ADVISORY COMMITTEE ON INFANT AND MATERNAL MORTALITY

US DEPARTMENT OF HEALTH AND HUMAN SERVICES

Virtual Meeting

Day 1

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Attended Via Webinar

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Reported by Gary Euell

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C O N T E N T S

P R O C E E D I N G S

WELCOME AND CALL TO ORDER

VANESSA LEE: All right. Good afternoon everyone, and good morning to those further West. I'd like to open this meeting, which is for the Advisory Committee on Infant and Maternal Mortality, formerly called the Advisory Committee on Infant Mortality. I'm Vanessa Lee. I serve as the Designated Federal Official or DFO for the Committee out of HRSA's Maternal and Child Bureau.

I'd like to welcome our committee members, our ex-officio members, and all of our invited speakers, panelists, and last but not least, welcome those of you that are joining us as members of the public. Thank you all so much for being here. We know this is a really busy time but are looking forward to the next two days together.

So, I'm officially calling the meeting to order and would now like to turn it over to our acting chair to introduce himself. Ed.

EDWARD EHLINGER: Thank you, Vanessa, and

good morning and afternoon to everyone. I always look forward to this meeting for a whole variety of reasons. It's been, like I said, this is our fourth December meeting and it's been two years since our last in-person meeting when we met in person in December of 2019, although I wasn't there, I was having a little medical problem in the DC area and Paul Jared stepped in and covered for me, but that was our last in-person meeting and I miss being together with you folks.

But like I said, really, I really always appreciate this meeting, because we come together from, you know, varied backgrounds and experiences and perspectives, all very interesting and we come together from various many places throughout the country and sometimes even France when Jeanne is over there.

But I come to you today from Minnesota, the land once inhabited by the Dakota and the Ojibwe peoples. A place whose health where, for better or for worse, is influenced by the history of the people who have lived in this place and

have made it their home for many, many centuries.

So, we also come together as part of a continuing history of SACIM, and I'll -- even though it's ACIMM officially, I'll continue to call it SACIM. That just seems to fit better for me. SACIM, which was established in 1991, thirty years ago. This year is also the 30th anniversary of the Healthy Start Program, which was established to reduce infant mortality rates by 50 percent over a four-year period. Didn't quite make that, but that was the goal.

A month ago, I was asked, along with Vanessa Lee and Belinda Pettiford, to talk about SACIM at the Healthy Start 30th Anniversary Celebration. In preparing for that presentation, I recall the initial discussions in 1985 around a bill, Senate File 1209, to establish a national commission to prevent infant mortality. A hearing on that bill was chaired by Senator Dave Durenberger from Minnesota and Senator Lawton Chiles from Florida, and it was held in Washington DC. And for some of you who have been around for

a while, there were some familiar names who testified at that hearing: James Mason, Vince Hutchins, who was MCHB Director or Chief at that time, Joel Klineman, Jim Marks, Sarah Rosenbaum, Stanley Graven, Charlie Mahan, and Sarah Brown. Also on that list were Paul Wise and me. Both of us were testifying before Congress for the first time. It was in Paul's testimony that I heard for the first time, the term social determinants of infant health and reviewing his testimony thirty-six later was somewhat distressing in that what he said then is still relevant today. Let me give you just five excerpts from his testimony.

He said, "The problems of low-birth-weight infants and infant mortality are not the product of geography. They are not the problem of being a heterogeneous society. They are a product of our policies."

He went on, "A major concern is the persistence of social and racial disparities, the technological capacity of modern medicine cannot erase the legacy or larger social inequities.

Equity in infant outcomes can only be achieved when inequity and infant outcomes is addressed and addressed directly and the reduction in black infant mortality related directly to a more fundamental commitment to a more responsible and just society." He was sort of reflecting many of the things that we talked about in our committee meetings over the last three years.

My statement at that testimony was much less eloquent than Paul's but reinforced many of the points that he made. I ended up my testimony by saying, "The problem of infant mortality in this country is an issue of social justice. The survival and growth of infants and children depends on our acceptance of the responsibility to address their pressing medical and social needs. To ignore that responsibility would be an injustice not only to our children but to our society. We need to make a commitment to the children of our country. We need to make them our highest priority and protect them from the political, social, and economic forces that

pervade our society and too often are to the detriment of mothers and infants," and I still hold that belief today.

So, in light of that thirty-six-year history, after which the issues affecting infant mortality in 1985 still persist today and in many areas have even gotten worse, we could get discouraged. But I think collectively, as members of SACIM, in our own limited way, we have made a difference. We have helped change the trajectory of the field of maternal and infant health ever so slightly so that thirty-six years from today, things will be different than they are today.

We have heeded the 1985 advice of Paul Wise and expanded the focus and shifted the priorities from programs to policies, from just medical care to medical care and social determinants of health, from race to racism, and we have helped highlight the needs of pregnant individuals and infants during a once in a lifetime pandemic and a humanitarian crisis on our southern border, and we are addressing the needs

of indigenous women and children, a group too often overlooked, all with equity, as our North Star.

I think we've done remarkable work and we continue to do this, and we have, for many of us only three meetings left as members of this committee. So, I urge all of us to make the most of these last three meetings and create some momentum that we can hand off to the next cohort of SACIM members.

So, let's recommit ourselves to finding a different, and I hope, better way to make the necessary changes in our society that protect mothers and infants.

INTRODUCTIONS

Now, I had anticipated that we would have many more members on our meeting that we could introduce, and we were going to take a longer time. But today we just have us, and Paul Wise is not here because he's actually dealing with an Omicron problem on the border. So, he will be coming tomorrow.

So, I won't do an expanded introductory time, but we will do a much shorter one. So, let's go around and introduce ourselves. So, let's have regular members introduce themselves and we'll start on my list up here as I see on my screen. Tara, go ahead and introduce yourself.

TARA SANDER LEE: Good morning. My name is Tara Sandra Lee. I'm the senior fellow and director of Life Sciences at the Charlotte Lozier Institute, which is in located in Arlington, Virginia. But today I am in Milwaukee, Wisconsin or just west of Milwaukee, Wisconsin. So, I'm really happy to be here and excited for the next couple of days.

EDWARD EHLINGER: Good. Jeanne Conry.

JEANNE CONRY: Good day to everybody. This is Jeanne Conry from California, often from Paris. I am past president of the American College of Obstetricians and Gynecologists and I'm President of the International Federation of Gynecology and Obstetrics. Thank you.

EDWARD EHLINGER: Good. Steve Calvin.

STEVEN CALVIN: Hi, Steve Calvin, Minneapolis, Minnesota. I'm a maternal fetal medicine specialist and I am currently working with midwives to promote midwife-led primary maternity care integrated with the larger health system.

EDWARD EHLINGER: Great. Magda Peck.

MAGDA PECK: Well, good morning, everyone. My name is Magda Peck and I'm an independent consultant with MP3 Health and maternal and child specialist. My academic affiliation is as professor of Pediatrics and Public Health at the University of Nebraska Medical Center in Omaha, Nebraska. I continue to serve as senior advisor of City Match, the national organization dedicated to urban women, children, families, and fathers' health, where I founded it as well thirty-three years ago, so part of that initial cohort along with Healthy Start and many other things from that initiative that started thirty-plus years ago, for which we are still doing due diligence.

And this morning I woke in Richmond, California on the banks of the San Francisco Bay, ancestral lands of the Ohlone and Muwekma peoples, to whom I give homage and appreciation.

Thank you, Ed. Glad to be here today.

EDWARD EHLINGER: Okay. Janelle Palacios.

JANELLE PALACIOS: Good morning, everyone. I'm Janelle Palacios. I'm a nurse midwife and I'm also a researcher and an independent consultant. I am currently in Sonoma County, which is the home to the Costanoan, Muwekma, and Pomo people, who are still here today. And I am looking forward to December's meeting with a lot of gusto. Thank you.

EDWARD EHLINGER: Good. Belinda Pettiford.

BELINDA PETTIFORD: Good morning, everyone. Well, it may be morning depending on where you are. Hello, everyone. I am Belinda Pettiford, and I am in North Carolina where I'm

here as head of Women's Health for our State Title V. It is so good to see everyone. I am also the president elect of AMCHP and, as Ed talked about, Healthy Start, I am a board member of the National Healthy Start Association. So, I do look forward to being with everyone today and I always enjoy our meetings. Thanks.

EDWARD EHLINGER: Great. Paul Jarris.

PAUL JARRIS: Hi. Paul Jarris. I'm currently working in the area of the interface between nature and human health. I'm a retired family physician, also a public health official. I was Commissioner of Health in Vermont, lead ASTHO, Association of State and Territory Health Officials, for ten years. and most recently was with MITRE Corporation leading as their chief medical advisor to their work with HHS. So, happy to be here.

EDWARD EHLINGER: Yeah. I can't even remember what ASTHO stands for anymore, you've been out for too long.

PAUL JARRIS: I know.

EDWARD EHLINGER: Colleen Malloy.

COLLEEN MALLOY: Yes, hi. My name is Colleen Malloy. I am a neonatologist and pediatrician at Feinberg University, Northwestern University School of Medicine and Lurie Children's Hospital in Chicago, and I look forward to this meeting.

EDWARD EHLINGER: Great. And, as I said, Paul Wise it won't be here today, but he'll be here tomorrow. Let's do the MCHB staff. Vanessa, do you want to quickly introduce yourself again?

VANESSA LEE: Sure. Hello again, everyone. I'm Vanessa Lee. I work at HRSA's Maternal and Child Health Bureau in the Division of Healthy Start and Perinatal Services, and I have the privilege of serving as the Designated Federal Official for this committee and a project officer in the Bureau.

EDWARD EHLINGER: And Dr. Warren.

MICHAEL WARREN: Good morning or good afternoon. Michael Warren, I'm the associate administrator of the Maternal and Child Health

Bureau here at HRSA and an ex-officio member of ACIMM.

EDWARD EHLINGER: Good. And Lee Wilson.

LEE WILSON: Good morning/afternoon, folks. Lee Wilson. I'm the director of the Division of Healthy Start and Perinatal Services, which has responsibility for the administration of the committee, and I'm very happy to be here with you and looking forward to the two days.

EDWARD EHLINGER: Yeah, good. And Michelle Loh.

MICHELLE LOH: Good afternoon and good morning. I am Michelle Loh. I'm the management analyst for the SACIM.

EDWARD EHLINGER: All right, good. And I know we have a bunch of ex-officio members on and let me see if I can -- can I -- Danielle Ely.

DANIELLE ELY: Hi. I'm Danielle Ely. I work on the link file with the National Center for Health Statistics. So, link file is the birth and infant death file combined. Thanks.

EDWARD EHLINGER: Kristen Zycherman.

KRISTEN ZYCHERMAN: Hi. I'm Kristen Zycherman. I am the acting technical director of Quality Improvement Centers for Medicare and Medicaid Services and the lead on the Maternal and Infant Health Initiative.

EDWARD EHLINGER: Great. Any other ex-officio members that I can't see on my screen or on my scroll? All right. Well, I hope we get some more as the meeting progresses. And we have some other speakers who will be introduced as they do some presentations a little bit later on. So, welcome all. I'm glad you are here, and I hope you are ready for four hours with one break in between of good discussion and deliberation.

REVIEW AND APPROVAL OF MINUTES

EDWARD EHLINGER: Let's now move to reviewing the minutes of our meeting, one of our official businesses that came in briefing book. Any -- does anybody want to move approval of the minutes before we talk about them?

PAUL JARRIS: So moved.

EDWARD EHLINGER: All right. And is

there a second to that?

MAGDA PECK: Second.

EDWARD EHLINGER: We've got a second. Any -- any comments on the -- the minutes?

MAGDA PECK: This is Magda. I just want to reflect that we tend to take for granted the staffing that comes with this particular endeavor, and it has been very helpful to have this documentation, especially in trying to get perspective on our very first meeting, especially conversations with you, Dr Warren. So, I just want to say thank you to the staff that make this happen, and the level of detail gives us a thread to follow through and a chance to circle back, so gratitude.

EDWARD EHLINGER: Yeah, I second that because I've been going through the minutes, and they've been very helpful to me, as comprehensive as they are. Any other comments? If not, all in favor say aye or raise your hand.

[CHORUS OF AYES.]

EDWARD EHLINGER: Any opposed? All

right. The meeting's -- the minutes are approved.

So, the next on our agenda is Federal Updates. And normally, we have MCHB kind of go first and do their updates. But we just heard from Dr Warren in September, and we have a couple of other updates that we would like to get to, so we're going to not hear from Michael -- Dr. Warren at this time for the MCH updates, although I do suspect that, during the course of our meeting, we will probably get some input from him or Lee or Vanessa on what's going on in the MCHB.

But one of the things that that I've asked him and they couldn't quite do this at this time, and I hope will, and what I hope will in what I hope will be our April meeting, kind of give us an update on the response of MCHB and other federal agencies on our recommendations that came out during the summer so that we will get a more complete review of some of the -- the action taken on the recommendations that we made. So, in lieu of that though we do have two federal representatives, Kristen Zycherman, ex-officio

member. She's acting technical director for Quality Improvement, Maternal Infant Health Initiative, Center for Medicare and CHIP Services, Centers for Medicare and Medicaid Services. That's hard to get on a business card, Kristen, but I'm glad you're here. So, let's -- I look forward to your update about what's going on in your shop.

FEDERAL UPDATES

KRISTEN ZYCHERMAN: Thank you so much. We can move on to the next slide. I'll try to keep it moving here, since I know we want time for all the presentations and questions. So, just an overview of what I'm going to talk about today. Next slide. Next slide.

Okay, so the Maternal and Infant Health Initiative was launched initially in 2014 based on recommendations by an expert panel within the field of maternal and infant health. Five years into the MIHI, we were ready to take stock on where we were, what progress has been made, whether there was still room for improvement. So,

we reconvened an expert work group to provide updated recommendations on where Medicaid and CHIP have a significant opportunity to influence change.

So, today, the MIHI is focused on three areas, based on recommendations by the work group, including an increase in use and quality -- sorry -- increase of the use and quality of postpartum care visit, an increase in the use and quality of infant well-child visits, and a decrease in the rate of low-risk cesarean deliveries. Next slide, please.

So, this figure shows the interconnectedness of these three areas and the emphasis that the work group wanted to put on the importance of both the mother-infant dyad care, as well as care throughout the life course of both the birthing person and the infant. Next slide, please.

So, obviously equity is a big focus in maternal health outcome. Currently, we are looking at three to up to five times the death

rate in Black and American Indian/Alaska Native birthing persons based on other demographic factors, but it is up to five times the rate of maternal mortality. So, it is something that we're focusing on across all three of our MIHI focus areas. Next slide, please.

And this slide shows the importance of that postpartum period, and that over half of deaths happen in the postpartum period with a third happening after a week postpartum, so usually after that initial discharge and almost 12 percent occurring in the -- what we would consider the late postpartum period or after 42 days postpartum. Next slide, please. Next slide. Next slide.

So, there are special considerations for our Medicaid and CHIP population, especially in regard to equity and postpartum care and these are statistics that were based on studies, particularly done with women, which is why it refers to women, but likely translates to all birthing individuals. And so, women enrolled in

Medicaid are more likely to be overweight or obese and have comorbidities compared with both uninsured and privately insured women.

Studies have shown that women who are Black and Hispanic and individuals that have a low level of education and those with co-existing morbidities such as mental health conditions have lower rates of this postpartum follow-up care and despite lower or higher rates of postpartum depression, people of color tend to have a lower screening rate for postpartum depression. Next slide, please.

So, this is the most recent core set reporting data from our Medicaid and CHIP adult core set and it -- it shows that around 72 percent of women delivering a live birth had a postpartum care visit this year. The -- the technical specifications for this measure had changed to expand it from seven days to eighty-four days after delivery. So, that's why it's gone up -- the median has gone up a little from previous reporting years, so not totally trendable;

however, there's still a lot of room for improvement there. Next slide.

And you can see on this slide that the yellow states are our lowest performing core states, while the gray states do not report on this measure. So, we're continuing to also work with states that aren't reporting this measure to encourage reporting. Next slide, please.

Along with the increase in attention to maternal care and postpartum care, there's also this evolving concept of postpartum care where ACOG recommendations recommends that all birthing people have contact with their health care provider within three weeks, and also a comprehensive postpartum visit, and that plays into the quality of the postpartum visit and the expansion of the scope that it's not just about recovery from childbirth anymore, but includes also health, education, and infant care and feeding, and contraceptive care, as well as chronic disease screening and management. So, to look for these conditions that contribute to

maternal morbidity and mortality post-birth and to connect them with the proper care.

We also understand that the systemic inequities are contributing in this -- in this period to the care that birthing people receive and so also addressing that. Next slide, please.

So, part of the MIHI, our MIHI, our first learning collaborative as part of this new phase of MIHI that launched in December 2020 was the Postpartum Care Learning Collaborative. So, here we had a three-part webinar series, which can all be found -- the recordings of the webinars can be found on medicaid.gov and currently, we have an ongoing Postpartum Care Affinity Group, where we're working with nine states on providing targeted technical assistance, one-on-one as well as group learning work group sessions to improve their rates and quality of postpartum care in their state. Next slide, please.

Our next learning collaborative is the Infant Well-Child Visits Learning Collaborative, which, as you all know, the benefits of high

quality well child visits do all these things. So, I won't read the slide. Next slide, please.

Our recent core set reporting on this measure showed a median of 66 percent of children receiving six or more well-child visits in the first fifteen months of life where the American Academy of Pediatrics and Bright Futures recommends at least nine well-child visits by the time a child turns 15 months of age. So, this isn't even meeting the best standard of care recommendations and only 66 percent of children are receiving those. So, we know that there is a large room for improvement in this metric as well. Next slide.

With the yellow states being the lowest performing core in this measure. Next slide, please.

And we know that Medicaid and CHIP beneficiaries are receiving these services at a much lower rate than other payors. So, that's what this -- with the lowest black line being Medicaid and CHIP and the highest being PPO,

private insurance, and HMO. Next slide.

And then, in addition, we know that the COVID-19 public health emergency led to forgone care with children missing a lot of these recommended visits during that time period and continuing, although it is catching up some at this point. Next slide, please.

So, the Infant Well-Child Visit Learning Collaborative, we a had similar webinar series with recording available at Medicaid.gov and we are currently in the -- in the middle of our Affinity Group providing TA to eight states to improve their well-child visit rate and quality. Next slide, please.

And then, our final MIHI learning collaborative of our final area focus hopes to be launching in the beginning of 2022 is lowering the rate of low-risk cesarean delivery or NTSV cesarean delivery to improve health outcomes, since it is a factor associated with the rising maternal morbidity, as well as infant complications as well. Next slide.

So, CMS has not been able to publicly report a lower cesarean birth metric. While it is one that is on the core set, it has never met the threshold of twenty-five states to be able to be reported publicly. So, for the 2021 measurement year, the -- we have replaced PC-02, which was the previous cesarean birth measure, with LRCD, which is a low-risk cesarean delivery measure based on CDC natality data. So, CMS will actually calculate this measure on behalf of all of the states so we will have data from all states, and we will access that through CDC WONDER. So, that will be reported with the next cycle of core set reporting. So, we will finally be able to publicly report on a low-risk cesarean delivery measure. Next slide.

And this is a little bit more about the collaborative and more information on that will be forthcoming, as we schedule the webinars and have more information on the Affinity Group. Next slide. Next slide.

We also have a -- coming in early 2022 --

a Tobacco Cessation for Pregnant and Postpartum Women on-demand series of short videos featuring subject matter experts and stories on successful programs to help Medicaid and CHIP beneficiaries quit smoking and remain smoke-free during pregnancy and after delivery, and there will be an opportunity for continued one-on-one coaching on an as-needed basis for that one. Next slide, please.

And at CMS, we have a lot of other maternal and infant health activities. It's a major priority of this administration and our administrator. So, you may have seen that the postpartum coverage extension guidance, a SHO letter came out this past Tuesday the 8th, on guidance for states on the implementation of the new spot option to be able to extend postpartum coverage and Medicaid and CHIP for twelve months post-delivery. In addition to that, we also have approved demonstration -- Section 1115 demonstration waivers for a number of states extending postpartum care coverage as well. I

included a little more information on the maternity core set. This says that we have six measures from CMS's child core set and four measures from the adult core set, which is the most current information with the newest core set just was released yesterday, I believe, maybe Friday. Next slide, please.

CMS also conducted an Equity Assessment focused on postpartum care, and it is -- and that is where we also identified the need and the strong disparities with and care for Black and American Indian/Alaska Native postpartum individuals and that led to a challenge.gov prize competition that we have partnered with the Office of Women's Health to put out. So, I just want to flag that -- that we are trying gather examples of innovative programs or ideas that have demonstrated improvement of care in this population and the deadline for that challenge submission is January 31st. Next slide, please.

We also have a Maternal Health Agency Priority Goal of improving maternal health and

reducing disparities nationwide and globally by assuring the equitable provision of evidence-based, high-quality care addressing social determinants of health including racism, discrimination, and other biases across the life course. So, I thought that that was good to share with this group, as it is in line with actions here as well. And then I included the Maternal Health Action Plan from the Department of Health and Human Services that fit with goals of reducing the maternal mortality rate by 50 percent in five years, reducing the lower c-section rate by 25 percent in five years, which we hope our Low-Risk Cesarean Delivery Learning Collaborative will help contribute to, as well as achieving blood pressure control in 80 percent of women of reproductive age with hypertension in five years. Next slide, please.

I just included a list of resources. I know that we can't -- that you can't click them directly from here, but when the slides are posted you'll be able to easily get to those web pages.

So, thank you.

EDWARD EHLINGER: All right. Thank you, Kristen. Let's open it up for a few minutes of questions and Kristen, I hope you can stick around after the presentation for the Office of Women's Health, because I think there will be some discussions about the White House Maternal Health Day of Action, and I'd like to have both of you and have that conversation. But if there are members of the committee, if you could use the raise the hand feature and -- and I think -- let me just see, we've got Paul Jarris.

PAUL JARRIS: Thank you, Ed, and thank you for the presentation, I appreciate it, particularly the potential to extend postpartum care for a year after delivery. I think that's incredibly important.

A couple of concerns. One is that I saw from the initial tasking of your work you did use, I think, the term effective use of contraception was in there, and that was dropped over time and, in particular, I'm concerned about the either

immediate postpartum or postpartum contraception to impact birth spacing, which is so important. And I know that when I used to oversee some of the insurance aspects of Medicaid, there were providers who actually after doing a c-section on their private patients, would do a tubal ligation while they were doing the surgery. On their Medicaid patients, they wouldn't, and they'd scheduled them back later so they could actually bill and collect better funding from Medicaid. So, there were particular problems with Medicaid around immediate postpartum and postpartum contraception. So, I'm wondering, you know, why that got dropped and if it is going to be a focus, because it's kind of buried if it is in there still.

KRISTEN ZYCHERMAN: While it is -- oh, I'm sorry. You can keep going.

PAUL JARRIS: Well, I'm -- I'm going to make this a two-for and you decide what you want to do. The other thing I was concerned about is a lot of your explanations of maternal mortality

were very clinical and medical, and I didn't see things like partner violence in there, drug overdose, and other things that fall outside the medical environment, but are actually much more impactful often with maternal morbidity and mortality than the classic health concerns. So, pick your pick.

KRISTEN ZYCHERMAN: Sure. I'll start with contraception. So, that was a focus in the original phase of MIHI and what came out of that was contraceptive care measures. And so, now we have two contraceptive care measures split into kind of four measures on our adult and children -- child core set. One contraceptive care measure for all women and one contraceptive care measure for postpartum women, and those are for the further split into LARCs. Where contraceptive care postpartum got wrapped into was kind of our comprehensive quality postpartum care.

So, one thing that we have been working with states a lot on is the unbundling of postpartum LARCs, because that was a real barrier

was the Medicaid separating out Medicaid payment for LARCs given postpartum, that it wasn't wrapped into the delivery and hospitalization fees. So, that's something that we continue to work on as well as exploring options for future measures related to a patient-centered contraceptive counseling and such.

PAUL JARRIS: Thank you.

KRISTEN ZYCHERMAN: Then, I'm sorry, the second question was on --

PAUL JARRIS: Well, all the other factors affecting maternal morbidity and mortality outside of the clinical conditions, which often are more impactful.

KRISTEN ZYCHERMAN: Right. A lot of our data comes from the CDC definition of maternal -- of severe maternal morbidity, which is those 21 codes better largely clinical based; however, as we work with states on this, a lot of states are starting to calculate their own severe maternal morbidity rates and then are including codes related to behavioral health and other things.

Intimate-partner violence gets into a little bit of like the pregnancy-associated versus pregnancy-related death. But it is something that is also -- we discuss as part of quality postpartum care is the screening and -- and referral for those types of situations as well. So, it is something covered under postpartum care as well and is something we are considering, especially like the behavioral health and SUD side of things as conditions of maternal morbidity and leading potentially to mortality that are being addressed.

PAUL JARRIS: Thank you.

EDWARD EHLINGER: Let's -- well, we have time for three more questions. We have Jeanne Conry, Steve Calvin, and Magda Peck in that order. Jeanne.

JEANNE CONRY: Thank you so much and Kristen, great summary and a lot of information. I appreciate it very much. I did want to make one comment about the postpartum tubal ligations that there are, rightfully so, some barriers or protections, depending on how you look at it, with

the, you know, the -- the waiting period that more often than not influences the ability to do a tubal ligation at the same time as a cesarean section, the mandatory wait for the Medicaid patients was put there to protect them, but in the end, it can also be a barrier, depending on how you're looking at it. So, just for us to all be cognizant of that.

The second comment has to do with one of the things that we looked at, and I believe it was a -- gosh -- a meeting about five years ago that looked at measuring the health of women as they can -- as they began pregnancy as an indirect reflection of preconception health, if you will, because too often our measurements are not gender-based and they're not reproductive health-based. So, you know, for example, the -- the measurements for hypertension control are not reflective of what ideal hypertension control can be. So, I would say that we're strong advocates for making sure that we've got some gender-based and reproductive health background-based measurements,

and we hold health plans accountable to those kinds of things. Postpartum, excuse me, preconception care is a very difficult measurement but the control of woman's blood sugar before she -- at her first prenatal visit is the blood pressure regulation at her first OB visit is her weight, her use of tobacco, her use of a prenatal vitamin. All of those are reflections -- indirect reflections of preconception health and can be used as a measurement of adequate care. So, thank you.

KRISTEN ZYCHERMAN: We -- we totally agree with you. We believe that, you know, healthy individuals become healthy pregnant individuals. So, definitely that preconception period, and while we can't at CMS necessarily tackle that before time if there's not for coverage yet. We're hoping -- our hope is that that extension of postpartum care will put people in a better -- a better health status before going into subsequent pregnancies. So, it's not ideal, but it's something.

JEANNE CONRY: And I will add, I will add Women's Preventive Services Initiative just updated our contraceptive guidelines. So, those will be posted very shortly. So, I'm very happy to say WPSI is addressing contraception access for all.

KRISTEN ZYCHERMAN: Great.

JEANNE CONRY: Within the Affordable Care Act. Thank you.

EDWARD EHLINGER: All right, Steve.

STEVEN CALVIN: Yeah. Kristen, thanks for the report. I have a quick question. So, looking at, Minnesota keeps -- is not in the list of states that is actually participating in. Is -- is that an issue of kind of the executive branch in the state or legislative? I mean, where, just in general, what -- what advice would you give those in states that are currently lagging behind, both in participation and in outcomes?

KRISTEN ZYCHERMAN: I Think it -- it depends on state -- state to state why -- why they don't participate. We tried to outreach,

especially to our lower-performing states, and see what we can do to try to work with them to help them be involved in some of these technical assistance opportunities. But sometimes it's a bandwidth issue, sometimes it's a priority issue. Just states are stretched for resources and people and so, sometimes they have to pick and choose what they participate in and how. But we definitely try to -- and that's why we're trying to roll out like, for example, the tobacco cessation on-demand short videos to be able to offer some of those technical assistance opportunities to states I can't commit to a full Affinity Group or we have our webinar series that can be watched at any time after the fact, and we have a Medicaid and CHIP Quality Improvement Mailbox that -- that states can reach out to at any time if they need some additional assistance.

STEVE CALVIN: Okay. Well, our hour-long thing later today too with the folks from New Jersey and California, I think that's the State and Community Projects on Maternal Health that I

think people will be interested in what those folks have to say. Thank you.

EDWARD EHLINGER: Magda.

MAGDA PECK: Thank you so much for the presentation. I have the privilege of co-leading the Data and Research To Action Work Group, so I'm going to put on the data hat and I am also going to harken back to the notion that we seem to have a theme here that we've been doing, at least this iteration, for at least a third of a century, if not a full century, if not longer.

So, I'm perplexed and help me understand the gaps in the data within CMS that you're looking at. You have a threshold of twenty-five states in order for something to be reported. Is that correct? That's what I understood and yet I look at your --

KRISTEN ZYCHERMAN: To report publicly.

MAGDA PECK: To report publicly. Thank you for that distinction. I'm just noticing the -- - the gap in geography between where we get data and which states are participating in terms of

Medicaid expansion and otherwise, and so, I wanted to know what are the incentives for states to participate in reporting so that we can have a more robust picture nationally? Is it a lack of capacity? Is it a lack of political will? Is it -- so, I'm trying to get a sense of why are we not hearing now in 20-almost-22 about basic reporting, particularly when the carrot is that you are funding these states in some way.

KRISTEN ZYCHERMAN: Um-hum.

MAGDA PECK: So, I'm looking at the correlation about who reports and who doesn't, and it tends to be states where, in fact, the outcomes may not be as good, and I am aware that at least in a couple of states, the governor's office will say we will not allow that to be reported public because it will make us look bad. And so, how do you wrestle with these data gaps that are there now thirty years into a program? And what, with Medicaid expansion, are you building in if that initiative goes forward with the Build Back Better funding if it is passed and more broadly, how do

you bring some sticks to the carrots, so we have data we can rely on, that we can disaggregate by race and ethnicity, that we can include birthing peoples? Help us figure out how to make the data stronger so that we can have more confidence in it and use it better.

KRISTEN ZYCHERMAN: Right. I totally hear you. We are limited someone by statute, because it is a -- the Medicaid and CHIP core sets are voluntary -- a voluntary reporting program by states. So, the states aren't -- we cannot require the states to report on this information. However, there are -- but in 2024, the entire child core set will become mandatory reporting. So, any -- any of the measures on the child core set will be required to be reported by states and in 2024, any behavioral health measures on the adult core set will be required to be reported by states. So, that will be part of the maternity core set will fall under that. Any of the child -- - any of the child measures and then, if any -- and currently we don't have a behavioral health --

any behavioral health measures on the maternity core set; however, they are -- there are some that are being -- that are being put forward to be put on to the maternity core set. So, if that indeed happens before 2024, then we -- those will be required, as well.

We currently can't require the entire adult core set, but we are -- we are hopeful that eventually we will be able to. But that's -- that's the reason currently that we can't and we are also doing our best to look at other data sources like with CDC WONDER, and as we're able to -- we're looking into drawing more out of our -- our own CMS data for -- to be able to calculate measures on behalf of states, so that we can reach that threshold in some of the lesser reported measures in order to report publicly.

MAGDA PECK: That's great response. Thank you for that, and I will just follow up by saying we at the Secretary's Advisory Committee on Infant and Maternal Mortality has the opportunity to make recommendations and, which may or may not

have influence. But we can -- we cannot be silenced. So, if this is an egregious gap, recognizing that it has been a voluntary system, and this is essential information for maternal and infant indicators to be part of mandatory reporting, perhaps we could have a follow-up conversation of what you hope that might look like, similarly --

KRISTEN ZYCHERMAN: Sure, and we have -- we have -- we have a process for annual core set -- - annual core set discussion, and anyone can submit recommendations for measures for that annual review work group. So, I would encourage you to utilize that process as well to be -- if they -- if this group has ideas for measures that should be included.

MAGDA PECK: Thank you. That is the role we were invited to play relative to the PRAMS data set, and so we have expertise and experience in doing so, and if we could have more specifics, that would be an opportunity and, similarly, as you talk about linkages, I will be talking

tomorrow about our linkage between health and housing, and I would be curious as a quick follow-up, what is the connection between CMS data sets and those in other branches of government, particularly around housing or say eviction? Do you link those data sets or are they being linked so that we can have a greater picture of upstream factors?

KRISTEN ZYCHERMAN: Yeah, I'm not aware of data linkages specifically with housing. We are exploring data linkages with -- with CDC data as well as HRSA data, but we are -- we are still working through privacy red tape as well, so that is definitely an area of interest and continued exploration. But housing is a good point as well.

EDWARD EHLINGER: Thank you. Thank you, Kristen. And if hang in there and we'll have -- open it up for discussion after our next presenter also.

Margaret Snyder is going to be presenting next from the Office of Women's Health. Dorothy Fink lost her voice. She's got something going on

with her. So, she couldn't make it, so Margaret is here. So, Margaret, maybe you could introduce yourself a little bit more, because we don't have your full criteria on the -- the agenda. So, Margaret, I'll turn it over to you.

MARGARET SNYDER: Okay, great. Thanks. Can everyone hear me okay?

EDWARD EHLINGER: I can, yes.

MARGARET SNYDER: Okay, great. Yeah, I thought I'd go with a festive background. I see Michael's got one as well. So, I'm in good company.

So, my name is Margaret Snyder. I'm a lead public health advisor in the Office on Women's Health and the Office of the Assistant Secretary for Health at HHS. I'm excited to brief you on some OWH initiatives that were promoted during last week's Maternal Health Day of Action. Next slide, please.

So, I'll start with a couple of the challenges that we have going on right now. So, this first one is Racial Equity and Postpartum

Care Challenge and it's aimed at improving postpartum care for Black or African American and American Indian or Alaska Native low-income beneficiaries enrolled in Medicaid or Children's Health Insurance Program, and that's a partnership with CMS. And the emphasis here is on follow-up care for conditions associated with morbidity and mortality in the later postpartum period including conditions like diabetes, postpartum depression, postpartum anxiety, hypertension, and substance use disorders. We're in phase 1 of this competition right now, aiming to identify effective programs and increase access, attendance, and quality of care for postpartum visits for Black or African American and American Indian/Alaska Native beneficiaries enrolled in these programs.

Submissions for this phase are due January 31st, and we encourage anyone interested or with questions to E-mail postpartumchallenge@hhs.gov. Next slide, please.

Great. So, our next challenge is on

Endocrine-Disrupting Chemicals and this national competition is aiming to identify innovative programs that address the negative impact of EDCs, which can result in adverse health and reproductive outcomes.

We're also in phase 1 of this challenge. We're aiming to identify and fund programs that demonstrate effectiveness, sustainability, and the ability to replicate and/or expand interventions that address gaps in knowledge and provide actionable solutions to reduce EDC exposure for Black or African American women.

You can see for both of these challenges, we have a firm focus on health equity, which is something our assistant secretary is particularly concerned about now.

Submissions for this challenge are also due January 31st. We welcome you to E-mail EDCchallenge@hhs.gov with any questions and we really encourage everyone here to share with your networks. We'd like to award programs doing great work on these important subjects and I'll add some

links in the chat here. We have a couple of webinars coming up today for the Postpartum Challenge and tomorrow for the EDC Challenge. So, please share with folks that you think would be interested in these challenges so we can get them on board. Great. So, next slide, please.

Great. So, this next initiative, I'm very excited about, it's a partnership with Premier and MoMMA's Voices, and we're focusing on improving maternal health data to advance health equity and creating a network of over two hundred hospitals to deploy evidence-based best practices and maternity care, and I'll describe both of these prongs, the health data side and the collaborative side, in equal measure. Next slide, please.

Okay. So, this is a multi-year partnership with Premier and MoMMA's Voices. So, we have the health improvement, healthcare improvement company on one side and coalition of patient advocates as our partners and with these partners we're beginning a maternal health --

Maternal and Infant Health Initiative to address maternal mortality and severe maternal morbidity through better data and the idea that in order to improve maternal health, we need better data about women and babies.

So, for the data collection, analysis, and reporting prong, this first section here, we'll identify the key drivers of maternal and infant mortality and morbidity, analyzing up to date and ongoing data. We're very excited about the timeliness of this data, and it describes the relationship between maternal and infant mortality. It's nationally representative from a standardized inpatient data and hospital discharge data platform. We'll go to the next slide.

I'll describe what that data will look like. So, this data will be a national baseline of maternal and infant outcomes from 2008 to present. Like I said, it's ongoing data, so it will be updated regularly. It will explore and establish relationships between maternal and infant mortality, explore associations with

important demographic variables, other conditions like age, race, ethnicity, cesarean rate, co-morbidities including obesity, hypertension, and diabetes, as well as other contributing conditions. We'll also look at cost analysis for maternal and infant mortality and morbidity, the cost analysis for maternal and infant mortality and morbidity, the impact by payor, hospital designation, and geographic region, and we'll create maps of severe maternal morbidity and mortality in the US to include racial, ethnic, geographic, and other disparities. As you can see, it's not a small amount of variables. Next slide.

We're also looking at COVID-19 impacts and how that impacts the outcomes for maternal -- the material delivery population and we already have some results that we're seeing from the COVID-19 pandemic period, which by this definition is March to December 2020. So, looking at the odds of in-hospital delivery-related mortality and severe maternal morbidity, we can see some pretty

definite trends. So, for the overall odds of in-hospital delivery- related deaths during this period March to December 2020, the in-hospital delivery-related deaths odds were not statistically significantly higher compared to previous years unless the patient had a COVID-19 diagnosis. Then, the odds of in-hospital delivery-related death with the COVID-19 diagnosis were nearly six times higher than those without a diagnosis of COVID.

We see the same kind of trend for the overall odds of severe maternal morbidity during this period. Overall, SMM was 14 percent lower than previous years, which is great news. However, for patients with a COVID-19 diagnosis was more than three times greater than those without a COVID-19 diagnosis. So, you can see that COVID is affecting the pregnant population.

Overall, there has been an 11 percent annual decrease in odds of in-hospital death compared to the previous year overall, and prevalence rates of SMM also remain steady during

the period study. Next slide, please.

Okay. So, I'm excited to talk about our Perinatal Collaborative, which is the second prong of this two-pronged approach. So, we have the data side and then this collaborative side where we work directly with hospitals to implement ad analyze evidence-based interventions. And so, we -- I'll talk a little bit about the goals in this slide and then in the next slide, I'll talk about how we're implementing those goals.

So, our goals are recruitment of at least two hundred diverse birthing hospitals to join the Perinatal Collaborative, clearly defining areas of focus with overarching disparities considerations and individualized hospital performance improvement support to help drive the change, analysis of the direct impact of evidence-based interventions on maternal and infant outcomes, measurements of the associations between maternal health and infant outcomes, and evaluation and analysis of the culture of safety in hospitals on health outcomes. Next slide, please.

Great. So, on this slide, I'll talk about how we're achieving those goals, and this is a collaborative of hospitals and hospital systems. Like I said, it's a multi-year initiative. So, we're working with these hospitals and health systems to create a culture and infrastructure to ensure the health of women and newborns and measuring outcomes, process, and implementation.

So, these strategies are aligning and augmenting national and state strategies. So, we're working with the strategies that are already in place and aiming at three main measurable deliverables, which are also tools provided to hospitals.

So, these three main tools/deliverables are the Perinatal Collaborative Outcome Dashboard, Measurable High Reliability Site Assessment that is both virtual site assessments and onsite assessments, as well as an Individualized Improvement Roadmap, and so we have quite a range of tools that these hospitals have access to and hospitals themselves are very intrigued and

excited to get these tools.

And we have to also mention our key partnerships with MoMMA's Voices and the National Birth Equity Collaborative. These are very important because they ensure patient's voices are heard, make sure the initiative is patient centered, and that care is equitable for all. Next slide, please.

This is a great map that shows the locations of our hospitals, you know, broadly speaking, and see in the little circles in the states of the number of hospitals in that state. And we have two hundred and twenty diverse US hospitals in each of the fifty states and the District of Columbia now. And in those hospitals, we have over half a million births per year. So, you can see we're not working with a small amount of data. We've got a nationwide collaborative here. Next slide, please.

Okay. So, here I'll talk just briefly about our twenty-three maternal infant areas of focus and these outcomes are linking mothers and

babies in outcome data. So, we can see the impact of the health of the mother on the infant, and this is kind of groundbreaking because we haven't previously -- no one has previously analyzed this kind of data at the national level. So, we're excited to keep sharing this with you as we find new information. But just to give an example what this will look like, the first item on the list is hypertensive disorders of pregnancy. So, we see not just the effect on the woman, but the infant as well. For example, if the woman has preeclampsia, we would see the effect of that on the infant. So, we can look at, you know, for example, the effect on prematurity, on diabetes, et cetera, et cetera.

And so, there are over one-hundred and fifty outcome measures that we captured to understand the clinical and non-clinical factors that impact overall maternal health and infant health outcomes. Next slide, please.

Okay. Just to sum up again, we have this two-pronged approach focusing on the data and one

side, looking at data-driven insights, identifying the drivers of maternal morbidity and mortality, and the other side, we have the Perinatal Improvement Collaborative, implementing solutions and evidence-based care practices to make America the safest place to have a baby, which is our excellent tagline here in the White House and we're excited to be a part of this overall initiative. So, thank you everyone. I look forward to questions and thanks.

EDWARD EHLINGER: Good. Thank you very much, appreciate it. Just one little aside, I would -- since I'm sort of involved in making sure that we stay on time, I would like that the leads from the three work groups to kind of keep track of some of the potential recommendations, because I don't want to miss any. So, if you could help me do that for future reference, because a lot of things will come up in these conversations.

And before I open it up, I just have -- have one question. How does your collaborative align with HRSA's Alliance for Innovation and

Maternal health, their AIM Program with both are hospital-based. How does -- how do you align with that?

MARGARET SNYDER: So, we're working with HRSA and just making sure that we stay in lockstep with what we're trying to do, and what they're trying to do. The hospital improvement programs, they're -- it's really based on what the hospital wants to do. So, you know, Premier helps us focus on -- helps the hospital focus on what the hospital is looking to do. So, we really -- we really let them drive that aspect of it. And then at the federal level, you know, we coordinate with HRSA as well.

EDWARD EHLINGER: All right, great. Steve Calvin.

STEVEN CALVIN: Yeah. I just had a quick question. So, out of your -- the two hundred hospitals, it is, I mean it's helpful to have -- they're probably all very large hospitals -- that's how you get to the 500,000 births -- but I would suggest it's still really important to look

at the critical access hospitals and the others, how they how they fit into that network, because, you know, you just don't you don't want to ignore, you know, even birth centers too. It's just a very small percentage. But, anyway, the feeders into those systems, I think, you just need to pay attention to those too.

MARGARET SNYDER: Absolutely. And in the hospital recruitment, it was very important to us to focus on the diversity of the populations involved, so that was definitely a driving factor. But thank you for that feedback.

EDWARD EHLINGER: Janelle.

JANELLE PALACIOS: Thank you. My question was similar to Steve's question, just that making sure that the -- this seems very similar to the California Maternity Quality Care Collaborative, CMQCC's work that they've done for a number of years and knowing that they have included a number of different levels of hospitals. So, I'm assuming that the hospitals that were invited to be selected were like level

0, level 3, between the level 0 and a level three hospital for this kind of care or were they limited largely to level 1s to level 3s?

MARGARET SNYDER: So, I can't speak specifically to California, although I'm happy to take that question back to the team. But I know they've -- they would have considered it pretty important to align with what the states are doing so that we can coordinate with them, you know, in in coordination, rather than against, yeah.

JANELLE PALACIOS: I guess my question then would be that there's diversity in the size of the hospital. Do you know if there's diversity in the size of the hospital, I guess?

MARGARET SNYDER: There is. To what extent, I can't speak to that. But again, I'm happy to -- to follow up with you.

JANELLE PALACIOS: Just because, you know, we have very rural states like Montana and there are five hospitals selected from that very rural state and, you know, like the Dakotas, I think there were two and three hospitals from one

of the Dakotas or so. So, knowing that those are pretty rural states, and they don't have very many level 3 center hospitals that have NICUs. So, just the level of care people are seeking and knowing that Native women -- Native American women tend not to deliver at level 3 three hospitals, they tend to deliver at lower-level hospitals. So, I would expect that the diversity of population, if that's driving some of this work, then some of those smaller hospitals would probably be included as well. So, I'm excited to see what happens and what is the long-term, if you can in a sentence or two, what is the long-term plan for after -- after this this initiative -- this collaborative? What are the plans to try to roll out and implement this nationwide?

MARGARET SNYDER: Sure. So, this is already a national level initiative. Do you mean beyond the hospitals that are in the collaborative now?

JANELLE PALACIOS: Yes.

MARGARET SNYDER: Sure. So, right now

we're really focused on analyze -- collecting and analyzing the data that -- that we're getting now and working on bringing the hospitals on board. That will be part of the planning process, you know, looking at how this -- this part goes and then plan for the next part. I'm sorry I can't speak to, you know, the much longer-term plan. But we're focused on the data analysis and the collaborative currently.

JANELLE PALACIOS: Thank you.

EDWARD EHLINGER: Thank you. Belinda.

BELINDA PETTIFORD: And actually, my question was very similar to Janelle's. I'm trying to figure out the distribution of the hospitals. Are you looking at more urban and the different sizes? So, my other question then is, is there a list somewhere of all of the hospitals on your website or somewhere where people can see them, if they're not --

MARGARET SNYDER: Yeah.

BELINDA PETTIFORD: -- aware of what is happening in their home state?

MARGARET SNYDER: Absolutely. There is a press release that went out recently. Let's see if I can dig that up. But yeah, absolutely. I -- I'm not sure if it's on our website right now. But yeah, that information is absolutely available, and we can share that.

EDWARD EHLINGER: If you have a link, you can put it in the chat.

BELINDA PETTIFORD: Thanks.

MARGARET SNYDER: Sure, yeah. I don't have it right now, but I will find that for you all.

EDWARD EHLINGER: Magda.

MAGDA PECK: Thanks so much, an exciting initiative. I think that this must have come from when you did all your listening sessions, when you went around the country. I think it's been a couple of years of building towards this. So, thank you for putting national data out there. I'm going to push again on the question of as you design this and move it forward, knowing that it is voluntary, knowing that you're getting the

hospitals to opt in, what is the likelihood of linkages with other data that are national but speak globally of before and after a hospital experience, particularly the federally qualified health centers and other national databases within the purview of HHS. How does this data set that's emerging from two-hundred and twenty-some hospitals align with and link with other MCH-related data one, and other sectors if a hospital is looking at a concern about environmental exposures or concern with eviction in housing, or a concern with mental health? I'm just trying to figure out linkages as you launch this. Are there receptor sites to connect it so that it tells a bigger picture, particularly as you collect data on social determinants of health and health equity, your number 18 and 19? Great to see, but what does that mean, and how does that link outside the hospital?

MARGARET SNYDER: Absolutely. So, we've recently finished bringing the hospitals on board for the collaborative and we're working to kind of

get them more on board and understand what they're looking for from the collaborative and that aspect of the project. I agree that would be a great benefit to be able to link and we are in conversation with other folks at HHS and other agencies, making sure that we're working in lockstep. But yeah, we -- those are conversations that are happening now. So, we look forward to sharing more about that later on. But thank you for the feedback, that is absolutely important.

EDWARD EHLINGER: Belinda did you have another question?

BELINDA PETTIFORD: I did. I wanted to ask a question around of the role of MoMMA's VOICES with the program. So, are they doing some qualitative support for the effort to actually listen to the voices of mothers or in the process? I can see that it's a collaboration. But much of our questions have been focused on the hospital, but what is MoMMA's Voices role in it?

MARGARET SNYDER: Sure. So, they've been involved since the very early stages of this

project and we've -- we've touched base with them a number of times to update them on how the project is going and get their feedback on what's been what's been done so far and just asking, you know, how can we make this project more -- more patient centered and they've been great partners in this regard, you know, meeting with us, you know, making their time available to us to -- to ask for that feedback. They've given us a lot of great insights.

BELINDA PETTIFORD: so then, are all of -- so, is there like a requirement of those hospitals to have like a consumer engagement or, you know, listen to individuals with lived experience as part of their work in this collaborative? I'm just trying to see what the total connection is.

MARGARET SNYDER: Sure. So, we're still in part developing a lot of that aspect. But changing the culture of a hospital, you know, as the hospital opts in is an important part of this project as well. I'm not sure not sure I can

speak to what each hospital will do because, again, it is -- a lot of it is very hospital driven, but we have brought MoMMA's Voices in and, you know, the key -- key points in this process, if that helps.

EDWARD EHLINGER: I want to bring Kristen back in here. We've got about five more minutes that will allow us to broaden our conversation between the Office of Women's Health and CMS and I'm curious with the -- the White House Action on -- Maternal Health Day of Action, I was just curious on -- on how the recommendations from SACIM were included or not included in that -- in that effort, you know, and how the input that we've had on many of these issues was embedded into those conversations and putting that day together.

MARGARET SNYDER: Sure. Are you speaking to specific recommendations for this project or general recommendations?

EDWARD EHLINGER: Generally. Generally, with, you know, CMS and the Office of Women's

Health.

MARGARET SNYDER: Sure. So, you know, we work closely with CMS, and we've had folks, myself included, you know, attending the SACIM meetings. So, you know, we're aware of the recommendations and, you know, have been taking them into account as we develop the program.

EDWARD EHLINGER: Good. Magda, you had a question?

MAGDA PECK: Yeah. Just for both of our speakers, so, fast forward five years and your -- your investment in this new hospital-driven system -- voluntary system or your data expansion and investments in Medicaid and CMS are there. What do we -- what should we hope will be wild success? What does it look like? Not just the process of what you're doing, but could you just tell us what you really hope will change if what you're doing -- what you've reported to us is successful? And I -- I just want to be caught up in your enthusiasm about what is possible to change because of the extraordinary efforts you're doing, and we can

start with you, Maggie, and then we can go back to Kristen. So, you got it, it worked. Now what? What is now possible?

MARGARET SNYDER: This is good. I love -- I love talking about long-term impact. So, again with the two-pronged approach, the great success for the National Maternal Infant Analysis would be to identify the drivers of maternal mortality and morbidity. In that ideal scenario, we understand why women are dying and we know what we need to do to reduce maternal morbidity and mortality. And then in terms of implementing solutions for the second prong, we have done that, and it has resulted in, you know, America becoming the safest place to have a baby, to reduce the maternal morbidity and mortality rates, so that we are no longer the worst industrialized nation for maternal morbidity and mortality rates, but that we have improved those rates and women are safer and healthier as they give birth.

MAGDA PECK: Okay. So, once -- if we're data to action, that's helpful. Thank you.

Kristen, do you want to respond? What does success look like for your reporting today?

KRISTEN ZYCHERMAN: Success for us would be -- would be similar. It would be starting to move that needle on maternal morbidity and mortality and to see if as we work with states and as they develop their PDSA cycles and their small tests of change and figure out what works, if we're able to assist them and hopefully, within the next five years, be able to scale and spread that and identify those best practices and help disseminate that information to other states to not only reduce the rates of maternal morbidity and mortality overall, but definitely chip away at those disparities as well because even if we lower it for women, that would be, you know, all postpartum birthing people, that would be great. But if we still have those wide disparities, then we're still doing something wrong. So, it would also be kind of looking at it through that equity lens and trying to reduce disparities, along with moving the needle on hopefully getting more people

into their postpartum care visits, connecting them with well-woman care, connecting them with the specialist that they need, and making those infrastructure arrangements and working with states to develop this quality improvement infrastructure, so even when we're not doing monthly one-on-one TA with them, they're able to run those cycles themselves and make those changes and figure out how to improve those outcomes on their own. So, that would be what success looks like for us.

EDWARD EHLINGER: Great, great. Well, thank you to both. We need me to move on. So, Kristen and Maggie, thank you very much for your presentations and for your responses to the questions and I'm sure that if we have some other questions, we will get back to you as -- as we move forward. So, thank you again for -- for your time with us this morning or this afternoon.

KRISTEN ZYCHERMAN: Great. Thank you.

COVID-19 FOLLOWUP

EDWARD EHLINGER: All right. We're going

to take about fifteen minutes because obviously COVID has influenced a lot of our work certainly a year ago, when we spent a lot of time developing some recommendations related to COVID and its impact on birthing individuals and infants, and certainly here in Minnesota where we're one of the top states now in terms of rates of infection and we're reaching 800,000 deaths, I mean, it's still influencing a lot of our work and a lot of the work in the healthcare field. So, I'd like to take something -- just a little bit of time to see what have we learned over the last couple of years, related to COVID and are there things that we should be recommending in addition to what we recommended in June of 2020 that we really need to raise -- push forward, and I ask this in light of the fact that in October, the COVID Health Equity Task Force issued their report and I read that report, and I was impressed by the fact that I don't even think they mentioned pregnant individuals and infants. You know, they talked a lot about equity but, you know, pregnancy was not

and infant was not a big focus. They focused on things that we talked about in terms of workforce and facilities and vaccination and research and telehealth, but yet never really included, you know, pregnant individuals and infants in that, and it -- it just really struck me, why not? And I would really ask Dr. Warren, you know, we made some strong recommendations related to all of those things, you know. Did they -- did they get advanced up to the task force in any way, shape, or form?

MICHAEL WARREN: So, the recommendations were submitted to the Secretary. I can't speak, I mean, I could -- we could ask. I don't know whether those were sent to a White House Task Force or not.

EDWARD EHLINGER: Yeah, because it seemed like they were very specific, and I was -- they're really amiss and I -- I -- and an opportunity that really we should have somehow been able to take advantage of.

But given that, even though that didn't

happen, are there things that we should recommend now? Are there things that we should move forward from any of the committee members? What have we learned, you know, what -- what -- are the gaps that still need to be addressed that we can play a role in?

JANELLA PALACIOS: You know, this is one big issue that I saw where I work in the Bay area that, you know, given that COVID is -- it was a new infectious disease process that was happening globally and on a short timeline -- on a rapid timeline, I saw my team really flounder and fail and it's because they had nothing like this ever in their experience. Nothing prepared them for what they had to encounter with a rapidly deteriorating birthing person and, you know, another rider alongside, you know, like two people together. So, the birthing person and the fetus or the neonate, the infant. It was very, very challenging to see my team fail. They felt like they failed when we did the best that we could. We did not have the best counseling. We did not

always have the best available studies to help guide the process, and we learned also that it's not just an OB-related issue. It's -- in a hospital setting, it is a multidisciplinary issue when you have someone who's infected with COVID who is rapidly deteriorating and trying to make a decision of what's going to happen, what kind of care, are you going to do a c-section on someone who is like 28 weeks to save one life, possibly not being able to save another? So, it was really challenging for the providers, not having, you know, definitely not having the guidance, because a precedence like this had not been set and so they're learning -- everyone's learning as we go along, but also recognizing that people had to work together outside of their own little hallways and that was something that we saw. So then, the ICU team, the hospitalists had to work really hand in hand with OB-GYN, and then this affected like our prenatal care and our postpartum care. So, it was -- I just had some such a situation unique to this population when we're looking at birthing

people or pregnant people that it really is not just looking at one segment of their care. It's -- it's looking at their whole care holistically, and so, any kind of recommendation where for the future that we recommend that any kind of facilitation of multidisciplinary care or teamwork or, I think, Paul Weis brought this up the number of times, or maybe it was Paul Jarris -- I'm sorry -- but just that we have no -- we didn't have a national plan in effect with the beginning of COVID it's going to take looking at a special set of team to actually care for pregnant people or birthing people in general.

EDWARD EHLINGER: Thanks, Janelle. Belinda.

BELINDA PETTIFORD: I think one of the other areas we learned [indiscernible 1:23:08] is around how we define the care team. I think we quickly eliminated doulas from this process. We were telling moms that you can have one support person, so they have -- many of them had a doula for their support person, but then they had to

decide between whether their -- their spouse, their good friend, their mother could go in or their doula because the doula wasn't considered part of the care team. So, I think that is another recommendation is that we need to make sure that how we're defining the care team that that shouldn't just be the clinicians that work in the hospital. It's got to be who is supporting that individual during the prenatal and the delivery period, and I think that was -- that was a big miss for us in conversations that we're still having with hospitals and health care facilities. So, I do think that was a miss, but I think that's a lesson learned as well.

EDWARD EHLINGER: All right, good. Steve.

STEVEN CALVIN: Yeah, I just wanted to second what Belinda said. I mean I -- Janelle's experience, I -- I'm not currently -- I'm past that point in my career of being in the hospital. So, I totally understand, having heard what has been going on with the more acute care, but I

would agree with Belinda that it's almost like the end of life and the beginning of life during the pandemic, there were people who were unable to say goodbye to their -- to their dying relatives and there are also people who, you know, mothers who were unable to have the support that they needed from doulas and family members. I think we just have to be more careful about it because I have debriefed with a lot of mothers that I see with low-risk pregnancies who said my experience in 2020 was horrific. I wouldn't have another baby unless I knew that I wouldn't be limited like that. I mean it really became extremely restrictive and I understand initially those restrictions, but we just have to be careful about those kinds of restrictions.

EDWARD EHLINGER: Thanks.

JANELLE PALACIOS: And along that line, Steve, you know, if certain populations were targeted, right, like I submitted the article, I think, in last September as a snapshot of my presentation. But, you know, when we -- when we

know that certain populations are -- have higher risk of having this disease that special certain populations were then targeted. So, like in New Mexico, women were separated from their infants at a hospital who knows if policies like that also were enacted in other places. It's pretty understandable that possibly in the very beginning, when we knew very little, that those kinds of separations were happening, as Belinda pointed out, separating the dyad from breastfeeding. That also was happening, and to this day still happens in some places. So, the understanding and trying to find, you know, not criminalizing a population for their high rates because they're at more risk, right, and then also when -- and then hospital policies that aim to keep the dyad together versus separate. Thanks. Sorry, thank you.

EDWARD EHLINGER: Magda.

MAGDA PECK: One your question reminds me of the power of an after-action review. The ability to say there are systematic ways to look

back, not just within the family, not just within the MCH world, but to find out where are the after-action reviews happening relative to the COVID response but it's certainly not over. It's really reinventing itself and morphing in new ways. So, I will be curious from a -- from a quality improvement, from a hospital and other data perspective, where is this question being asked systematically in a way that women, children, families, father's, birthing people are not an afterthought? I think that's what we're seeing systematically is that we were constantly in catch-up mode. We had recommendations, but it was like, oh yeah, pregnant women. Still now, oh yeah, and not being able to get ahead and always being catch-up, whether that was in hospitalization, whether that's in vaccination. And I think that we have a duty to ask where is the after-action review happening and how do we put a standard set of questions and infuse that -- that look back to look forward, which specifically can be the three key questions that every agency

should be asking, every hospital should be asking, every healthcare member should be asking. Say what more could more could we have done and what will we do differently. So, I think we have an opportunity to frame this, not only in this conversation, but as a tool to offer cross sector going forward, because if we don't ask that question, who else will?

EDWARD EHLINGER: Paul.

PAUL JARRIS: I guess my question would be who, if anyone, has the responsibility and the authority to do such an after action with regard to maternal child health and, Michael, maybe you know, but I think given our very federated system, it's not clear who that would be. I don't think anyone has the ultimate responsibility, but who would have the authority to step up if they want to take the initiative?

EDWARD EHLINGER: And I want to add to that before Dr. Warren responds is that is there something that we could still do to move forward those recommendations, getting the ones that we've

already made, and additional things that we have, to the Health Equity Task Force -- COVID Health Equity Task Force so that actually all of our work can actually be put into action? So, two questions and is there still something we can do proactively and then who will do that after action response and then we'll -- then we'll move on to their next topic.

MICHAEL WARREN: I'll start with the second part of that. I think certainly if the committee would like those forwarded -- your recommendations were to the Secretary. If the committee wanted to request that the department consider moving those forward, we could certainly pass that along to the Office of the Secretary.

I think in regard to your first question around the after-action review, it depends on the scope, right, in terms of who would do it and who would be best poised to do it. So, I think figuring out what's the what -- what is the exact question? Are there particular aspects that you're interested in thinking about? That may

help hone down who would be best to do that and whether that's -- does that make sense for a government entity, who would have the authority or is that a nongovernment entity? But I think getting a better handle around the scope of it would be a first -- a first step.

EDWARD EHLINGER: All right. Well, and -- go ahead, Magda.

MAGDA PECK: Are you aware of -- the locus of accountability and Maternal and Child Health Bureau has often been called, I think this is a bit of [indiscernible], the locus of accountability for the health of all women, children, and families in the nation. So, if there's appetite, this could be something that SACIM can be helpful about, given that this is not the last pandemic or emergency and -- and I'm just -- I think this is an opportunity not for blame and shame and pointing fingers, but again lessons learned, not to have history repeat. And so, I'm curious if MCHB sees itself as that locus of accountability, because that's what we're talking

about, accountability. It's not -- in addition to authority, Paul, for the well-being of pregnant people and infants at the start.

MICHAEL WARREN: I mean, certainly our mission is broad. I think when you think about the various facets of the emergency response across the pandemic, that is far bigger than MCHB and frankly, it's far bigger than the federal government. And so, again, I think, thinking through what the specific questions are and whether that's us, whether that's a sister federal agency, whether that someone else, I'd be happy to continue to think through that but also want to know better what the what is before we --

MAGDA PECK: Yeah.

MICHAEL WARREN: -- say yes or no.

EDWARD EHLINGER: Yeah. So, Dr. Warren, let me follow up with you after this meeting on both of those issues on an after-action thing, but also how do we move our previous recommendations -- move them again to make them as engaged with the process as possible. So, I'd like to be able to

move on both of those. And speaking of moving, let's move on to our next topic, which I think is also going to be very interesting. Birth Defects and Congenital Anomalies, as you know, are a leading cause of infant death. So, we are going to take this next session and really focus on that, and I've asked Tara Sander Lee, one of our members, to coordinate and moderate this session. So, Tara, I'm going to turn it over to you.

BIRTH DEFECTS AND CONGENITAL ANOMALIES

TARA SANDER LEE: Thanks so much, Ed. Yes, I'm very excited for this session. Thank you for the opportunity so that we can discuss this.

So, I just wanted to give you some really quick brief remarks just so that we can stay on track with timing. According to the CDC, which you'll hear from our first speaker, birth defects are the leading cause of infant deaths, and they affect approximately 1 in every 33 live births or about 3 percent in the United States each year, and accounting for 20 percent of all infant deaths. So, it's so important that we have this

discussion today, that we are presented with the most up-to-date data and information, and we look forward to making recommendations.

Our second speaker is going to discuss how we can -- how we can actually treat some of these birth defects once they are diagnosed inside the womb but before these babies are born. And this is this incredibly new and exciting field and scientific evidence proves the effectiveness in providing some of these interventions for these women and their children in reducing infant deaths. And almost monthly, we hear the news about another baby diagnosed inside the womb with disorders such as spina bifida that receive lifesaving fetal surgery or babies with twin-to-twin transfusion syndrome that both survived after given the chance of life with advanced medical techniques.

So, as part of our Quality and Access to Care Work Group, we have been discussing ways in which women can have better access to prenatal fetal therapies and interventional care to

decrease infant mortality. Also, better diagnostics to have better fetal monitoring -- perinatal fetal monitoring.

And so, we also know all women who face for prenatal diagnosis are aware, or even have access to the type of medical treatment that is needed and care that is needed to prevent some of these deaths. And not all women are given the option or do not feel that they have the resources needed to accept the option of fetal therapy when offered. So, for example, there's -- there are barriers such as access to care itself, also access to childcare for their other children, financial constraints, relocation, loss of work time. So, and this is an exciting relatively new field when we talk about fetal therapy. So, additional research is also needed to determine medical necessity and identify maternal fetal risks associated with fetal therapy procedures, as well as improved reporting of outcomes.

So, it's a big field, and I think it's important to start this discussion today. I thank

you and so, I'm going to introduce our first speaker, which is Dr Naomi Tepper, Captain of the US Public Health Service, Senior Medical Officer, Birth Defects Monitoring and Research Branch for the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. So, thank you, Dr. Tepper, and we look forward to your talk.

NAOMI TEPPER: Great. Thank you, Dr. Lee. Can you hear me okay?

TARA SANDER LEE: Yes, we can hear you just fine.

NAOMI TEPPER: Okay, terrific. Thank you so much. Good afternoon and good morning to some of you. As Dr. Lee, mentioned I'm an obstetrician gynecologist at CDC. I'm in the National Center on Birth Defects and Developmental Disabilities and I'm really honored today to represent our Center at this meeting. I'm representing on behalf of our centers committee members, Dr. Karen Remley and Dr. Cheryl Broussard, who you all probably know and who are unable to attend today.

And we were asked to share with you some thoughts on the impact of birth defects on infant mortality and some potential opportunities for improving outcomes. Next slide, please.

So, I wanted to give a little context for the contribution of birth defects to infant deaths and, as you just heard, birth defects are the cause of approximately 1 in 5 infant deaths. Next slide, please.

This table shows data from CDC's National Center for Health Statistics on the leading causes of infant deaths in the US in 2019. As you can see in the first row, congenital malformations, deformations, and chromosomal abnormalities which is basically the ICD-10 coding terminology, these were the leading causes of infant mortality, there were approximately 4,300 infant deaths in which congenital malformation were listed as the cause of death. This represented 20.6 percent of infant deaths and a mortality rate of 114.8 per 100,000 live births. Next slide, please.

The causes of infant death are not

uniform throughout the first year of life. However, congenital anomalies are the second leading cause of death in the neonatal period, which is less than 28 days of life and are the leading cause of death in the post-neonatal period, 28 days of life through 11 months. Next slide, please.

This graph shows mortality rate by race and ethnicity in 2018 and, as you can see, there are differences mortality rate by race/ethnicity, with the highest rates in non-Hispanic Black, American Indian or Alaska Native, and Hispanic infants all higher than the rate in white infants. Next slide, please.

This figure shows trends from 2003 to 2017 overall and by race/ethnicity. From 2003 to 2017, rates of infant mortality attributable to birth defects actually declined, which is what you can see in the solid blue line. However, even with the overall decline, racial and ethnic disparities remain, and this figure shows that deaths among Black and Hispanic infants, which are

the top two lines, are higher than white infants, which is the bottom line. Next slide, please.

This analysis was published by members of my branch at CDC, and they offered some thoughts on the reasons for the overall decline, as well as the disparities. The declines could be due to improvements in prenatal care, implementation of birth defect prevention measures, and improvements in medical care of infants with -- born with birth defects. The disparities, however, may be influenced by differences in access to and utilization of healthcare both before and during pregnancy, differences in frequency of prenatal screening, differential losses, and terminations of pregnancies with fetal anomalies, and different insurance types. Next slide, please.

My colleagues also looked at insurance coverage and found that infant mortality among infants with birth defects differs by payment source for delivery. So, this graph shows the mortality rate among deliveries covered by private insurance, which are, in the light purple bars and

Medicaid, which are the darker purple bars. As you can see, mortality rate is higher among deliveries covered by Medicaid than private insurance, and this is found overall and when stratified by gestational age at birth, maternal race and ethnicity, and maternal age. The author's theories were that this may be due to some of the differences that I mentioned on the previous slide -- differences in health status, access to and utilization of healthcare, differences in prenatal screening, and differences in terminations for fetal anomalies. Next slide, please.

From that same report, the most common birth defects associated with infant mortality were central nervous system defects, congenital heart defects, and chromosomal abnormalities. These three categories of birth defects contribute to 57 percent of neonatal and 76 percent of post neonatal mortality among infants with birth defects. Next slide, please.

So, in thinking about where there may be

opportunities to improve outcomes related to birth defects, I thought about it in terms of four realms of activities, including surveillance research, prevention, and treatment. I will share some thoughts and some of CDC's work in these realms, although particularly the area of treatment is addressed more comprehensively by other agencies and organizations. Next slide, please.

So, we have to conduct surveillance to understand the scope of the issue. Next slide.

Surveillance for birth defects is going on in many states, several of which are funded by CDC, and these surveillance efforts can provide information that is critical to inform the understanding of trends in birth defects, the conduct of research on risk factors, planning and evaluation of prevention activities, ensuring that affected babies and families are referred to appropriate services, and assisting states in allocating their resources and services. Next slide, please.

However, our surveillance is only as good as the data we collect. This graphic shows what CDC is working toward in terms of managing public health data. We know that current data systems can be slow, outdated, resource intensive and not very user friendly. We are working to modernize our data systems to make data more timely, accurate, and accessible. In an ideal world, we would have national birth defects surveillance system where data was available in real time and could be linked between systems and states and could be analyzed quickly to inform next steps. Even if we can't reach that ideal world, investing in improvements in data systems could have a huge impact on our ability to gather and use public health data. Next slide.

Turning to research as an opportunity. Next slide, please.

Research is clearly important to further understanding the causes of birth defects. Within our center, we coordinate several multistate studies to examine the causes and risk factors of

birth defects. There have been many important findings from these studies, which have been used to inform clinical practice, confirm previously observed associations, generate hypotheses for future study, identify areas for prevention, and provide information to the public. Next slide, please.

These are the birth defects included in our currently ongoing study called BD-STEPS, and BD-STEPS is really aiming to study risk factors that may be modifiable such as medical conditions, medical -- medications, and other exposures. So, we hope that the findings can be used to move the needle on reducing preventable birth defects. Next slide, please.

Ideally, we would prevent birth defects before they occur, but unfortunately there is still a lot that is not known about preventable causes of birth defects. Next slide, please.

There are some challenges in preventing birth defects, most developed during the first trimester, often before pregnancy is recognized.

The cause of the majority of birth defects is still unknown and the study of modifiable risk factors is difficult due to challenges in case ascertainment, case classification, exposure assessment, particularly potentially multiple exposures, and statistical power to detect associations. Next slide, please.

However, there are certain modifiable risk factors that we do understand and for which we can make an impact on the incidence of birth defects. For example, promoting optimal folic acid to prevent spinal bifida and controlling diabetes to prevent several birth defects, including congenital heart defects. Next slide, please.

And finally, I wanted to mention treatment which may impact survival and also may impact the quality of life for individuals living with birth defects. Next slide, please.

First, we have to identify affected infants. Newborn screening identifies infants at risk for congenital disorders, for which early

intervention has been shown to improve outcomes. The number of disorders in the recommended uniform screening panel is now 35. Hearing loss and critical congenital heart defects are detected through point-of-care screening and 33 other disorders are detected through dried blood spots. Newborn screening is estimated to identify almost 13,000 infants with one of these disorders each year. Next slide, please.

As an example, early detection of congenital heart defects leads to improved survival. Some of my colleagues who focus on congenital heart defects found that survival of infants with critical congenital heart defects has been improving. Newborn screening for congenital -- critical congenital heart defects through pulse oximetry was added to the Recommended Uniform Screening Panel in 2011. This screening decreases early infant death by 33 percent, preventing 120 early infant deaths per year. Although all states are screening for congenital -- critical congenital heart defects, not all states are

systematically collecting and analyzing their data on the timing and mode of detection. Systematic data collection could help identify program improvement opportunities and monitor the impact of early identification of critical congenital heart defects. Next slide, please.

Another example of looking at treatment to improve outcomes is the UMPIRE protocol. UMPIRE stands for urologic management to preserve initial renal function protocol for young children with spinal bifida. My CDC colleagues and experts in the field developed this protocol in which infants up to 3 months old with myelomeningocele are identified, monitored, and treated using this protocol. The goal is to use this standardized protocol to identify early problems with bladder and kidney function and intervene to help preserve function. Continued assessment of this protocol is leading to improvements in the protocol and improvements in outcomes for infants. Next slide, please.

I won't spend a lot of time on this,

because our next speaker will be discussing this further. But fetal surgery, as mentioned, involves surgical intervention for conditions with poor prognosis, such as those listed here on the slide. This field has been expanding rapidly and can lead to improvement in fetal outcomes. However, these surgeries are very complex and require specialized centers with multidisciplinary teams. They can also result in adverse outcomes for the pregnancy and the mother. Ongoing research is looking at whether and how these surgeries improve outcomes. Next slide, please.

So, this is kind of a summary slide of the preceding slides and with some general thoughts on the opportunities to improve outcomes. In the realm of surveillance, we can continue work on modernizing our data collection and management to make data more timely accurate and accessible.

In the realm of research, we need to further understanding of causes and risk factors of birth defects, particularly those that are modifiable so that we can inform prevention,

treatment, and future research.

In the realm of prevention, we can use what we know about preventable birth defects and work to ensure that all people of reproductive age have access to quality preconception and prenatal care.

And in the realm of treatment, we can continue research on and access to surgical intervention and quality care initiatives. Next slide, please.

I just wanted to finish by sharing CDC's agency-wide strategy to integrate health equity into all of our work. And a particular relevance to this discussion we've seen there are health disparities in infant mortality related to birth defects. CDC is committed to working to better understand and address these health disparities as a key part of impacting health outcomes. Next slide.

I think this is my last slide. I really appreciate the opportunity to talk with you today. I'd like to thank my CDC colleagues and our many

collaborators who are doing the work that I shared. I thank you very much and I'm happy to try to answer any questions. Thank you.

TARA SANDER LEE: Thank you so much, Dr. Tepper. That was fantastic. I think we do have a couple of minutes, so if people do have some questions, I think, if you don't mind, can you stop sharing your slides? We have a couple of minutes. So, do we have some questions for Dr. Tepper? Yes, Janelle.

JANELLE PALACIOS: Thank you so much for that presentation. I was struck with one of the very first slides you shared. It was the rates of infant mortality attributable to birth defects from 2018 and it showed African American and American Indian/Alaska Native infants had really high rates and then subsequent slides you shared; it was likely data for -- surveillance data from the CDC that the American Indian population just fell off. We have no historical rates of birth defects that are -- that were included in these larger studies from 2003 onward. And so, I'm just

wondering, can you comment on the missing data for this population and why not pull from Indian Health Service as a potential data source for, you know, just including historical data, and then the second part would be how do you propose that adequate surveillance in the time of health equity for this population will be met? Thank you so much.

NAOMI TEPPER: Yes. Thank you for those questions. Yeah, the differences in rates are really striking and certainly concerning. The data that I showed comes from the National Vital Statistics Data and I pulled from different reports, and so the one where I showed the trend lines that does not have the American Indian and Alaska Native population is just because in that report, they -- they did not report on that. However, that data is likely available. I couldn't tell you right off hand how far back that's available, but that -- that data is available by race/ethnicity for infant mortality and -- and causes of infant mortality. So, we do

certainly have that, and I think we need to, you know, dive more into that, you know, looking at the differences as well as the reasons why and a lot of the reasons are probably not captured in the data, unfortunately.

TARA SANDER LEE: Danielle.

DANIELLE ELY: Hi. I just wanted to follow up a little bit on that. I was on that MMWR paper that you presented and so, one of the reasons we did not include American Indian or Alaska Native is simply because, even though the rates are very high, in that report to break it down the way you would need to by groups, the numbers become so small that, unfortunately, they are unreliable. So, in a lot of the research that we put out, it's very difficult to include some of the race and Hispanic origin groups simply because we're not combining years together. I did want to point out that we do have the mortality rates for congenital malformations in the Annual Infant Mortality Report that we put out. I noticed that you have 2018 data in the presentation by race and

Hispanic origin. We did just release the 2019 last week. So, obviously, you wouldn't have had time to include that. I did include a link in that in the chat.

TARA SANDER LEE: Wonderful. Thank you so much. Ed.

EDWARD EHLINGER: I'm just wondering if you're having any specific activities related to sickle cell. I know it took us a long time in Minnesota to screen for sickle cell, and I don't know how many states are doing that. Any special efforts related to sickle cell anemia?

NAOMI TEPPER: Yeah. Well, that's a -- that's a great question that I would actually have to defer to other CDC colleagues. We have a division within our center, the Division of Blood Disorders, that actually focuses on, among others, sickle cell disease, and they have been, you know, very interested in certainly increasing, you know, the diagnoses and the care of these individuals, you know, both infants and through the lifespan. So, increasing recognition of challenges that

these individuals face throughout their lifespan. And so, I think if there are specific questions about sickle cell, I'm happy to take them back to that group. They are working hard and do a lot of great work. So, I'm happy to -- to -- to communicate anything back to them.

EDWARD EHLINGER: It's just a good example of some of the inequities in newborn screening that have been there, and I think that it's a good case study on the way we've disadvantaged populations over others.

TARA SANDER LEE: All right. Okay. I think there's no other questions. We're going to move on to our second speaker.

So, our second speaker is Dr. Julie Moldenhauer. She is the Director of Obstetrical Services and George Leib Harrison Endowed Chair in Fetal Therapy at the Center for Fetal Diagnosis and Treatment. She is also the Children's Hospital of Philadelphia Director of the Division of Obstetrics and Gynecology and professor of Clinical Obstetrics and Gynecology in Surgery at

the Perelman School of Medicine at the University of Pennsylvania. So, thank you, Dr. Moldenhauer, for joining us today and taking time out of your busy schedule to present.

JULIE MOLDENHAUER: Well, thank you so much for having me today and letting me present on something that's pretty near and dear to my heart, and I'm hoping that by the end of this, I'm going to convince you all that this is not science fiction, but that this is something that is a reasonable treatment option for patients in certain scenarios. Next slide, please.

You know, so, what exactly is fetal therapy is a common question that we get. And so, you know, in a nutshell it's pretty much any intervention that is performed on the maternal fetal dyad specifically for the benefit of the fetus. And so, in this context, the mom is accepting the risk and, you know, we sometimes think of the mom as the innocent bystander in this dyad. And we are a relatively new field. We've really only been around for about 60 years, and if

you kind of think about the disorders that we treat, you know, some people use the term orphan disorders, but we're really not truly orphans, but we are in the context of we don't really have like a governing board. There's not, you know, the American Board of Fetal Therapy type of thing. And so, it's really multidisciplinary. It's groups of people from surgery, maternal fetal medicine, obstetrics, anesthesia, all the pediatric subspecialties, cardiology who come together to make fetal therapy work and to make it safe for mom and baby. Next slide, please.

I would be remiss in talking about the fetal therapy if I don't talk about the diagnostic aspect of it. And again, this is sort of where we are such a neophyte in terms of when we started. The first publication that had anything to do with making a diagnosis in obstetrics and gynecology was in 1958, and these images are true to the word of what they saw. This was a fetal head basically and so imaging was -- was quite poor. Next slide, please.

And things moved fairly quickly as far as our ability to diagnose various disorders prenatally; so spinal bifida, anencephaly, you know, we could do that by, you know, the 70s. We were screening for open neural tube defects throughout the 70s and 80s and Down Syndrome into the 80s, and then, you know, cell-free DNA -- fetal DNA in 2000s. And I put these, you know, images below because looking back to the image that we saw of what basically looked like black and white schmutz, you know, we have come a long way. We can use 3D, 4D ultrasound, we can use MRI, we can use CT scanning to make diagnoses. And so, in this sequence of events that has come for our ability to make a good diagnosis in utero of various fetal findings, we then can apply our ability to treat those findings in utero and hopefully impact, you know, mortality and morbidity. Next slide, please.

So, you know, kind of looking on the flip side of things, the diagnostic aspect is on the top side of the timeline and where we are coming

as far as fetal intervention is underneath. And so, shortly after we saw the first publication for ultrasound in OB, the first intrauterine blood transfusion was performed in 1961 for Rh disease. We were doing diagnostic fetoscopy, so literally, you know, if you have a cholecystectomy and they do it through laparoscopy, in this instance, the scope is going inside the uterus to look inside the amniotic cavity and make a diagnosis in the fetus. And so, we could do that, and we could do it relatively safely as far back as the 70s and 80s. Things really exploded on the fetal therapy scene in the early 80s to 90s, where we developed animal models, we really expanded what we were doing from a fetal therapy standpoint, and things included not only open fetal surgeries but minimally invasive surgeries that were done under ultrasound guidance and then we kind of crossed over into twin therapies because before that, it had always sort of been taboo to do fetal therapy when there was more than one fetus present. And that takes us up to where we are in the 2000s

where, you know, probably what most people are familiar with is the management of myelomeningocele trial that started in 2002, but there was about a decade of work that happened before that trial even got kicked off and it took us almost a decade to finish it. And that was published in 2011 and since really the early 2000s, the number of fetal centers have grown exponentially and they're more situated throughout the country, but it also dilutes the experience that each fetal center has when you have so many. Next slide.

This is really just sort of a depiction showing the variety of things that we can take care of from, you know, in the upper left, that's a shunt in a fetal chest, as the babies being born for lung lesions, the placenta and the twins are for twin-twin transfusion syndrome. The middle row is open fetal surgery for a long lesion. The two next to that are sacrococcygeal teratoma, debulking in utero, and then what the baby would look like if they were born without the surgery in

the middle row on the right. The bottom row is open fetal surgery for myelomeningocele. The middle picture is EXIT procedure for a fetus that has airway compromise, and then on the bottom right is what the gravid uterus looks like when we are operating on them. So, it's quite a scene to be in the operating room. Next side.

Historically, the conditions that we've treated with fetal therapy have been those that are life-limiting or lethal, but particularly with the publication of the MOMS trial, the paradigm is really shifting to improving the quality of life as well. Next slide.

There are some tenent that we use to help guide us decide, you know, to decide who's a candidate, who's not a candidate, what are the prerequisites and, you know, hands down, we have to be able to make an accurate diagnosis prenatally, we need to know what the natural history is, and how can we impact that so that we are, you know, avoiding the potential for fetal death or organ destruction and can we do it, and

can we do it reliably and repetitively in the same safe manner. Next slide.

Conditions that we can treat, you know, range anywhere from a fetal cardiac arrhythmia that we treat with mom, you know, with transplacental pharmacotherapy where we just give mama medication. It goes through the placenta and treats the fetus all the way to the, you know, more invasive procedures like fetoscopy or ultrasound-guided procedures. And then, you know, the most invasive end of things where we are doing open fetal surgeries and EXIT procedures. Next slide.

This just gives us a synopsis sort of what -- what it is when we're looking at what the anatomic defect is and what it leads to from a physiological standpoint. So, when a fetus has a general urinary obstruction, they don't have amniotic fluid circulating, and it results in pulmonary hyperplasia and renal dysfunction. Twins who have vascular anastomoses on their placenta develop twin-twin transfusion syndrome in

10 to 15 percent of cases, and this can ultimately to fake fetal death. Diaphragmatic hernia, which I'll also talk about, results in pulmonary hypoplasia, that in many cases can be lethal. Lung lesions, such as cystic adenomatoid malformation, can also lead to high-output cardiac failure, hydrops, and fetal death. The same thing with sacrococcygeal teratoma. And myelomeningocele is sort the game changer where it's not just, you know, a life-or-death situation, but the goal the fetal therapy is that we can intervene and try to minimize some of the side effects, like the hydrocephaly, paraplegia, and incontinence issues. Next slide.

I kind of hit on this already, you know that we have a wide range of interventions that come from minimally invasive to the more significantly invasive. Next slide.

This really impacts, you know, what the risk factors are both for mom and baby. And so, you know, the list is long and it can not only impact the current pregnancy for mom but also

subsequent pregnancies because a lot of times, things that we do require that, you know, mom have a cesarean delivery with this pregnancy and in every future pregnancy, and it puts -- puts the future pregnancies at risk for having poor outcomes that could be related to uterine rupture. And then, there's always the possibility that, you know, we could have a fetal death or loss or that what we're trying to do may not be successful, or we could cause more injury then good. And so, we always have to weigh the risks and benefits both for mom and for baby. It's not, you know, in most fields, there aren't two patients in one, which is, you know, kind of what we are dealing with on an everyday basis trying to weigh the risks and, you know, balances both ways for mom and baby. Next slide.

Now I don't want to be Debbie Downer because despite the risk, there are benefits. You know, some of the key tenets that we have to live by is that, you know, the benefits are there when we are choosing appropriate candidates. And so,

you know, for the procedures that we do, there are fairly well-defined criteria for who would be a candidate versus who would not be a candidate. Experience does matter. So, it matters in the ability to make the diagnosis and to have a team who has the technical ability to perform the procedure safely and with, you know, outcomes that are reproducible and centers who do this also need to have representation from all the various disciplines that are involved. It truly takes a village in this case.

And then, the maternal informed consent is also a huge part of the process. So, not only does the patient need to understand what the risks and benefits are in the current pregnancy, but as well in the future pregnancies that she may want to carry and then also, you know, what are the limitations with the fetal therapy, because many of the things that we do are not necessarily a cure-all in utero, but there are to temporize so that we can, you know, get the baby to be live born and then there's still issues that we'll have

to deal with after the baby is here. Next slide.

So, I wanted to kind of talk about some of the more common things that we see to provide an understanding of the impact that we can have.

So, complicated monochorionic twins are one of the biggest diagnostic groups that we see. And so, you know, the majority of twins are dichorionic, meaning they each have their own placenta. But depending on when that fertilized egg separates into twins, determines geographically how things are arranged on the inside. And so, if it separates after the first four days, we have monochromatic presentation, so twins who share a placenta. And then whether or not they're diamniotic, they each have their own sac, or monoamniotic, depends again when they split, whether that's, you know, after eight days or not. Next slide.

And so, the problem is when they share a placenta, is that there's typically some unequal sharing. One generally has a larger share of the placenta than the other, but there's also by

definition vascular connections between the twins. So, whether there are artery-artery, artery-vein, vein-vein type of thing, this can ultimately result in imbalance in those anastomoses and unequal sharing of the placenta that can lead to the complications that we see. The inferior picture is actually that we took during a laser for twin-twin, and it shows the two ends of the vessels from each different twin coming together and creating an anastomosis. Next picture.

And so, twin-twin transfusion syndrome complicates about 10 to 15 percent of monochorionic twins and what the resultant physiology is that there's a donor who is pumping blood to the co-twin, who is the recipient, and it basically results in the donor twin working very hard and becoming the fetal equivalent of dehydrated. So, there's less amniotic fluid in that sac. They do tend to be the smaller twin. And then, the recipient has to manage all this extra volume that is coming on board and they do this by, you know, having higher levels of

amniotic fluid, because they're trying to get rid of all that excess volume. It stresses the heart to have to pump all of this blood volume through and so, they can have cardiac failure. And in this process, they can develop, you know, develop all-out cardiac failure and it puts both babies at risk for -- for passing way on the inside. Next slide.

And so, you know, what -- what is the impact of twin-twin transfusion? So, in the states, it's about 6,000 babies a year who are impacted. And for twin-twin that's diagnosed less than 28 weeks, the overall survival is only about 10 to 30 percent when twins are not managed aggressively. So, we do stage twin-twin, and for the sake of time I won't go into that, but for twins who have advanced stage twin-twin with this low survival rate somewhere around 10 to 30 percent, there's also a high risk for neurologic morbidity because of these vascular connections. Next slide.

And so, how we treat this is through

fetoscopic laser photo coagulation, where the scope is literally placed through a small incision on mom's abdomen. It's about 2- to 3-millimeters. The scope is quite long so that we can visualize what we need to see, but we're looking at the surface of the placenta and everywhere that we see that there's an anastomosis between the two, we fire the laser. And so, what firing the laser does basically, is it spot welds those blood vessel connections shut so that there's no longer communication between the twins and it functionally separates their placental shares. And we basically do this down the vascular equator between the two, and you can see how we're now flipping the statistics about survival. And so, the likelihood that we will have twins survive to a reasonable gestational age where they can become viable and have a reasonable outcome is about 70 percent and singleton is at least 80 percent. This is sort of the national statistical data. Some centers higher outcomes and some centers have lower outcomes, but this is sort of where we are

on an average. Next slide.

Another diagnosis where we can make an impact is a congenital diaphragmatic hernia. In the states, this is about 1,600 babies per year, or one in 3,000 births, and what this is a defect in the diaphragm that allows the contents from the abdomen basically to grow and develop in the chest. And so, it pushes the normal lung to the side and results in severe pulmonary hypoplasia. And, as a result, the lung that does develop is not exactly normal. So, there's pulmonary hypertension. These kids spend a very long time in the NICU after they're born. They're almost always on ventilator support and depending on the severity of the diaphragmatic hernia, they may actually require ECMO as well. And then part of this is, you know, if I'm really hypoxic early on and I spent a long time in the NICU, developmental delay and feeding issues also become a part of my outcome.

In the grand scheme of things, about 80 percent are left-sided and about 20 percent are

right-sided and if you look at the overall survival rate among all diaphragmatic hernias, it's improved. It used to be about 50 percent, but unfortunately we're only up to about 70 percent. Next slide.

And so, tracheal occlusion was developed because what we saw in different tracheal obstructive disorders, is that fetuses would have very large lungs. And so, this has been tried as a fetal therapy, to improve lung development in cases of diaphragmatic hernia. And so, the current method that we use is fetoscopic endoluminal tracheal occlusion or FETO and under ultrasound guidance, again, a fetoscope is advanced into the fetal mouth -- because once we get the scope inside, we can see where we're going -- and so, we directly visualize the fetal face. The scope goes into fetal mouth, through the vocal cords, down into the trachea, and a tiny balloon is placed. And the balloon, before it's blown up, it literally looks like a piece of long grain rice, it's really, really tiny, and we put this in

between about 27 and 29 weeks. The balloon is deployed and then it stays in the trachea until about 34 weeks, and the goal is it obstructs the trachea and all the fluid that is normally coming from the lungs gets trapped and then all that stretching results in fetal lung growth. Next slide.

And then the goal is that we keep the balloon in place until about 34 weeks, and then we go back in and basically do the opposite, and we take the balloon out and the pictures show looking directly at the vocal cords of a fetus -- that's what the top picture is -- and then the slide -- the picture below is the tip of the balloon placed inside the trachea and then on either side of that circle where the image is, those are the actual fetal vocal cords. So, it will go through the vocal cords to deploy the balloon. And then once the balloon comes out, the goal is that we keep mom pregnant to at least term, so 37 weeks and beyond, and hopefully impact the outcomes. Next slide.

So, Jon Deprest, who is our colleague in Europe who's been working on FETO for years, recently just finalized the total trial, looking specifically at the group of left-sided diaphragmatic hernias that are in the severe range where the survival is less than 25 percent and in this randomized trial, there was definitely an improvement in survival for the group that had FETO. So, 40 percent of these kids compared to 15 percent for the, you know, expected management group survived, and they survived not only to hospital discharge but for the first six months of life. We didn't see the same benefit with moderate severity left CDH. And so, we're not doing that. It's not been really adopted for that group yet, but we, in our series of fetal patients, have also seen a decrease need for ECMO, a shorter hospital stay, and some other improvements with the degree of pulmonary hyperplasia or hypertension that they have. So, it's probably going to pan out that there's going to, you know, be a tremendous impact not only on

mortality for these kids but also some of the morbidity they experience in the first year of life. Next slide.

And then, myelomeningocele, which is a form of spinal bifida, often considered to be the most severe form, impacts about 1,500 babies a year here in the states and this -- having the presence of MMC results in severe hydrocephalus that requires a shunt, hindbrain herniation, and then neuromuscular disorders that can include weakness, paralysis, and incontinence. Next slide.

And the rationale for doing fetal surgery is that if we can intervene and do the same basic closure of the MMC before a baby is born, that we can reverse some of the damage that we see that happens throughout the course of the gestation. And so, closing the defect, creating a watertight closure can prevent further damage to the nerves that innervate the bowel, the bladder, the lower extremities, as well as improve the hind brain herniation and decrease the need for fetal

shunting. Next slide.

And so, this is a pretty big surgery for mom. So, currently the adopted kind of gold standard for fetal myelomeningocele surgery is open maternal fetal surgery, though fetoscopic techniques are being developed. And so, the picture on the left is mom -- a depiction of mom, sort of where we make the laparotomy. It's about halfway between the pubic bone and the belly button. We use ultrasound to map the placenta and the fetal position and then in an area free of fetal parts, placenta, umbilical cord, stay suitors are placed to enter the uterus and then a uterine-stapling device creates the uterine incision, and it basically cuts and staples at the same time, so it's a bloodless incision on the uterus. Next slide.

I know this is a little bit graphic, but what happens then is that the repair is done very similarly to what happens when babies are, you know, 24 hours old, and so the neural tube defect is basically incised with care being taken to, you

know, not damage any of the nerves that are or there any of the spinal cord that is there. Next slide.

And then, the myofascial flaps, so the muscle on either side of the vertebra or spinal cord, are sort of freed up so that they can be brought over the top of the nerve tissue and then closed over the top of it in a watertight fashion to protect whatever nerve tissue is there, so that we can optimize the function in that. Next slide.

And then, this is what the baby's back looks like after it is closed. It just looks like, you know, a running layer of suture in the skin. Next slide.

And so, in the MOMS trial where patients were randomized to either have prenatal closure or routine postnatal closure, there's a whole lot of data on this slide but the next slide is the nuts and bolts.

So, the biggest things are that, you know, the risk of needing a ventriculoperitoneal shunt placed was basically cut in half. So, for

the group that had postnatal surgery, it was around 80 percent and the prenatal group, it was 40 percent. There was an improvement in motor function for the prenatal surgery group. A large majority of patients who had prenatal surgery had reversal of the hind brain herniation and you were twice as likely to be an independent ambulator in prenatal surgery compared to postnatal surgery. Next slide.

Now, there are a lot of risks that went along with this, you know, there's a large proportion of babies that were born preterm. There's a lot of preterm labor, membrane rupture, and membrane complications. And so, you know, again, it's risk-benefit and trying to sort out where -- where we are and what parents, what families can tolerate. Next slide.

One of the big questions that came out shortly after the MOMS trial is okay, these procedures were done at three centers and the trial, you know, is this data reproducible and applicable to the general population, and if this

becomes, you know, a procedure that's done across the country, and the North American Fetal Therapy Network sponsors the Fetal Myelomeningocele Consortium and created a registry and the PI on it, and we track outcomes for any center that's willing to participate and we presented at the Society for Maternal Fetal Medicine in 2019 our outcomes on the initial approximately 500 patients, and the bottom line is that this collaborative effort showed that in real world, you know, medicine and real world fetal therapy outside of a trial, that we could reproduce outcomes very similar to a randomized trial. Next slide.

But the big question is, are there disparities in fetal intervention, and I think using the fetal myelomeningocele closure statistics is probably the most straightforward and probably what we have the most data on. You can see here, looking at the -- MOMS trial breakdown of race and ethnicity, the middle row is our CHOP on our 300 cases we've done since the

MOMS trial, and then the Fetal Myelomeningocele Consortium Registry that has over 1,000 patients in it. Overwhelmingly, the patients are white non-Hispanic. The other groups are much less represented, as you can see, and the breakdown is different depending on how the data is collected. But the educational background tends to also follow with this as well. Next slide.

Now, the irony here is that if you look at the prevalence of spinal bifida, Hispanic women are much more likely to be diagnosed as carrying a fetus with spina bifida compared to non-Hispanic white women or non-Hispanic Black or African American. So, the prevalence is different in these populations, yet they're not equally represented or represented with the same proportion in women who are undergoing open maternal fetal surgery or any type of surgery for spinal bifida. Next slide.

You know, why is this? We don't know. There aren't a lot of great studies about this. I think anecdotally, probably some of this has to do

with access, whether women are getting, you know, prenatal care in a timely fashion, are they getting referred to a fetal center, do they live in a reasonable distance to travel to a fetal center, are they aware that this exists, you know? So, women who don't have Internet, who aren't readily, you know, accessing Internet, who may have language barriers may not be seeking out alternate treatments or, you know, looking for alternate therapies. And then, when you have any type of fetal procedure, we put the moms on bed rest. We sort of limit what they can do. Many times, they need to relocate into the area where they're having the fetal therapy so they can be close to the fetal center. So, that means, you know, there's a lot of financial constraints not only for the patient, but her caregivers, her partner, there's a lot of last work, and then, what do you do with your other children at home? Do you leave your children at home with a family member? Do you all relocate for the time being? And then there's also some cultural differences in

how they view these procedures, even though some of these procedures have been around for, you know, twenty and thirty years, you know, they're still perceived as, you know, research and there's a lot of medical hesitancy in some of the groups. Next slide.

There there's a lot coming in the future trending towards minimally invasive procedures to minimize maternal risk. You know, gene therapy and stem cell transplant are very minimally invasive and may have a humongous impact on what we're seeing and then the artificial placenta to support not only fetuses and newborns who may have complications with fetal surgery, but also prematurity. You know, I think some of those things are a little bit off in the future, but really where, you know, we're going to get a bang for our buck and where we need to do a lot of work is with outcomes monitoring and transparency in reporting. You know, there's not a formal program. Fetal therapy centers do not have to report their outcomes. It's really -- it's a

collaborative effort, it's a little bit of an honor system, you know, and that's kind of where we are with it. Next slide.

You know, in the setting of all that's developed, some of the key points along this journey were in 1982 when a group -- basically a consensus group -- got together and they wrote a letter about the tenets of fetal therapy and it was published in the *New England Journal of Medicine*, led by Dr. Mike Harrison. And this really sort of spelled out what we should be doing from like a care standpoint, an ethical standpoint, the support that should be there for patients. And, you know, from 1982 really until 2017, when we reinvigorated that statement and reinvested in it, things have kind of stayed stagnant. But along the journey, in 2004 is when we really had a lot of traction. So, up until that point in time, centers were sort of doing their own thing, and it was haphazard, and it wasn't really collaborative. And so, in January at the Society for Maternal Fetal Medicine, there

was a Fetal Therapy Working Group that came together and that group, at the same time, met with NICHD in August and really what kind of happened at the end of that was that there needed to be a group that could follow and track these outcomes and that's how the North American Fetal Therapy Network was formed. Next slide.

And so, NAFTNET was established in 2005 and initially only included 12 centers. Membership is now 40 centers pretty much throughout North America. Members -- so member centers pay annual dues, and we do have a little bit of funding from the NICHD but the mission of NAFTNET is to provide a clinical research network that's collaborative in nature and develop therapeutic options to improve outcomes. It also is an educational and training resource so that we can continue to have folks who are in this field. But, you know, the scaffolding is there, the background is there for us to do a better job of tracking outcomes and monitoring who has access, we just haven't matured to the point where it's

facile yet. Next slide.

So, I thank you. This is our favorite day of the whole year here at CHOP. This is when our fetal families come back for a reunion and, unfortunately, because of COVID, we haven't done it in a while. But it's truly amazing to see these families after they've, you know, sort of seen the worst day possible and what life can look like for them and the smiles on their faces when their kids are 2 and 5 and 10 years old. Thank you.

TARA SANDER LEE: Thank you so much, Dr. Moldenhauer. That was fantastic. All right. Janelle, I see that you have a question.

JANELLE PALACIOS: I apologize. I do not have a question. I'll lower my hand. Thank you.

TARA SANDER LEE: Oh, okay. Steve. Oh, you're on mute, Steve.

STEVEN CALVIN: Yeah. Julie, thank you for the great presentation. I have a question to. During the fetal procedures and the myelomeningocele open procedures, what kind of

anesthesia are used for mother and baby?

JULIE MOLDENHAUER: So, yeah. So, the fetoscopic, the more minimally invasive procedures, it depends. We, here at CHOP, we use like IV sedation with local on mom's skin and then sometimes, depending on the fetal movement, we need to give general. But the baby also gets an intramuscular shot that includes like vecuronium and a fentanyl type of mixture because if we don't paralyze the baby, the balloon will come right back out. And so, then with the open fetal cases, mom goes under general, and so the baby gets some of that through the placenta. But then, once the uterus is open, we also give the baby an IM shot in the same way.

STEVEN CALVIN: Okay, thank you.

JULIE MOLDENHAUER: Yep.

TARA SANDER LEE: Magda.

MAGDA PECK: Well, that was a brilliant presentation.

JULIE MOLDENHAUER: Thank you.

MAGDA PECK: And I feel honored to hear

how this field has progressed. So, thank you. I agree with Dr. Conry's marks about this is a superb and balanced discussion. So, I want to lead with gratitude.

This is relatively new air for me. I've not been a hospitalist or clinician for a number of years, although I'm an old Philly girl. So, thank you so much for representing very well.

Here's a question. I -- if I heard you right up front, because I do public health, right, and I'm in -- I'm in population-based side and the prevention side. I really appreciate how you spoke to the nuance of balance of risk that is a series of tradeoffs and I think your quote upfront was this is where a mom is an innocent bystander who agreed to take on risk and I'm really struck with that language about her being a willing innocent bystander. If I -- I did a little bit of research before talking. I looked at the review article around risk of fetal therapy that I think is now revised, published in 2017, looking at the complication rate for moms in minimally invasive

is about 5 percent.

JULIE MOLDENHAUER: Yep.

MAGDA PECK: And I was wondering, after all that you have convinced us -- that was your point -- convinced us about this, then you put on a hat that says what about the other side of the equation? We are the Secretary's Advisory Committee on Infant and Maternal Mortality. And so, can you speak to the maternal risks in a little bit more depth? What is the risk for severe maternal morbidity in this particular pregnancy, at what point of gestation, and then what about for subsequent reproductive life course either with or without fetal therapy. So, not taking away the brilliance of your presentation and asking if you can zoom out and talk about her and how is this innocent bystander dynamic established? Help me understand that.

JULIE MOLDENHAUER: Yeah. I mean, honestly, when I'm counseling a mom, I almost see my job is that I'm trying to talk her out of it, and if after I've told her every negative

possibility and she's still, you know, engaged and wants to do it, then that's truly informed consent. So, I think, you know, like for us when we do open fetal surgeries, it's a two-day process for patients to go through all the diagnostic workup and get counseling and then meet with like neonatology, anesthesia, you know. We don't even want to hear what her decision is until she's met with everybody under the sun and understands every single risk. And so, the risks are a little bit different depending on if it's like minimally invasive versus open maternal fetal surgery. So, you know, major complications with minimally invasive are rare, it's a couple percent. But overall, there's more, you know, we still -- we transfuse moms who have had minimally invasive surgery. You know, it's a rare thing to have happen, but it's there. The likelihood of having like a uterine rupture in the index pregnancy or subsequent pregnancy with a minimally invasive procedure is not zero, but it's pretty low. And as far as this is how it like impacts her

reproductive life plan. You know, for a mom who's, you know, this is her first pregnancy, and she thinks that she's, you know, going to plan to have five or six kids, having open maternal fetal surgery in pregnancy number one is probably not a good idea. You know, what that means for her is that we're making that incision in the thicker active portion of her uterus. So, the risk for uterine rupture and dehiscence is there not only in the, you know, index pregnancy, but for every future pregnancy.

Probably the best data that we have for uterine rupture in subsequent pregnancies came out of the myelomeningocele registry and it was 10 percent, and of those, we had two babies that were lost. One mom ended up having, you know, a laparotomy, massive blood transfusion, bowel resection. So, it's not insignificant. You know, I agree with you. Like, you know, these are not things that we can take lightly. You know, there are sometimes moms who have high risk factors, but, you know, they're not a candidate to have

open fetal surgery. So, you know, like moms who have a cardiac arrhythmia or, you know, hypertension that's poorly controlled, diabetes it's poorly controlled, they may not actually even be candidates for fetal surgery because the maternal risk is simply too high.

MAGDA PECK: And a quick follow-up. Who -- who pays -- who pays for this? I really appreciate you're talking about the disparities and the financial hardship, but does private insurance pay for this? Does Medicaid pay for this procedure?

JULIE MOLDENHAUER: Yes, both.

MAGDA PECK: Thank you.

JULIE MOLDENHAUER: Yeah. It's the support, you know, like at CHOP, I showed our data, and we have a very, you know, well-developed network here that's basically from our former patients who've given back in, you know, philanthropic roles and we have a pretty robust fund for patient travel and housing, so that they're not limited by resources to get to us and

have, you know, therapies done if they need it. And, you know, you saw our data. Our data are still very much skewed to educated white people. So, and that's having a very robust, you know, support system for patients that don't have resources.

MAGDA PECK: Thank you again.

JULIE MOLDENHAUER: You're welcome.

TARA SANDER LEE: Thank you so much. Colleen. This will be the last question.

COLLEEN MALLOY: Yes, thank you so much. I am just wanted to ask Dr. Moldenhauer a question. I'm a neonatologist, so I see things from that side of things, and I really am amazed by everything you do, and I appreciate it so much, and I can tell you from meeting with many, many families who have had fetal surgery at Northwestern, like they are so like amazingly grateful for this, and I think it's such a really unique journey that they have. And I had a -- we had a family that was lined up to kind of give a personal experience narrative about their story,

but we kind of didn't have time for it, I guess, but maybe in the future, we could, because it's really great to hear from the families who have gone through this with you because that's where you really kind of understand, and I think speaking to, you know, yes, the families have to understand the risk, but what I find is if they're not, you know, if they're not actively seeking it out on the Internet or maybe they heard of a friend of a friend, that the gatekeepers are truly the obstetricians.

JULIE MOLDENHAUER: Agree.

COLLEEN MALLOY: And midwives that see them in the beginning, and if those people aren't at least offering them, you know, keeping the door open that they could learn about it or be exposed to it, or have an introduction to it, you know, they have a right to know that this is an option, and I think that any obstetrician or woman's provider that doesn't tell them about this option, like this therapy, is really doing them a disservice and not like serving their patients in

a complete way. So, I just wanted to thank you for this. I think, you know, you know you have a great attitude and you're very open and honest and I think that if we didn't have a great center in Chicago, I'd send patients to you on the east coast. So, it's just another --

JULIE MOLDENHAUER: You have great people in Chicago.

COLLEEN MALLOY: Yeah, they are really good. Yeah, thank you.

TARA SANDER LEE: All right. Thank you to our speakers. Thank you so much Dr. Tepper and Dr. Moldenhauer. I really appreciate your time and I think, as you can see, everybody can see this is a huge topic with lots of areas so that we can improve access for all women, no matter what their race. And so, hopefully we can continue this discussion in future meetings. So, thank you so much.

And so, Ed, I'll turn it back over to you.

EDWARD EHLINGER: Thanks, Tara. What a

great presentation. It's always a good day when I learned something, and I learned something in the session. In fact, I learned a whole bunch of things in this session. So, thank you very much.

We're going to take, let's see, a ten-minute break instead of a fifteen-minute break. And so, we'll come back at 3:50. So, I guess it's a twelve-minute break. So, come back at 3:50 for the next presentation or 2:50, excuse me.

BREAK

EDWARD EHLINGER: Welcome back to the second part of our first day of our SACIM meeting. We're going to be talking about State and Community Projects on Maternal Health. In this area, we've sort of put the cart before the horse, based on input from our community members, we actually included recommendations related to the Quality Care Collaborative and some of our recommendations before we even had a formal session to talk about them. But I trust in all of our members to bring us the good information. So, so we're going to be doing the horse part, now.

We did the cart, and now we're going to do the horse.

So, Steve, I want to turn it over to you to take us through this session.

STATE AND COMMUNITY PROJECTS ON MATERNAL HEALTH

STEVEN CALVIN: Great. Thank you, Ed. So, what we're going to be planning for, we have three presenters here that we're hoping for ten-minute presentations followed by questions and comments at the end. Each of our presenters really does deserve more than ten minutes, but I'm sure that their presentations will really whet our appetite for further investigation of their really good work.

So, our first presenter is Tammy Snyder Murphy. She has been the first lady of New Jersey since 2018. In 2019, she launched Nurture New Jersey, a statewide awareness campaign that was committed to reducing maternal and infant mortality and ensuring equitable care among women and children of all races and ethnicities. It focused on improving collaboration and then

programming between all the departments, agencies, and stakeholders with a goal of making New Jersey the safest and most equitable place to give birth. In January of this year, she unveiled the Nurture New Jersey Maternal and Infant Health Strategic Plan. That was a plan to reduce maternal mortality by 50 percent over five years and eliminate racial disparities, and it's a culmination of a lot of work. We welcome Ms. Murphy to present to us, and we're thankful for her being able to take the time.

TAMMY MURPHY: Well, good afternoon, everyone. Dr. Calvin, I am grateful for that introduction and for your work as part of the Advisory Committee on Infant and Maternal Mortality. I also want to share that we are keeping our eyes on Minnesota. Earlier this year, the University of Minnesota School of Public Health submitted a response to our request for information to aid in our -- in planning our Maternal and Infant Health Innovation Center and I cannot overstate how thrilled I was that the work

we are doing in New Jersey is making rumbles all the way to Minnesota.

It is an honor to be with all of you, and I want to thank Secretary Becerra for his recognition of the United States National Maternal Health Crisis and his support of our work here in New Jersey. I also want to thank Dr. Ehlinger, Chair of this advisory committee for his leadership and dedication to our nation's mothers and babies.

In his inaugural address, President Biden spoke of quote, "A cry for Racial justice some 400 years in the making, a cry that can't be any more desperate or any more clear." In New Jersey, I have spent four years listening to this cry grow louder from Black mothers who have lost their babies or very nearly their own lives, fathers who have lost their life partners, and countless women of color who have told tragically similar stories, stories of not being listened to, or receiving the care that they needed and deserved at a time when they could not have been more vulnerable. And as

we have worked to raise awareness of this crisis, as well as solve it. I have seen New Jerseyans from every corner of our state respond, some with shock and outrage, others with sadness, but all with a determination to raise up these collective voices and demand an answer to their plea for racial justice through reproductive justice. Through Nurture NJ, we seek to answer that call.

Over the past four years, we have taken a comprehensive and meticulous approach to understanding the scope of New Jersey's maternal health crisis, made significant and often groundbreaking policy changes. We've enlisted national experts to help us design our Nurture NJ Maternal and Infant Health Strategic Plan and we have begun implement many of its recommendations.

Some of our most significant accomplishments since the start of the Murphy administration include becoming among the first states in the nation to establish a statewide universal newborn home visitation program, expanding Medicaid coverage to 365 days

postpartum, providing Medicaid reimbursement for doula care, and the list just goes on. I am incredibly proud of the steps we've taken thus far, but as we work to fully transform New Jersey's maternal health landscape, we understand that sweeping change requires persistence and unfailing dedication. At the same time, we know that the urgency of this crisis remains, and that its root cause is institutional racism, plain and simple.

Black women in New Jersey are over seven times more likely than white women to die due to maternity-related complications and Black babies are over three times more likely than white babies to die before their first birthday.

As a mother of four incredible children, this terrible knowledge weighs heavily on my heart, especially because I know, but for the color of my skin, that could have been me or one of my children. And that kind of personal commitment and motivation is reflected in every Nurture NJ partner. We're not seeking to simply

improve our maternal health statistics or data; we're working to make sure that every New Jersey mom and baby gets off to a healthy start and is put on a trajectory toward a full and healthy life.

In January of 2021, nearly one year ago, we released the Nurture NJ Maternal and Infant Health Strategic Plan, which is the culmination of over a year of enumerable conversations with hundreds of relevant and invested entities, ranging from departments and agencies, health systems, physicians, doulas, community organizations and, most importantly, mothers and their families, designed to make transformational change in a system that has historically failed our mothers and babies of color. This plan is our blueprint to make sure New Jersey is the safest and most equitable state in the nation to deliver and raise a baby.

At its most fundamental level, the plan meets the specific needs of women in their local communities, where they live, work, worship, play,

and love. The recommendations range from increasing prenatal care and support for women of color to creating a groundbreaking Maternal Health Research and Innovation Center so that our work can continue to grow, evolve, and inform itself. Most importantly, it makes broad reforms aimed at dismantling the structures that for generations have prevented women of color from living in environments that provide the resources needed to simply be healthy.

The goal to reduce our maternal mortality rate by 50 percent over five years and eliminate the racial disparities and birth outcomes will require all sectors, health, education, business government, academia, and more to play an integral role and ultimately, the success of our plan relies on the active partnership and collaboration of all of us.

Since the start of our administration, we have held quarterly Nurture NJ Inter-Departmental Maternal and Infant Health Work Group meetings with over eighteen different departments. We've

held six family festivals to bring together state, county, and local resources to over 5,500 families in our cities with the highest rates of Black maternal and infant mortality, which was accomplished in large part due to our partnerships on the ground with community organizations, faith leaders, school districts, elected officials, hospital systems, and more. And, most recently, we held our fourth annual Black Maternal and Infant Health Leadership Summit, where over 350 participants, including doulas, nonprofits, activists, state departments, and agencies and, most importantly, moms came together to discuss and identify solutions to our maternal and infant health crisis.

I am proud that, because of our work to dismantle silos, build trust among our over 800 Nurture NJ partners, and amplify the voices of the mothers affected by this crisis, we have been able to hit the ground running. We are third in the nation to reimburse doula care through Medicaid. We have the most robust universal nurse home

visitation program in the nation for new moms and we are the second state to expand Medicaid coverage to a full 365 days postpartum.

My husband, Governor Murphy, has signed over thirty-seven maternal health-related pieces of legislation from ensuring hospitals ask any patients presenting in the emergency room simply if they have delivered a baby in the last year to no longer reimbursing for early elective c-sections through Medicaid. We have made small and big changes with a major impact. In less than a year from its release, we have already completed or made headway on over half of the more than seventy recommendations outlined in our strategic plan, ranging from establishing a Maternal and Infant Health Research and Innovation Center to expanding coverage for reproductive health for undocumented mothers and several of the achievements I already listed.

With our collective and persistent commitment, we will root out the institutional racism that has affected every corner of our

society all the way to our mothers and babies. It's clear that our country has reached a crossroads, but I do not say that with fear. I say it with the utmost sense of optimism and hope for what we can endure together.

As we come together to face our nation's racist past and present, where better to start them where life starts with our mothers and babies. When we do this work, we do it for the 10s of thousands, even millions of mothers and children, we will never know. But we also do it for our own mothers, our own children, our grandmothers, our aunts, nieces, and our friends. We do it for those who are no longer with us and for those who have yet to be born. We do it because we're ready to turn the page to a future where every family gets off to a healthy and happy start. And New Jersey has a plan to get us there, a blueprint that we hope, not only for the garden state, but for tackling systemic racism across the country and leading the nation in maternal health.

So here, I would like to express my

gratitude to all those who contributed to the development of our plan, and I want to give a very special thank you to the women of color who shared their deeply personal and painful stories with us. Your voices are the DNA of this movement. In New Jersey and we have a lot more work to do, but because of the leadership of the Biden administration and all of our Federal and State partners, like New Jersey's Senator Cory Booker and Congresswoman Bonnie Watson Coleman and Congresswoman Lauren Underwood, when I say that Black mothers' lives matter, I know that along with those words comes action. Not the kind of action that a small change here and there, but the kind that's going to transform New Jersey into the safest and most ethical place in the nation to deliver and raise a baby and our nation into a haven for mothers, babies, and families.

Thank you for your attention. Thank you for your concern. Thank you for looking to New Jersey for guidance and joining us on this journey, I truly feel the momentum growing behind

us, and I know that together we will solve this crisis and ensure a healthy start for every mother and every baby. Thank you.

STEVEN CALVIN: Thank you very much, Ms. Murphy. New Jersey is fortunate to have someone who is so passionate and driven about improving maternal and infant care. I'm really grateful. So, we'll look forward to some questions at the end of the other two presentations.

Our next presenter is Dr. Elliot Main. He is the Medical Director of the California Maternal Quality Care Collaborative and he's led multiple state and national quality improvement projects. I've been aware of him for a long time. It's an honor to have connected with him last week before this presentation and to hear this presentation. He's been chair of the California Pregnancy-Associated Mortality Review Committee since it was started in 2006. He has been chair of a very large hospital OB-GYN Department and he's currently clinical professor of OB-GYN at

Stanford. He has chaired also many national committees on maternal -- maternal quality measurement including those sponsored by ACOG and the Society for Maternal Fetal Medicine, I think, for sure AMA, the Joint Commission, Leap Frog, Centers for Medicare and Medicaid Services. He's just -- he has been very active and it's not an overstatement to say that hundreds of thousands, indeed millions of mothers and babies have benefited from his work. So, we are thankful that he could join us today.

PAUL JARRIS: You're muted, Elliot.

ELLIOT MAIN: Thank you very much, Steve, and I want to give a special shout out to First Lady Murphy for the tremendous work she's doing in New Jersey and it's really bringing the power of the governor's office and the power of the collective work of everyone in New Jersey to bear on this, and we're learning from her as we work in our progress in our in our state.

So, I'm going to show you the power of Public Private Collaborative to work on maternal -

- on the maternal side. We have a parallel group in California called CMQCC that's working on neonatal health. California is particularly important because we're very large, larger than most European countries, with almost 500,000 births, a little fewer in the last years of the pandemic, and a very diverse population actually 47 percent of our births are Latina, 6 percent or so are Black, and 17 percent Asian American, and only about 30-odd percent are white in California.

Our collaborative was formed in 2006. So, we have fifteen years of track record here, which is an important as we look at other states that are starting out. And you can't expect change to happen in one or two years. It's taken us with the development of relationships and track record a long time to get where we are today.

But we were formed by the -- by the Department of Public Health and Dr Connie Mitchell is going to follow me, talking about their side of the story and they've really been the leaders in this and got us going.

First, with a look at maternal mortality, we did not have maternal mortality committee in California until it was started shortly after 2006. Our mission was to turn the results of the mortality reviews into action.

So, I'm going to look at two of the key slides of our outcomes in California. One is maternal mortality. Again, we started around 2007 looking at maternal deaths, and then I'm going to go through the steps that we took to start making change at scale. And again, California is 1 out of every 8 in the United States bigger than most European countries. So, this is really about change at scale from maternal mortality and then more recently low-risk first birth c-sections. Again, our story was we were the same as the US in rates, not very good, 26 percent for the low-risk first birth c-section or NTSV, and then with a combined public-private operation initiative, we were able to significant lower that. The green line on the right-hand curve is baby outcomes -- severe unexpected newborn complications, and you

can see that we were -- we did this because we want to show that they were not harmed by having a lower c-section rate and, in fact, they actually improved with a lower c-section rate.

There are a lot of important steps in this, and this is the mantra that we have taken for most of our journeys. First off, being by statewide public health data like mortality review committees, developing a toolkit, engage every partner organization that we could around the state, hospital change collaborative with rapid cycle data, and this has been a pretty particularly important part for us to lead to change at scale. For example, on the right-hand side here, our statewide initiative for reducing primary c-section or supporting vaginal birth, we combine hospital QI collaboratives that were data driven, had a lot of professional organization leadership, driven by collection of data in the toolkit, indirect participation of women. At the same time, we engaged health plans, our Medicaid agency, purchasers, public health department,

actually the Secretary of Health and Human Services for California, gave awards to hospitals of who achieved targets, and we have public reporting, a lot of transparency, which was the key element. These all combined in a synergistic way to actually create that change at scale.

Quality improvement toolkits, we've been -- these are, you know, 50- to 100-page documents talking -- giving all the nuts and bolts of how to create change locally at your facility for various topics. We just finished an update to the preeclampsia toolkit that was paired with the National Safety Bundle and had 2,000 registrants for our webinar releasing that.

These are paired with collaboratives, and these are IHI type of collaboratives where hospitals work with each other and with community groups to reduce -- to address the specific issue. What's important here is that one collaborative does not change the world. You have to do them repetitively do that you develop a change in culture of the unit, so that you really are

changing the outlook, changing the approach. We have done a whole series of these, starting small, twenty hospitals, and then up to ninety hospitals, up to one hundred and thirty hospitals at a time. We have two hundred and thirty-odd hospitals in California making the change process a challenge.

Underpinning this is Maternal Data Center and this, we're going to spend a couple slides on this, because this is super important. We were able to, with our Department of Public Health, turn our birth certificates into quality improvement tools. So, we get feeds every month from our Department of Health of every birth certificate in our state 30 days old -- 30 days old, link that to hospital discharge diagnosis files from every hospital in the state. Again, those are now about 45-days-old, and we can put those together -- mother and baby and birth certificate -- and then turn that around to use for hospital QI and for supervision of state practices in near real time. So, hospitals, we have reports that enable our hospitals to

calculate and report to outside agencies and to benchmark against each other a whole series of quality measures and stratify them by race and ethnicity, and we'll talk about that in a moment, because we are able to use the race and ethnicity on the birth certificate, which is probably the best or the gold standard.

We create enough value for the hospitals in this process that now they're supporting the data center with a modest fee per year from all two hundred and fifteen or so hospitals. Because -- and that's really the key -- a key point in all this is that you want to create value for every stakeholder along the way to get them to buy in. This is doable at potentially every state. It is about breaking silence between birth certificate, i.e. health department, and the agency that collects and stores the hospital discharge diagnosis files. But in many states, these are burdened by rules. So then, that requires leadership. We don't want to invent the rule with a whole new data system. It's there. It's there

in every state. So, our mission, I think, here ought to be to really impress upon states that they need to change the regulations and laws to accomplish this.

So, I mentioned stakeholders and partners. I think our strength as a public-private organization has been to engage actively everyone we could think of who touches maternity care and that involves a series of state agencies. Dr. Mitchell will talk more about that. Membership associations, our hospital association has been a big player. All of our health systems, we have a lot of health systems in California; Kaiser, Sutter, Sharp, Dignity, Providence public hospitals, as well as a series of professional groups and public consumer and community organizations. But importantly also the health plans, the people who pay the bills are really important in this because they can provide incentives to participate and incentives to achieve targets.

But national partners also play a big

role. We've been able to work extensively with the Joint Commission in my role both in California and with the HRSA-supported AIM project that's based at ACOG and follows many national organizations to adopt the hemorrhage and hypertension bundles and to promote a set of perinatal quality measures.

State Perinatal Quality Collaboratives, like CMQCC, have been supported by HRSA and it's a shoutout Dr. Warren and Dr. Wilson here in the audience today. They have been able to help create national safety bundles, which really provide a guidance to what we should be doing locally. The CDC, in turn, has been supporting PQCs and again a shoutout Dr. Barfield here for supporting us initially in California and now turning to newer state perinatal quality collaboratives. But it takes time to nurture.

CMS more recently has been involved with the Inpatient Quality Report as a new measure for adoption in the state perinatal -- state perinatal safety bundles and participation in state PQCs and

indeed, we have participated actively with our state's Medicaid agency in supporting OB quality through 115 waivers, which is something open to every state, but I don't think that's an opportunity to be able to re-channel significant support in that direction.

I'd like to say, you know, that we made a lot of progress, but in other areas, we haven't made as much progress as we should, and this is areas that First Lady Murphy has really highlighted today. We, in our Hemorrhage Collaboratives, we were able to narrow significantly the morbidity for Black women compared to white and Latino women by about 50 percent, but not -- that's not the same but it led us to look at antecedents and prenatal care and other areas, such as preexisting anemia that need to be addressed.

Our Cesarean Collaborative reduced the rates for all racial and ethnic groups in California but did not close the gap. We still have a 30 percent reduction as opposed to a 6

percentage point difference between Black and white women is now 4 percentage points. So, progress, but not there.

There's two ways of looking at maternal mortality. I looked -- I showed you the first graph that was the WHO definition, which is up to 42 days. The pregnancy-related mortality rate goes up to a year and after a 30 percent reduction in pregnancy-related mortality in the first few years of our project, it's been flat. So, now, there's still a significant disparity between Black and white women and this is the area that we're focusing on now with a lot more community engagement than before, and it represents a shift of deaths, the postpartum period away from L&D.

And our feeling now is we're late to the game on this, I will admit. We really can't do quality improvement without really addressing equity. That's some of the learnings we've had over the last three or four years, and so we're trying to weave intimately equity into every quality improvement project.

But in our health care system, such that it is, there's a lot of connections that are lacking. Communities and health systems do not speak often with each other. Medical model and the public health model can do much better to work together. Physicians do not understand the resources available to them in the public health world. And, I would say, visa versa. And in- and out-patient worlds are pretty distinct in quality improvement. So, these are opportunities.

Going forward to our work with racism, I'd like to make one illustration here in the last couple of slides. This is the hospital's NTSV c-section rate. They thought they were doing great, 22 percent, national target was 23.6 for Healthy Person 2030. They had no idea of how they were doing by race and ethnicity until we were able to show them in our data center a stratified by every race on the birth certificate that their Black mothers were doing 6 percent higher. Huge disparity, even though overall, they were doing great. With this knowledge in hand, they were

able to go back and focus on equity and quality improvement together and two years later, two and a half years later, they had a significantly lower rate for their Black mothers, 22 verses 28 -- 22.9 verses 28 but are still a difference 18 verses 22 overall. So, they're -- but this is a start. First is that they have to recognize what is happening locally in your own facility.

So, our feeling about keys for improving care at scale was to use the public health surveillance data to create the Burning Platform for change to drive actions. You've got to mobilize everyone you can think of, including communities. You create a system of rapid-cycle maternal infant data to support and sustain the QI projects, and then also have a data-driven large scale quality improvement projects to change the culture, because it's really about culture at the end of the day. And you want to pull all the levers at once, not just do a collaborative, not just, you know, show some data, but to engage everybody, you know, at the same time, with the

transparency, with all the levers that I showed you on the earlier slides, and you have to do equity and clinical QI together.

Thank you very much.

STEVEN CALVIN: Thank you so much, Dr. Main. This has been great, and I would just -- as you were describing all of this, I think you're the composer and director of a very large quality improvement orchestra and, you know, you know that all the -- all the sections and all the players and sometimes soloists, they're all playing, but it's amazing what is being accomplished and it's a model, I think, for the rest of the country.

Our next speaker is Dr. Connie Mitchell. She's an emergency medicine physician and her career has spanned the spectrum from the highest acuity interventions in the emergency department to health policy for primary prevention. As I was reading her bio, I -- it brought me back to something that I heard thirty years ago from a head of department that said that, you know, we could always be down at the bottom of the cliff

picking up the people that have fallen off and putting them in ambulances. And he said, we need to put -- we need to put fences at the top and stop people from falling off. And so, I think that's what Dr. Mitchell has been doing. She has a particular focus now on maternal, child, and adolescent health. She helped start the California Pregnancy-Associated Mortality Review and is a colleague of Dr. Elliot's. She was author of the state's first report on maternal mortality, and she is on the front line of quality assessment and improvement, and we're grateful for her participation.

CONNIE MITCHELL: Thank you very much. It took a there for it to clear. I'm very happy to be here and very happy to follow the two speakers that you've just heard. I'm really appreciative of the First Lady's remarks because I do -- I have found through experience that it requires just such a strong vision and goal setting in terms of, you know, all leadership and all forces and then you have to align the

resources with your values. So, if you -- if you talk about starting with the people who give life as a good starting place for our work around equity and antiracism, then giving all -- aligning your resources with that is really important.

And then, I think, I really appreciate how she talked about building a big tent but making it easy for others to join that big tent. Sometimes, we have a big tent and it's people who have the means and the mechanism and the recognition to join. But you have to make it easy for people who have the lived experience, who come from the community, who understand the barriers the most to participate. So, I really appreciated her comments.

And Elliot described something that we're very, very proud of in terms of our public health department, and that is that you really can provide important seed funding to an organization and then foster and support them as they become -- as they grow and learn and become more independent, yet still part of your team. We were

really happy that not only did we use our Title V funding in California to help to create the California Maternal Quality Care Collaborative, Stanford University is the home for that collaborative, and we continue to contract with that collaborative, but worked with them to then take it to the next step, the next step being okay, if we can do more real time quality improvement, what would it take? What data would you need to get to that point? And we tried to facilitate that for them so that they could do that.

And then we made it really clear that while we couldn't fund that, we would support it in terms of supporting their ongoing executive committee. They continue to under contract lead our current Maternal Mortality Review Committee. So, we have a very close partnership, but even more importantly, that seed money was critical for all of the success that you've seen Elliot define that now they are able to add additional payor mechanisms and incentive hospitals to participate

so.

Anyway, if you go to the first slide. I was asked by this committee to talk about our approach and how it started up. In a way, maybe I should have gone first, but we'll talk about how this all started up and will also -- I was asked to talk about some of our challenges that we still have that remain and maybe some ideas for how federal agencies can work with us to support our improvement. Next slide, please.

So, we started, like any good public health endeavor would be, is that we started with hypothesis generation, and we had a lot of hypotheses as to why in 2006 and '07 and '08, we saw our rising rates of maternal mortality. And one of those hypotheses was had something changed in terms of obstetrical care? Was something different going on in either the care provided or the status of the patients or, you know, what was happening either prenatally or in the hospital phase? So, it made sense for us to begin with the medical record and looking at the medical record

because it's available data that's already there and we have the authority through the public health to be able to get into that data, ask for that data, but what was critical in California -- and we shared this belief -- was that if we did it as an oversight agency, we would not engender the goodwill of the hospitals to let us look at some of their most private moments where we did discover that wasn't always -- didn't always reach the standard of care that we hoped to reach. So, we made sure from the very beginning that this was about working together and using the medical records, conducting the public health investigation, using the expertise of our committee, to try to not only ascertain -- not just gather the data, but also to ascertain were there moments there as we read about this case where it might have gone differently if something else had happened instead. And I remember being in those first reviews, where the room would go completely quiet because you realize that it might have gone differently -- this life might have been

saved if something -- at that point, you went right instead of left and the room is silent and everybody felt this pain we had to have the trust of one another that we would -- had to move beyond the pain to convert it into meaningful data and that that data could then inform some guidance for hospitals, and then we needed a trusted partner to bridge and provide that guidance and work with hospitals who wanted to do better, and that was kind of our mantra from the very beginning, is that we all want to be excellent. We all want to serve. We all want to prevent these deaths and we want to do this together. And so, CMQCC provided that bridge to the hospitals and the healthcare community and did some real-time quality improvement. They helped us to develop these toolkits, these guidance documents based around quality improvement. They worked with hospitals, who signed on to these learning collaboratives, and they gave them the information that they needed to see if they were moving in the right direction or not. So, it was truly not only a

partnership in moving forward, but it gave us real-time accountability, very visible accountability, so that the hospitals could know that they were making progress. Next slide, please.

So, you saw this slide with Elliot. This is a slide that I've seen a lot of people point to, and they want me to explain it and what I have to really tell you is that I have to really address this with all humility and that while we were able to use -- make some -- some changes, I don't know exactly what they were. I can tell you the things that we did, but it may not have been exactly those things, because we had so many people in California committed to reducing maternal deaths, that it may have been little things that that accumulated. I can't tell you that it's specifically what we did that contributed to this, but we did see a gradual decline, and this is again maternal mortality rate, meaning up to 42 days using death certificate data alone and the ICD-10 codes for

obstetrical deaths. It's readily available, it's feasible in all jurisdictions and allows for cross state comparisons. Next slide, please.

But it's not telling the whole story, and we need to be very honest about that, because I think we need to do to a much better job at telling the whole story. So, you can see in this slide that again that maternal mortality rate, the gray dotted line at the bottom, that's that same data line. And you can see the top line. If we look at maternal mortality up to 365 days, and this is something that we're very committed to doing, and also, I heard that New Jersey is and other states are, you can see that our rates -- are pregnancy-related mortality ratio rates are higher, much higher -- in 2016, 14.1 compared if you go to 365 days and 5.9 if you go to just 42 days.

The middle line, the dotted line, is the data that we have. If you look at our data on pregnancy-related mortality ratios, which comes from multiple data resources, vital stats, medical

records, ambulatory care records, coroner, and autopsy reports. So, you have multiple records because you're trying to identify all of the deaths and if you look at that only to 42 days, what we think is a more reliable data source -- multiple data sources, gives us a pregnancy-related mortality ratio -- because it's not based off just some vital stats -- of 11.9 in 2016 compared to 5.9 from death certificates alone. And again, the 14.1 is, if we go out to 365 days. So, this right away, I want to tell you, is an important thing is that the snapshot that we use on maternal mortality ratios is not sufficient to really describe what we think is happening and we're so appreciative of the policy efforts to extend prenatal care and postnatal care to -- to extend postnatal care up to one year. That's one example of things that we can do to perhaps address this. Next slide, please.

So, again, with all humility, we have made some improvements. We know that, but we are facing a persistent and very discouraging

disparity and I just listened to the First Lady and I felt uplifted that I think that if we have an all hands on deck approach to this, and that we really do the hard work that we need to do that is around the environment and addressing historical institutional racism that we will come up with strategies and we will make some progress.

But when you look at -- this is our data -- it's a three-year moving average, you can see, at the bottom, and you can see the division by racism. I think that Elliot showed us a similar slide to this. It shows -- it looks like there is some improvement and you can see the narrowing of the disparity ratio. But when you actually calculate the ratio, which is the dotted line in the middle, we have not improved. We are at the same disparity ratio that we were in 2003 to 2005 of 3.9 is that ratio. Next slide, please.

And this is again where if you look at the pregnancy-related mortality ratios up to one year and it's the same slide that I just showed you, and what you see here is that at one year,

the deaths among Black women, the rates, the ratios increase to 42.5 and 14 to 2016 and you can see that the ratio, because the deaths in white women went down a little bit, these ratios really jumped up. So, instead of being a ratio of 3-4 times -- a death rate of 3-4 times that you get at days, it's a ratio of 5-6 times that you get when you look at one year. Now, that's important information, because then you want to say well what's happening with that group. We know that -- and I do want to point out that we have to take this with some caution because that's -- these differences are not statistically significant, but the trend is concerning -- so, I want to be really clear on that. The ranges that we see are -- could be expected by chance alone, so this disparity ratio should be interpreted with caution, but I want to present it to you.

We know that our pregnancy mortality ratio is higher in older age groups, and those with higher BMI greater than 40, those with less education, those with public pay versus a private

pay system, but very importantly, it's higher in those living in the most disadvantaged communities in California. Next slide.

So, I was asked what does California see as major challenges to improving maternal health. Certainly, addressing the disparities and perinatal outcomes by addressing systemic racism and social determinants of health. Women remain a social economically vulnerable population and the intersectional effect that comes with joblessness and mental health, loss of housing, food insecurity, structural racism, and low rates and access to health insurance all contribute to poor outcomes in pregnancy.

We must use the life course approach to risk reduction and resiliency promotion. I think one of the things that we did when we developed the toolkits and we engaged hospitals in quality improvement efforts, but I think we did improve rescue care. But I really think that we can do so much more upstream and thinking about reproductive health as a continuum from childhood to

parenthood, and that experiences prior to pregnancy matter, so that the health of girls and women prior to pregnancy is optimized before pregnancy.

We need to increase support for other health risk conditions such as behavioral health and chronic diseases that I think are all contributing to rising rates of maternal morbidity. Something that we don't think about a lot is reproductive health literacy for all, including understanding of the pregnancy health burden and high-risk conditions. In our Black Infant Health Program, we surveyed the women participants, and they were not aware prior to enrolling in our Black Infant Health Program of their individual risk just because of their race. So, we now have a campaign that's being developed to try to raise that reproductive health literacy and understanding of the pregnancy health burden, particularly in Black pregnant people.

And we want to continue to work to improve the quality of reproductive health care,

but that's across the continuum, access to high quality sexual and reproductive health education services, continuity of care after delivery, and connecting mothers to needed, health, social and mental health services, decreasing experiences of racism and disrespect or mistreatment that is regularly reported by people of color in the healthcare system and to focus on the quality of rescue care, but also the quality of prenatal care and the quality of preventive care and women's health. Next slide, please.

So, I was asked what can federal agencies help do to support improvement and maternal health for all pregnant people. Right off the bat is this opportunity with COVID to provide equity-based COVID recovery assistance for families and women, and I know we've already done some of this, but we have not yet done enough. Women and particularly women of color dropped out of the workforce to serve as family caregivers. Caregivers are asked to sacrifice their time, their salary, their professional advancement, and

their own health. We need to have some clear data guidance from the feds for indirect long-term impacts on families so that we know where to direct our support.

We need to have an increased focus on rising rates of maternal morbidity. That's not talked about enough and the complexity of addressing maternal morbidity maybe even more so than maternal mortality. There's currently twenty-one indicators and corresponding ICD codes that can be used to track hospital deliveries, but the administrative data doesn't document disease severity, so it does hinder some of our studies.

Another suggestion is to prioritize social support during pregnancy as a routine part of prenatal care, addressing immediately housing and food insecurity, any safety issues, and the need for trauma informed care.

I'd like to suggest to you that we have a National Learning Collaborative. I want to have a meeting right away with the First Lady so that we are all learning from one another and that we can

focus specifically on morbidity and mortality in our perinatal outcomes for Black people, increase our support for parents, and the national vision that child rearing is the shared societal responsibility. Certainly, universal home visiting, paid parental leave, and caregiver leave, and childcare support.

We need to incentivize a stronger and more diverse reproductive health workforce. We need to think about Medicaid payments to licensed birth centers and remove the scope of practice barriers by certified midwives, improve opportunities for racial concordance of care, train and incentivize use of doulas, midwives. I know that HHS has proposed to increase scholarships for disadvantaged students to educate midwives and support that and student loan repayment for health providers should be included and finally address the data quality issues, move from maternal mortality rate to a pregnancy-related mortality ratio to capture causes of death up to one year. We need to identify best

practices for identifying the complete cohort of pregnancy, standardize our processes, require coroner reports and autopsies on all maternal deaths, probably require every maternal death to be reported so that we all commit to this being a high priority need to get this information.

I wrote the last here, conduct a LEAN assessment of federal processes to increase flexibility and reduce procedural and reporting burdens. This came from my local health departments and my staff is that they said, wherever we can self-assess and we can remove barriers and make work easier, people have more time to do the work at hand. So, that -- I added that to make sure that we all have a responsibility to remove barriers and make it easier and more flexible, so that we can meet the needs of our communities.

I want to conclude here that we don't have to -- there's some great resources on this last slide, I have there a list of some great resources -- policy resources. So, if you can go

one more slide, thank you.

There are lots of great documents that already tell us what to do. It's now time to start doing it. That's my last advice is that we -- we know what to do. We certainly have models for the political will to do it, we just need the processes for aligning the resources with the values and with the goals that have been set. And if you want to make it really simple, next slide, please, I really found that the work for the Center for Reproductive Rights simplified it really easy for us in these categories. We need to improve healthcare access and quality, while addressing underlying determinants of health. We need to eliminate discrimination and law and practice. We need to assure accountability, and we need to include and empower all of the voices that will be essential for us to resolving these big problems.

So, thank you for including me, and thank you to my co-panelists, who I find you both to be very inspiring.

STEVEN CALVIN: Thank you very much, Dr. Mitchell, and First Lady Murphy, and Dr. Elliot. I think we have a little bit of time. Are there any questions? I guess we'll start with Dr. Conry.

JEANNE CONRY: Mine is not a question. Mine is just a thank you for fifteen years of being inspired by the work that they're doing. I'm delighted that they were able to share their knowledge with this group because I think it's this knowledge and evidence going forward that's so critical for us. So, thank you to everybody and First Lady Murphy, an inspiration for what we need to do with political will.

STEVEN CALVIN: Great.

JEANNE CONRY: Thank you.

STEVEN CALVIN: Thank you. Ed.

EDWARD EHLINGER: Yeah, mine was a political will question for all of the -- and political not just on the political side and, you know, the public policy side, but also in the hospital side. This requires a lot of sharing of

information and requires hospitals to be willing to share some of their data and be visible and be and be vulnerable. It takes politicians on both sides of the political aisle to respect the fact that we work collaboratively. How -- how did you do it in New Jersey and how are you doing it in California to get people to play well together and not have an us versus them or a public-private, get government out of activities like this? How do you build that political will? How do you form those partnerships that were so obvious in both of your presentations that are so essential?

ELLIOT MAIN: First Lady, do you want to go first, please?

TAMMY MURPHY: Sure, absolutely. So, it's funny, this is the same question I've been asked literally three times this week already, which is extraordinary, because we're only -- we're only in Tuesday. The -- the answer from my side is that we have gone out and spoken to so many stakeholders across the state of New Jersey, in Washington, in New York, truly across the

country, and I think that this topic, from my vantage point at least here in New Jersey, is a unifying topic. Whenever my husband gives State of the State speeches or the budget address, this is the one topic that comes up where both sides of the aisle clap and there's no descent. So, I would say to you that, you know, I think it's a little bit of leaning and trying to meet with all the stakeholders, you know, whether it's the Black Legislative Caucus on the one hand and being thoughtful about including potential outliers up front. So, in a lot of the conversations we've been having, if we kind of could think down the road where we might have a speed bump, we've actually gone out of our way to include those specific individuals in conversations at the very beginning, so we can make sure that we are all understanding one another.

But all the work we've been doing is literally bringing together great people who are working in silos all across our state and beyond. Because there's a lot of fantastic work that's

being done, as you all know, but the fact of the matter is that people don't reach out and talk to one another, and I think when you open up those lines of communication, I think that what you'll find is that actually, this is a very compelling topic and I think most people -- most people here in New Jersey agree.

STEVEN CALVIN: Thank you.

ELLIOT MAIN: I think in a similar way, you know, our first or six years was spent entirely on networking and on communicating and really creating premise that we're here to help people improve care and reduce mortality and morbidity, which is hard to be against. And so, we've tried to accent the positive throughout this process, i.e. giving awards rather than penalties, though -- and incentives for achieving goals and that, by and large, has been very well received.

But we do have economic competitors working together on this, different healthcare systems are sharing data with us. We don't, you know, a limited amount of data gets public

release. But transparency is a very powerful tool. That is not -- is not in place in some of the states in our country where they don't believe in transparency and that's a missed opportunity.

STEVEN CALVIN: Yeah, thank you. I guess, Magda, you have a question, unless Connie Mitchell, do you have a response as well to --

CONNIE MITCHELL: Go ahead. Please go ahead.

STEVEN CALVIN: Okay, Magda.

MAGDA PECK: Thank you, Dr. Mitchell. I appreciate that. I am always in awe of what the California Maternal Quality Care Collaborative has been doing. So, and I appreciate that it's taken fifteen to eighteen years, a lifetime, to harvest. So, I just want to extend my gratitude to my colleagues who are also my neighbors now.

I am struck also by the data that were presented by Dr. Main and later, I think, by you, Dr. Mitchell, around the extraordinarily good outcomes for foreign born Latina or Latinx women and I just -- that has been part of the paradox

that Sylvia Goodman and others have written about for a long time. When you do your work and the disparities are so great, have you also looked at why, in the face of economic challenge. This particular population apparently by the numbers does better than their white counterparts who are non-Hispanic. Do we ever look at what are the positives in the data, in addition to the disparity of our Black and American Indian women who have poor outcomes? So, it's a California thing, but I'm wondering if it's beyond a California thing on this paradox.

ELLIOT MAIN: Connie, do you want to start and then I can answer too.

CONNIE MITCHELL: I'll make a couple of comments around that in that it's an important question because these communities want us to elevate their strengths and their abilities. We used to have a -- we used to call it a disadvantage index, and they said no, that means that you are not perceiving the strengths that we have and so now it's called a Healthy Places

Index. We recently did a report on American Indian/Native Alaska Maternal Health Report, and we did that with the communities and how would do look at this data and interpret it. What do you see in here? What would be your analysis and then how does that relate to what you see as opportunities and barriers, and that report then went in a whole different direction, and we're doing the same thing with a report that will be coming soon around Black Infant and Maternal Health.

So, I would say that don't identify the strengths and the richness of a group of people, unless you ask them and engage them and let their perspective be a part of your analysis and your final conclusions.

ELLIOT MAIN: It's clear in our analysis that there are a lot more strengths in the Latin community that is reflected by their income or their personal wealth, which are some of the traditional metrics that are used. But also, when we look at comorbidities as a driver of maternal

morbidity and we develop adjustments for this so you can compare hospital to hospital. When you look at race and ethnicity, actually immigrant Latina women have much fewer co-morbidity -- many fewer co-morbidities other than other racial groups. And so, their outcomes are not perhaps quite as good as you would expect when you when you do the risk adjustment. They're still good comparatively for their -- for those traditional income and education level type of measures. But that, as Connie says, does not really reflect the strengths of the community.

STEVEN CALVIN: Great.

MAGDA PECK: And I'm just appreciative of that around the weathering effects, if you will, the protective factors, the veneer that wear off with subsequent generations. So, over time, your data may tell us something that they can talk about those forces.

STEVEN CALVIN: Okay. Well, I think our last question is from Janelle, and then I think Ed will wrap things up for the day. Go ahead,

Janelle.

JANELLE PALACIOS: Thank you. You know, it's very similar, thank you for your presentations, and it's very similar to what Magda was bringing up, just, you know, why are the Native American -- where's the data on the American Indian/Alaska Native people and Connie has provided with the Health Equity Work Group. Thank you, Connie, for the California department's report on American Indian Maternal Health and I was looking through E-mail really quickly so I could send the link to everyone on chat. So, I'll do that as well. And yes, looking at it from a positive perspective versus a negative defect perspective is always key. And so, my question then, Dr. Main and Connie, please, and Dr. Mitchell, please just also share how are you going about including this data on American Indian/Alaska Native communities' maternal infants and three data points, if you include myself and then my three children for the state of California. And how are you collecting the data

and what kind of partnerships did you have to do to make way? Thank you.

ELLIOT MAIN: So, we have the ability to stratify, as I said earlier, all of our outcomes by race and ethnicity and we had been hesitant to look at Native Americans as a separate category initially because there were about 1.5 percent of the population overall, but when you divide it into hospitals, they're very small and we were worried that they may be interpreted poorly because, you know, one or two poor outcomes in small end can give you very high rates.

We've since changed that and are now in our current reporting going to be showing Native American as a separate group rather than as an other with advice about how to interpret small numbers.

The other issue that we found, similar to the US census, is if you look at women or birthing persons who are multiracial, i.e. Native American plus white or plus Hispanic or plus something else, you would actually more than double the rate

of Native Americans in our state and that's something that's seen nationally as well. And so, that's something that we're looking at as to whether you want to include the Native American plus Native American as part of multiracial in the same category and we're going to seek guidance on that. But that almost more than doubles the rate of Native Americans.

JANELLE PALACIOS: Thank you, Dr. Main. You know, what you're sharing is reflective of just, you know, historical policies that have targeted our people and continue to target as how we are defined, and it is very tricky, I agree. And what we're really trying to capture right, experiences -- experiences of those people and we're using ethnicity in this point as like a -- it's a poor measure of experiences. Thank you.

ELLIOT MAIN: The more I've gotten into reporting by race and ethnicity, the more I realize that race and ethnicity are bogus labels. It's very difficult.

JANELLE PALACIOS: Thank you.

STEVEN CALVIN: Thank you very much. I think I'd better turn it over to Ed, because we're nearing the end. But I really appreciate the three presenters. This has been incredibly helpful.

SUMMARY OF THE DAY

EDWARD EHLINGER: Yes, I agree. This is what a great session -- this whole day has been good, and it highlights, for me, when you look at -- there are things where we needed a lot more information -- congenital anomalies. You know, there's a lot of stuff that we don't know about it and the interventions have been very medical in their orientation. And there are -- on the other side is all of the community activities that are going on. Again, where we do know a whole lot of what works, but on the -- on the things we don't know on the medical side we've got the NIH with lots and lots of money who can fund research and move things along. On the other side, where you're dealing with the social issues, there's no agency that says we're going to give you some money to look at all of the things that you're

doing that work that that really can make a difference. They've been demonstrated in New Jersey and California and everyplace else. So, we -- that's why I asked that question about the political will. It is -- it's a community well, it's a community taking on the fact that moms and birthing individuals, and babies are really crucial, and we need to focus on all of the issues that are there. We know a lot what's working, you know. First Lady Murphy, you identified a whole lot of things that, you know, you're doing and are making some progress. California certainly identified it. We know what works; we just need that the political broadly defined to make that work. We need an NIH for the social determinants of health with the same kind of resources, whereas now, you know, 95 percent of it goes to medical care and only 5 percent goes to, you know, sort of the prevention activities. We need to have a little bit different balance and so thank you for instructing us about the kind of the nature of the universe that we have to work with. So, thank you

all for your contributions today and I look forward to really talking about some of those social determinants tomorrow in some of our sessions when we get back together again at noon Central or Eastern time and so, have a good night and we will see you tomorrow.

[Whereupon the meeting was concluded.]