresented populations be revised. Dr. Peck suggested that "underrepresented" to describe the scientific workforce might be appropriate. Dr. Peck said that this topic did not include a recommendation for evaluation of impact and there may be a blanket statement to include monitoring and measurement in all recommendations. Dr. Ehlinger suggested that a blanket statement could go into the preamble.

DAY TWO: Wednesday, June 23, 2021

Finalize SACIM Recommendations to HHS Secretary

***Edward Ehlinger,* SACIM Acting Chair**

Dr. Ehlinger used a metaphor of throwing horseshoes to describe the importance of "targeting the middle" when pitching, recognizing that even a pitch that comes close to its target gets a score. Likewise, the goals in developing these recommendations are to pitch towards the middle to include all ideas and to aim as close to the target as possible.

Dr. Ehlinger invited Mr. Wilson to speak about conflicts of interest and ethics in the development of the recommendations. Mr. Wilson first commented on the importance of the recommendations to move data into action. He talked about how the role of Committee members is to bring their expertise to SACIM, which sometimes means that personal experiences are highlighted. Under the Federal Advisory Committees Act (FACA), there are policies, procedures, and a Designated Federal Official to ensure that each member meets the requirements of the role. He asked Committee members to let him know if anything changes in the information they provided in the initial paperwork. He also requested that Committee members abstain from voting on issues that may pose a conflict of interest or recuse themselves from any recommendations that may appear to be a conflict of interest. Mr. Wilson suggested

that members can discuss specific issues with the Ethics Officer and urged them to speak to SACIM staff for further questions.

Mr. Wilson also said that the set of recommendations being put forward to the Secretary will be among many reports of recommendations. He suggested reviewing the recommendations with a lens toward ensuring that each is specific and is directly related to SACIM's charge.

Committee members reviewed specific language in the recommendations. Dr. Ehlinger said that the term "BIPOC" is now used consistently throughout the document. Dr. Peck clarified the language should be "encourage" rather than "facilitate" in the recommendation for data interoperability. Dr. Conry said that "same rate" does not necessarily mean equal and suggested using "equitable" instead of "equal" for the recommendation about funding across different providers. Dr. Calvin asked Dr. Pettiford to comment on the recommendation to fund doulas and community health workers and Dr. Pettiford said that the current language was appropriate. Dr. Peck suggested that language used to describe funding should be harmonized across the document because there are multiple types of payment.

Dr. Calvin talked about the importance of including "risk-appropriate care" in the care systems recommendation. Dr. Barfield talked about a Levels of Care Assessment Tool developed with CDC as a concept to determine capacity in a delivery hospital. Dr. Ehlinger suggesting working with MCHB to harmonize the recommendation with the tools available.

Dr. Calvin reviewed a suggestion from Dr. Barfield to fund pilots for the bundled payment model financed by Medicaid and talked about a suggestion to include the Office of the National Coordinator in an implementation pilot for bundled payment models. Dr. Conry asked to include data for maternity outcomes within alternative models of care and Dr. Ehlinger concurred.

Dr. Palacios reviewed the report highlighting the underfunding of IHS. Dr. Ehlinger asked if this significant issue can be adequately addressed in this set of recommendations or if it should receive more dedicated discussion at future meetings. Dr. Peck suggested that a recommendation to adequately fund maternal health should be a proxy to adequately fund IHS. Dr. Palacios said that tribes face different issues than other populations and, should SACIM dedicate a future discussion to address the issue more thoroughly, she would be willing to retract the request to include a specific recommendation.

Updates from Stakeholders on Efforts to Address Racism's Impact on Maternal and Infant Health

Facilitator: *Janelle Palacios,* SACIM Member
Panel Members:

- *Arthur R. James,* Member, Franklin County Board of Health; Consultant, First Year Cleveland; Evaluator, Indianapolis Healthy Start Program
- *Jonathan Webb,* CEO, Association of Women's Health Obstetrics and Neonatal Nurses
- *Scott Berns,* President and CEO, National Institute for Children's Health Quality
- *Denise Pecha,* Deputy Executive Director, CityMatCH
- *Deborah Frazier,* CEO, National Healthy Start Association

- *Caroline Stampfel,* Interim CEO, Chief Strategy and Program Officer, Association of Maternal & Child Health Programs
- *Aletha Maybank,* Chief Health Equity Officer, SVP, American Medical Association
- *Kathleen Sebelius,* Co-Chair of Aspen Health Strategy Group; 21st U.S. Secretary of Health and Human Services (2009-2014); former Governor of Kansas (2003-2009)

Dr. Palacios introduced the panel discussion by describing her identity in her tribal community and how systemic colonization and assimilation has negatively impacted the community's health. Today, BIPOC women and infants die at as much as five times the rate of White women and infants. BIPOC are also disproportionately affected by incarceration, housing and food insecurity, and toxic environmental exposure. For decades, the responsibilities of these disparities were laid upon the shoulders of individuals rather than the policies and institutions that created the inequitable conditions. SACIM has purposefully centered its work on equity, acknowledging the mounting evidence that structural racism is the primary cause of infant and maternal health disparities. This panel discussion was established to share their vision for how SACIM can move forward to address these grave disparities. The first panel represents the Consortium on Maternal and Child Health Organization, which provides guidance to influence policies and programs.

Dr. Arthur James began the panel presentation by noting that, despite mounting evidence that race is the most significant contributor to health disparities, health inequities persist. The most troubling of these inequities are those found in infant and maternal health. Given that the infant mortality rate is a barometer for a society's commitment to health, it is all the more troubling that the nation's BIPOC infants and mothers continue to die at much higher rates than White infants and mothers. He hopes that the bold collaboration between AMCHP, CityMatch, the [National Healthy Start Association](), and the [National Institute for Children's Health Quality (NICHQ)]() will result in the steps necessary for overcome the challenge of eliminating race-based infant and maternal mortality.

Mr. Jonathan Webb talked about the organization's interest in bringing together leading public health organizations to collectively commit to (and lead by example) the actions necessary for addressing racism as a public health crisis. Their work has evolved to include different focus areas, but the common expectation was that all partners to commit to anti-racism efforts. Additionally, they evolved towards action over optics, developing a declaration of actions for which all would be held accountable. Mr. Webb spoke of lessons learned in this effort. First, thoughtful leadership was critical to navigate through the politics and different types of organization. It was also important to remain mindful of the resources needed to act on these commitments, including both financial resources and the ability to increase board and leadership involvement—for which a tiered commitment process may allow a building of participation over time. Lastly, they learned that organizations that could not make the commitment were still interested in partnering and future participation.

Dr. Scott Berns reviewed their first commitment area of internal processes, which indicates that systems change must begin within each organization's core policies (such as training requirements.) Ms. Denise Pecha reviewed the second commitment area of external processes, which examines the local, state, and federal policies that impact equity and advocacy against

policies that perpetuate racism. Debra Frazier reviewed the third commitment area of communications, which includes a deliberate acknowledgment that racism is a public health crisis, use of language that demonstrates respect, and candid dialogue to allow voices of the community to drive their efforts.

Ms. Caroline Stampfel talked about the organization's way forward. They will develop accountability measures, such as staff training, which they will track quarterly. They will review progress with organizations such as SACIM and share lessons learned and best practices with other organizations that might be interested in joining the commitment.

Dr. Palacios introduced Dr. Aletha Maybank of the American Medical Association (AMA). Dr. Maybank reviewed the mission of AMA, which primarily represents physicians but is also inclusive of public health professionals. As the Chief Health Equity Officer, her job was to facilitate a process for embedded equity throughout AMA staff, members, and the larger medical community. The health inequities related to the COVID-19 pandemic and the public murder of George Floyd propelled AMA to declare racism as a public health threat and commit to actively dismantle the discriminatory policies and practices that affect health equity. This declaration took steps towards action when their House of Delegates passed a formal policy to acknowledge racism as a public health threat and to prioritize its elimination in the health care system.

These policies opened the door for AMA to become bolder and more direct in their actions. They recently released a strategic plan that outlined their vision and strategies for dismantling the pervasive racism and white supremacy that undermines health equity. These strategies are based in theories of change, include narratives from those who have been most marginalized, and focus on upstream factors of health. She reiterated that medical and public health approaches must intersect for organizational transformation. Dr. Maybank pointed out the need to incorporate trauma-informed systems and to recognize the potential that these efforts may re-traumatize people. She concluded by saying that no institution can move forward in anti-racism work without examining their own history and people. To that point, AMA looked back at their history and reported those past actions that caused harm as an effort towards healing and reconciliation.

Dr. Palacios introduced Ms. Kathleen Sebelius, former HHS Secretary and co-chair of the Aspen Health Strategy Group. Ms. Sebelius introduced the Aspen Health Strategy Group, which is a group of 22 payors, providers, advocates, and policymakers who have come together to tackle racism. She reviewed their five "big ideas" towards reversing the maternal mortality crisis in the U.S. These included 1) a national committee by the government and private sector to address the crisis; 2) support for community care models; 3) redesign of insurance for women's needs; 4) commitment to tackle racism undermining women-centered maternity care; and 5) investment in research, data, and analysis.

Ms. Sebelius shared her regret that, during her service as Secretary, their focus on equity did not primarily concentrate on dismantling systemic racism. As the only country that has experienced increases in maternal mortality and severe maternal morbidity, the effort to reverse these alarming trends must start by addressing the systemic racism that drives those rates. She talked about the opportunity that SACIM has to call on the Federal government to use all of their tools. There must be a national commitment at all levels of government and within the private sector to

call out maternal mortality as unacceptable and work towards reversing the upward trend. This includes revisiting the Healthy America 2030 goals and leveraging models with demonstrated success. People are unaware of the issue, and it is important to raise awareness. Community care models in culturally appropriate settings should be lifted up in models of care that CMS pays for.

She concluded by advising the Committee not to shy away from making recommendations. She reiterated the importance of the different recommendations that were being refined at this meeting. Women's voices need to be amplified, especially so for BIPOC, whose needs in particular are not heard or respected.

Discussion
Dr. Palacios asked panelists to provide one or two recommendations for SACIM going forward. Ms. Stampfel recommended that federal agencies partner with impacted communities and organizations to understand who is impacted, how, and their needs. She suggested that these partnerships truly commit to pursuing anti-racism not just as a declaration, but also with measurement and accountability. She said it was also important for organizations to examine their internal processes and policies and to consider trauma-informed approaches for the people they work with and serve. She said that SACIM could recommend and model these steps for other agencies.

Ms. Sebelius urged SACIM to be specific and direct in their recommendations and to ask the Secretary to leverage the tools within HHS that can be actioned. There are several operating agencies and a lot of activity, so it is important to direct practical steps for rapid action. The current administration is eager to tackle these issues, offering a unique opportunity to call for an all-hands effort. Dr. Ehlinger acknowledged that all previous Secretaries were involved in the advisory committee and asked how best to leverage this kind of power to change the narrative of maternal and infant health inequities. Ms. Sebelius suggested asking the Secretary and/or the Surgeon General to publicly call out structural racism and health inequity as a public health crisis and raise awareness of the increasing mortality rate.

Dr. Maybank said that sustainability of these efforts ties closely with accountability and metrics, as well as understanding the need for resources to do the work. Too many assumptions are made—efforts should be supported with data. Now, more than ever, is the opportunity to collaborate towards closing the gap in maternal mortality.

Dr. Peck expressed gratitude for the panelists' tenacity and commitment to action. She asked if they had recommendations on strategic and thoughtful language for communicating urgency. Dr. Maybank answered that the use of "crisis" creates both a sense of urgency and vision. Once funding for the crisis is secured, deconstruction and redesign can occur. But if the focus is on "threat," efforts will not be sustainable, even if funding is secured. It is important to embed a sense of vision in the communication. Mr. Webb added that he has used "crisis" over "threat" because "crisis" implies that a solution is on the way versus a "threat" that is in the moment.

Dr. Peck asked how to align the messages of maternal mortality and severe maternal morbidity with infant mortality in the context of anti-racism. Dr. Berns answered that the emphasis should be on the maternal-infant dyad. Disparities in maternal mortality are essentially aligned with

disparities in infant mortality. SACIM could raise awareness of the maternal-infant dyad and the data that support it.

Dr. Conry pointed out that September 17 is World Patient Safety Day, and will focus on safe maternal and newborn care with a slogan "Act Now for Safe and Respectful Childbirth." She talked about the current limitations of the Affordable Care Act and asked how to improve access to care without universal health coverage. Dr. Berns agreed that access to care is a vital upstream factor for health. There is no simple solution, but all efforts to expand access to coverage, including those in SACIM's recommendations, are important. Dr. Ehlinger suggested that September 17 may be an opportunity to recommend that the Secretary publicly endorse the recommendations or raise awareness of the crisis. AMA has marketing tools that may help leverage these messages. He suggested advocating for SACIM to evolve to the "Secretary's Advisory Committee on Infant and Maternal Mortality" to reflect the maternal-infant dyad.

Data and Research to Action Workgroup Updates and Issues

Dr. Peck began by suggesting that the language of data is one of the most powerful communicative tools. Both quantitative and qualitative data inform decision-making, action, and accountability. For instance, continual measurement of disparities sustains the sense of urgency for anti-racism work. This Workgroup focuses on the data and surveillance that allows SACIM to provide evidence-based recommendations.

Dr. Barfield noted that MCHB supports many surveillance systems. Unique among these is PRAMS, which provides an opportunity to listen to women's stories and understand their pregnancy and postpartum experiences. There is an opportunity for an important revision to PRAMS, and she invited Dr. Lee Warner from the CDC Women's Health and Fertility Grant Division and Dr. Ada Dieke from PRAMS to share the details.

Dr. Warner provided an overview of PRAMS, a population-based surveillance system that has collected data on maternal behaviors and experiences for nearly 35 years. The system links these data with birth certificate data to provide jurisdiction-specific estimates across the nation. In May 2021, a new funding cycle began that currently funds 50 jurisdictions, representing 81 percent of live births. They recently released 2019 data, which now includes indicators for prescription opioid use during pregnancy and maternal disabilities. They expect to release 2020 data next year with a new indicator for COVID-19 experiences. Their current data represent a diverse set of relevant factors, from preconception care to intimate partner violence to infant sleeping environments. Although they have added several supplemental questionnaires, there has not been an update to the survey since 2016, presenting an opportunity to gather feedback for an update.

Dr. Dieke reviewed the proposed revision for a phase 9 of the PRAMS survey. There are three goals for this revision, which are to 1) ensure that topics are still relevant and address emerging priorities, 2) engage with an array of internal and external partners to capture these priorities, and 3) align with national performance measures such as the Healthy People 2030 and MCH Title V Block Grant measures. The conducted planning and consultation meetings with CDC and other federal partners to learn how they manage questionnaire revision processes in their own data systems. They solicited feedback from more than 300 partners for emerging priority areas. Suggestions to enhance existing topics included contraception use, mental health, maternal

vaccination, and urgent maternal warning signs. Suggestions for new topics included adverse childhood experiences (ACEs), social determinants of health, emergency preparedness, and patient-centered care. From now until August 2021, they will evaluate these proposals and then develop survey questions. They will continue to engage with their partners throughout the revision process and will finalize the questionnaire by December 2021 for launch in April 2023.

Discussion
Dr. Calvin asked what barriers exist to states' involvement in PRAMS. Dr. Warner answered that some states can internally fund and support data collection, but they miss out on the PRAMS infrastructure. They try to align their questionnaires and methodologies with state efforts, which if counted, increases nationwide participation from 81 percent to around 96 percent. Dr. Calvin followed up with a question about long-term plans for expand the effort across the life course, possibly integration with electronic health records. Dr. Warner agreed this was a compelling suggestion and they are always considering future efforts. They have considered follow-up surveys as infants age and did complete a follow-up survey as part of the opioid survey. Dr. Barfield added that CDC is exploring linking PRAMS data to hospital discharge data or other surveys to capture breastfeeding rates, for instance.

Dr. Ehlinger appreciated the addition of ACEs, which was recently supported in an article in the *Journal of the American Medical Association (JAMA)*. There are other social determinants of health, such as voting, that could be important to include in PRAMS. Dr. Warren said they have also begun to analyze data from Healthy Start participants towards understanding the effectiveness of the program.

Dr. Pettiford asked for detail on questions about discrimination and racism. Dr. Warner said they wanted to use appropriate wording for these questions, but there are some challenges in aligning wording across states. He emphasized that these are proposed revision and that they will report outcomes at a future meeting. Dr. Dieke added that there are different iterations of questions about discrimination, whether about race, gender, or language. Dr. Warner said that it is important to hear from their partners if they want these questions to be included in the core questionnaire.

Outcomes of the GAO Report on Maternal Mortality and Morbidity

***Lee Wilson,* Acting Designated Official, SACIM**
Dr. Peck invited Mr. Wilson to speak from his new role as Division Director of Healthy Start Perinatal Services. Mr. Wilson provided a brief update on a Government Accountability Office (GAO) Report on Maternal Mortality and Morbidity based on a review from January 2020 to April 2021. GAO conducts audits, surveys, and studies of federal programs and activities to assist in the development, administration, and oversight of their duties. Maternal mortality and morbidity has received significant legislative and funding attention in the last five years. Congress is aware of the increasing numbers and the increased risk in rural and other underserved areas where health services are limited. MCHB participated in the GAO review through a series of meetings, data collection, and draft reports. GAO also met with other relevant agencies and departments, calling out CDC for its responsibility for data surveillance and HRSA for its charge to improve healthcare for vulnerable populations.

The GAO report included a recommendation for the Director of CDC and the Administrator of HRSA to oversee the systematic disaggregation and analysis of maternal health program data by rural and underserved areas. Both agencies accepted this recommendation and are working on the action steps to fulfill the request. There was also a recommendation to coordinate efforts with the Healthy People Project's Maternal and Infant Health Working Group and Infant and Child Health Working Group towards monitoring maternal health efforts across HHS. This recommendation was also accepted and is in the process of developing action steps.

Updates from the Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD)

***Karen Remley, M.D., M.B.A., M.P.H., FAAP,* Director, National Center on Birth Defects and Developmental Disabilities, CDC**

Dr. Remley talked about the history and purpose of the National Center on Birth Defects and Developmental Disabilities (NCBDDD), which was started 20 years ago with a vision to prevent infant mortality through the research and prevention of birth defects and to improve the health of people living with developmental disabilities. NCBDD is the smallest center at CDC, yet their funding is distributed across 21 different funding lines. Birth defects and developmental disorders are significant issues that affect people across their lifespan, but they can be associated with stigma and a general unwillingness by the public to address them.

Birth defects are a leading cause of infant mortality, accounting for one in five infant deaths. In the U.S., approximately 23,000 infants die each year as a result of birth defects. According to a 2020 Morbidity and Mortality Weekly Report (MMWR), approximately 11 infant deaths related to birth defects occur for every 10,000 babies born in the U.S., but these rates differ by race, ethnicity, and gestational age. Although more research is needed to understand the cause of these disparities, NCBDDD hypothesized that they may be influenced by access to care, prenatal screening variability, loss of pregnancies with fetal anomalies, insurance type, and access to and quality of care for the infant.

NCBDDD funds 10 of the 43 states with state-based birth defect tracking programs. These data are used to understand if the rate of birth defects changes to guide planning and resource allocation. The Centers for Birth Defects Research and Prevention (CBDRP) is funded by CDC to conduct research to identify causes of birth defects. They are currently conducting the National Birth Defects Prevention Study (NBDPS), one of the largest birth defects studies undertaken in the U.S. CBDRP also evaluates pregnancy exposures through its BD Steps program. The Committee on Obstetric Practices at ACOG published an opinion paper on drugs used for urinary tract infection and birth defects, which used the BD steps data. These data and research findings inform clinical practices, confirm and generate hypotheses, identify areas for prevention, and provide information to the public.

Dr. Remley reviewed their work with spina bifida and congenital heart defects. Although survival rates of infants born with spina bifida has recently improved, there are race/ethnicity disparities, with Black and Hispanic infants surviving at lower rates than White infants. NCBDDD promotes the use of folic acid during pregnancy to prevent spina bifida and other neural tube defects and conducts public health research to reduce mortality and improve health outcomes. Congenital heart defects are the most common of birth defects, affecting nearly 1 in

110 births in the U.S. Although one-year survival for infants with congenital heart defects has improved in recent decades, mortality remains very high. CDC collaborated on an article published in *JAMA* showing that a mandated, population-wide screening for congenital heart disease reduced early infant deaths by 33 percent. They are now tracking state implementation of the screening.

Dr. Remley reviewed other NCBDDD priority areas including race/ethnicity disparities and in utero exposure to alcohol and other substances. They have established the MAT-LINK network to monitor maternal, infant, and child health outcomes associated with treatment for opioid use disorders during pregnancy. This network funds seven clinical sites to follow child outcomes for up to six years to determine long-term outcomes. The sites include different race/ethnicity populations and socioeconomic conditions, and the study results will inform clinical practice recommendations.

NCBDDD also conducts surveillance for emerging threats to mothers and babies including the SET-NET system to track new health threats such as COVID-19. As of May 2021, 25 jurisdictions have submitted birth and infant outcome data to SET-NET. Representing data from nearly 19,000 pregnant women and their infants. These data showed that COVID-19 was associated with an increased risk of preterm birth. Dr. Remley also reviewed their efforts to monitor and understand the risk factors associated with fetal death. They funded CBPRDs in Arkansas and Massachusetts to expand their tracking system to include all pregnancies that result in stillbirth to understand disparities and to create recommendations, policies, and services to reduce the risk of fetal death.

Dr. Remley talked about aggressively working to collect data to fulfill CDC's commitment to health equity. They are cultivating health equity science, optimizing interventions, expanding partnerships, and enhancing workforce capacity to maximize their efforts to reduce health disparities. CDC is also undergoing a data modernization process to align existing data systems with birth and death data to better understand birth defects, developmental disorders, and newborn screening outcomes. They hope to leverage machine learning to develop algorithms for cost-effective, large scope surveillance.

Discussion

Dr. Lee asked if they are monitoring the available fetal treatment options such as fetoscopic procedures or fetal surgery. Dr. Remley answered that NIH has a series of events on gene therapies and fetal surgeries, and she hopes to collaborate with Dr. Barfield, Dr. Warren, and Dr. Diana Bianchi at NIH to determine where the field is going and if CDC is conducting appropriate surveillance. She suggested that there should be a public health commitment that all new parents have access to information about these different therapies.

Dr. Lee asked if the SET-NET system includes COVID-19 vaccine data. Dr. Remley said that it is being piloted and there is also the CDC V-Safe app for collecting vaccine data. A significant number of women identified as pregnant in V-Safe, and they are closely following them post-vaccine. Dr. Barfield added that they also have collected data from close to 5,000 women about their reaction to vaccination.

Dr. Peck challenged the Committee to consider in their recommendations the expansion of data systems such as SET-NET and PRAMS and the opportunities for harmonization and integration. She also commented that data modernization has advanced machine learning and artificial intelligence, but their ability to predict outcomes will only be as strong as the equity that is built into the algorithms and code. Dr. Remley added that they never have enough numbers for tribal populations and data modernization should include efforts to ensure enough data to make decisions for all populations.

Public Comment

***Lee Wilson,* Acting Designated Official, SACIM**

Mr. Wilson provided Dr. Brenda Bandy's public comment in the Chat Box and invited Ms. Pat Loftman to provide her public comment. Ms. Loftman is a midwife and serves on the New York City Maternal Mortality Review Committee. During her clinical practice, she learned two important aspects of care: establishing a relationship and providing respectful care. She spoke of a British midwife, Saraswathi Vedam, who published a study on the integration of midwives for improved maternity outcomes and a study that described BIPOC women's birth experiences as often coercive and disrespectful—so much so that 25 percent of Black women opted for out-of-hospital birth. She asked the Committee to emphasize the importance of race-concordant care.

Committee Vote on Recommendations to the HHS Secretary

***Edward Ehlinger,* SACIM Acting Chair**

Dr. Ehlinger invited to Committee to provide final comments on the recommendations before calling for a motion to approve.

Dr. Wise reviewed a final discussion point in Migrant and Border Health in recognition of the special needs of pregnant women in immigration detention.

Dr. Barfield emphasized the amount of time needed to expand diversity in the workforce and urged the Committee to consider other solutions for promoting diversity in the meantime, such as implicit bias training. Dr. Ehlinger said that he is including race concordant care on the September meeting agenda. Dr. Peck added that the Committee should also consider the burgeoning numbers of public health education and training programs and the opportunity for integrating anti-racism systems perspectives in the curriculum.

Dr. Ehlinger asked Dr. Palacios and Dr. Peck to work offline on the recommendation for funding IHS and suggested the Committee can vote on its general direction.

Dr. Peck recommended revisiting the recommendation for Maternal and Infant Mortality Review processes because it may be too narrow given the presentations provided on different surveillance systems. Dr. Ehlinger said that this topic is also on his agenda list for the September meeting. The Cover Letter will state that SACIM will continue to develop recommendations for each of the broad areas.

Dr. Conry asked if World Patient Safety Day could be included and Dr. Ehlinger said it could be included in the Cover Letter.

The Committee unanimously passed a motion to approve the recommendations to the Secretary (with some revisions of specific language by the Workgroup Chairs).

Next Steps

***Edward Ehlinger,* SACIM Acting Chair**

Dr. Ehlinger said that next steps include revising the Cover Letter and Background Document. He asked if there was a need to prioritize the recommendations, suggesting that he could send a poll for Committee members to rank priorities. If there was consensus, the letter to the Secretary could highlight the top priorities as timely issues for immediate attention. Committee members discussed identifying recommendations that could be deferred or that were ranked based on urgency instead. They determined that this exercise would represent individual perspectives rather than the Committee perspective. Dr. Ehlinger said that the document would move forward without prioritization. He reminded Committee members that he had asked for their individual priority areas at the beginning of the meeting and requested that they continue to raise the issues they want to see move forward. He reviewed his draft list of agenda items for the September meeting and asked Committee members to contact him if there were other, more timely topics.

Mr. Lee talked about administrative next steps. He requested feedback on the meeting structure, which is currently virtual and set across two four-hour days. Dr. David de la Cruz, the current Designated Federal Office for SACIM, has taken a position with DHS and Ms. Vanessa Lee has accepted the responsibility for serving both as SACIM lead and as Designated Federal Official.

Mr. Lee asked Committee members to consider a definition for severe maternal mortality and its classification and data collection. He also asked them to consider the definition and data collection of birthing facilities, which would help quantify shortages. Finally, he asked members to weigh in on the issues around race-concordant care, terminology, messaging, and inclusivity to identify terms that are inclusive but that are also understood by the public.

Ms. Lee said there were two remaining meetings in 2021, tentatively scheduled for September and December. SACIM has been advised to make all 2021 FACA meetings virtual because of the ongoing uncertainty of federal buildings reopening. Exact dates have not yet been selected, and they may consider pushing the December meeting to January 2022 with the hopes of conducting it in person. Committee members will receive a poll for their input on preferences. Dr. Ehlinger and Mr. Wilson discussed the possibility of holding an offsite in person meeting.

Mr. Wilson updated the Committee on the new member nominations, which is moving forward. They continue to accept nominations and they will use a matrix process to ensure diversity in expertise, gender, region, and race/ethnicity. The updated Charter will need to be approved by September 30 and is currently in the queue for review.

Adjourn

Dr. Ehlinger adjourned the meeting at 4:10 p.m.