I am Juanita Chinn. I am a sociologist and demographer as well as a Program Director in the Population Dynamics Branch in the Division of Extramural Research at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) which is a part of the National Institutes of Health (NIH). In this written testimony, I will describe the organizational structure of the NIH, discuss the US codes that provide authority to NICHD to conduct and support research on maternal health and demography, describe the portfolio of research I direct, and highlight key findings from that research and related activities. I will conclude with information regarding maternal health data.

The National Institutes of Health

The mission of the NIH is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. Its goals are to: (a) foster fundamental creative discoveries, innovative research strategies, and their applications as a basis for ultimately protecting and improving health; (b) develop, maintain, and renew scientific human and physical resources that will ensure the Nation's capability to prevent disease; (c) expand the knowledge base in medical and associated sciences in order to enhance the Nation's economic well-being and ensure a continued high return on the public investment in research; and (d) exemplify and promote the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science.

The NIH is made up of 27 Institutes and Centers (I/Cs). Each has its own specific research agenda, often focusing on a particular disease or body system. There are some that focus on specific population groups. Several I/Cs support research on maternal health, morbidity, and mortality. In fact, NIH expenditures on maternal health research totaled approximately $334 million (2019). NICHD funds the majority (about 60%) of the NIH supported maternal health research; however, 20 other I/Cs and NIH Offices funded one or more research projects in fiscal year 2019.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

NICHD's mission is to lead research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all. NICHD's strategic plan can be found here: https://www.nichd.nih.gov/sites/default/files/2019-09/NICHD_Strategic_Plan.pdf. In the strategic plan, NICHD identifies maternal mortality as an area in which it will concentrate efforts. The U.S. Code includes all of the laws of the United States. The sections of the U.S. Code listed below are relevant to the organization and purpose of the NICHD.

- 42 USC 281 (Sec. 401): Organization of the NIH. Identified NICHD as one of the 27 national research institutes at NIH.

- 42 USC 285g (Sec. 448): Purpose of the Institute. Provided legislative authority for NICHD to conduct and support "research, training, health information dissemination, and other programs with respect to gynecologic health, **maternal health**, child health, intellectual disabilities, human growth and development, including prenatal development, **population research**, and special health problems and requirements of mothers and children."

The NICHD Division of Extramural Research (DER) supports the research, training, and activities within its scope of scientists external to NICHD, e.g. researchers at universities. DER contains several scientific branches that support research on maternal health, morbidity, and mortality, including the Population Dynamics Branch (PDB). PDB supports research and research training in demography, reproductive health, and population health. Within this branch, I direct a program of training and research on Mortality, Demography of Health, Demography of Health Disparities, and Population Composition.

The Role of a Program Director[1, 2]

Program directors, officially referred to as Health Scientist Administrators or Medical Officers, aid in the advancement of science by identifying knowledge and research gaps and bringing them to the attention of the agency leadership. To facilitate this, they convene scientific workshops and conferences as well as develop funding opportunity announcements (FOAs) to stimulate research in specific areas of science[1]. Moreover, program directors at the NIH manage funded grants. Program directors help potential applicants with the application process. Once a proposal is funded, program directors monitor the progress of the science.

Recent NICHD Maternal Mortality Workshops[3, 4, 5, 6]

Research plays a crucial role not only in understanding the breadth of the maternal mortality crisis, but in identifying innovative evidence-based solutions[7]. To identify maternal mortality research gaps and needs, NICHD convened two workshops, one a scientific meeting and the other a community engagement forum. At the community engagement forum, panelists shared experiences about patient-provider interactions and processes for making clinical care decisions and discussed opportunities and challenges that communities, healthcare providers, researchers, and policy leaders should consider when planning to address maternal morbidity and mortality at the local level. The scientific meeting convened national experts to discuss and identify research gaps in three major themes, Data and Demography, Obstetrical and Health System Factors, and Disparities and Social Determinants. A summary paper of the scientific meeting was published October 2020[8].

> "The inclusion of groups underrepresented in biomedical research (racial and ethnic minorities, low socioeconomic status and rural populations, and women at higher risk of maternal mortality and other adverse maternal events) in MMRCs* and in research was stressed as a research need and

* Maternal Mortality Review Committees

challenge. Other needs included ways to measure healthcare provider access and availability, healthcare provider knowledge and ability to handle acute events, and healthcare delivery factors, as well as approaches to address culture mistrust and implicit bias. The inability to link maternal and infant health records was cited as a challenge to fully understand the risks associated with SMM and maternal mortality. Participants identified technology, such as telehealth and the use of wearable devices, as research opportunities[8]."

The NICHD and the NIH Office of Research on Women's Health (ORWH) co-sponsored a more recent (May 2020) scientific meeting, *Pregnancy and Maternal Conditions that Increase Risk of Morbidity and Mortality Workshop.* This meeting was in response to increasing U.S. maternal mortality rates. The goal was to develop a research agenda targeted at the clinical causes of maternal morbidity and mortality. An interdisciplinary team of experts explored why women die from certain conditions (e.g., postpartum hemorrhage, hypertension, cardiovascular disease, infection, etc.), what can be done to identify patients at risk, and what interventions are required to reduce maternal morbidity and mortality. A summary of this meeting is in preparation.

PDB Maternal Mortality Portfolio

A 2016 study conducted by Dr. Marian MacDorman and colleagues, supported by NICHD, found that previously reported maternal mortality rates in the United States had been under-estimated and that the maternal mortality levels were actually much higher than it had been reported[9]. US maternal mortality rates were much worse relative to those of other industrialized nations than expected.

In January 2020, the National Center for Health Statistics (NCHS) published official maternal mortality statistics[10]. These were the first published maternal mortality statistics NCHS and its parent agency, the Centers for Disease Control and Prevention (CDC), had published since 2007. The delay was due, in large part, to the poor quality of data available. The 2020 publication reported that the 2018 U.S. maternal mortality rate was 17.4 maternal deaths per 100,000 live births.

"This rate is higher than the last time NCHS published a national rate (12.7 in 2007), but the increase in the *maternal mortality rate* largely reflects changes in the way the data were collected and reported. In 2018, 658 women who died of maternal causes. Wide racial/ethnic gaps exist between non-Hispanic Black (37.1 per 100,000 live births), non-Hispanic White (14.7), and Hispanic (11.8) women, which is consistent with earlier data. The maternal mortality rate for women aged 40 and over (81.9 per 100,000 live births) is nearly 8 times that for women under age 25 (10.6)[10]."

NICHD is currently funding another project by Dr. MacDorman, *Methodological Issues in Maternal Mortality Research*[11]. This study is analyzing the 2015-16 the literal cause of death data (that is, the actual words written in the cause-of-death section of the death certificate) to identify and correct problems in the collection and coding of data on maternal deaths— for example, by identifying death records that incorrectly identify the cause of death as a "maternal death," for instance, because the decedent is male or either too young or too old to have been pregnant. Dr. MacDorman is also developing methodologies

to provide more detail on the specific causes of maternal deaths, linking deaths to specific organ systems and disease pathways. Dr. MacDorman will use these new estimates of maternal deaths to assess the level of error in traditional estimates of maternal mortality and to analyze maternal mortality levels and trends by sociodemographic characteristics (e.g. race and age) and cause of death. This research will increase scientific knowledge on maternal mortality disparities related to maternal age, race, ethnicity, and region, and should lead to more accurate identification of populations at high risk of maternal mortality.

To reduce maternal deaths, preventable severe maternal morbidity must be reduced or eliminated. In an NICHD supported study, *Understanding Severe Maternal Morbidity: Predictors, Trends, and Disparities*[12], Dr. Stephanie Leonard and colleagues used 1997-2014 California hospital records data to examine both overall trends in severe maternal mortality and trends racial and ethnic disparities in severe maternal mortality. They found that racial and ethnic disparities in severe maternal morbidity have persisted and increased[13]. Furthermore, the researchers found that the increased prevalence of the known risk factors for severe mortality morbidity —e.g., blood pressure disorders, asthma, and Caesarean birth—do not fully explain the increase the persistence and increase in racial and ethnic disparities. Severe maternal morbidity was highest among non-Hispanic Black women (1.63 percent), followed by non-Hispanic American Indian or Alaska Native women (1.30 percent), non-Hispanic Asian or Pacific Islander women (1.10 percent) and Hispanic women (1.09 percent), and was lowest among non-Hispanic White women (0.84 percent). During the period studied, severe maternal morbidity increased by roughly 170 percent for all groups. The researchers called for future studies, using information not available from hospital records and health care providers, to explain the racial and ethnic disparities in severe maternal morbidity.

In the same study, Dr. Leonard and team found that the increasing rate of severe maternal morbidity overall is also not accounted for by the simultaneous increase in known risk factors for these complications, (e. g. changes in pre-pregnancy health and cesarean delivery rates)[14]. Severe maternal morbidity increased by 65 percent from 2007 to 2014. The known pre-pregnancy risk factors for severe maternal morbidity (older maternal age, maternal obesity and pre-pregnancy comorbidity) also increased during this time, but cesarean delivery did not. The researchers estimate that combined, the pre-pregnancy risk factors contributed to 13 percent of severe maternal morbidity overall, and cesarean delivery contributed to 37 percent. However, *changes in the prevalence of these risk factors did not account for the increase in severe maternal morbidity during this time period*.

If older maternal age, maternal obesity, asthma, and other known clinical risk factors do not fully account for the changes in severe maternal morbidity rates—and, ultimately maternal mortality—then other, non-clinical, risk factors should be examined, including social determinants of health such as hospital quality, access to quality care, culturally and linguistically appropriate services, as well as institutional policies and practices.

Dr. Elizabeth's Howell's research, supported by the NIH National Institute of Minority Health and Health Disparities (NIMHD), has found that women from racial and ethnic minority groups give birth in lower quality hospitals and hospitals with higher rates of severe maternal morbidity[15, 16]. Her qualitative research reveals that many Black and Latina women giving birth in low performing hospitals experience poor patient-provider communication and difficulties in obtaining appropriate prenatal and postpartum care.

Additionally, NICHD and the NIH National Institute of Nursing Research (NINR) supported the development and validation of an *Obstetric Morbidity Scoring System* for predicting overall severe maternal morbidity and non-transfusion severe maternal morbidity[†]; this system will allow consistent comparisons of severe maternal morbidity between groups of patients, such as patients from different hospitals[17, 18].

Dr. Maeve Wallace, and her colleagues at Tulane University, are conducting NICHD-funded research on social factors associated with maternal mortality, including income inequality, structural racism, and residential segregation. Their research examines how specific state-level policies influence maternal (and infant) mortality. The researchers are examining how state-level policies intended to protect women's health and improve access to health care affect the incidence of infant and maternal mortality and whether the effects of these policies differ by race and socioeconomic status.

Homicide is a leading cause of death during pregnancy and postpartum, yet it remains understudied. Homicide is not typically captured in examinations of pregnancy-related deaths or maternal mortality. It is usually classified as a pregnancy-associated death. It is not considered to be something resulting from a chain of events related to the pregnancy (see glossary). The answer to the question, "would this have happened had the woman not been pregnant?" remains debatable. Dr. Wallace posits that failure to identify and address factors underlying pregnancy-associated homicide will perpetuate racial inequity in mortality during pregnancy and postpartum. NICHD also supports a research project by Dr. Wallace in which she and her team are examining how, "key features of the social context in which women live – income inequality, structural racism, community violence, and spatial social polarization – increase their risk of death during pregnancy/postpartum and contribute to racial inequity in mortality[19]." They are working to identify which social contexts increase risk for pregnancy-associated mortality, examine trends over time, and identify mediating pathways between social contexts and pregnancy-related mortality and pregnancy-associated homicide.

Some results have already been published from this study. Researchers found that homicide is a leading cause of death among pregnant and postpartum women in Louisiana[20]. They estimated that, for every 100,000 women who were pregnant or postpartum, there were 12.9 homicide deaths, which outnumbered deaths from any single obstetric cause, including hypertensive disorders (3.2) and amniotic fluid entering the bloodstream (4.8). The risk of homicide among women, particularly young women, is increased with pregnancy. Risk of homicide death was twice as high for women and girls during pregnancy and the postpartum period, compared to women and girls who were not pregnant. Pregnancy and postpartum deaths were highest for women and girls ages 10 to 29. Nationally, pregnancy-associated homicide was greater than 3 times more likely to occur in non-Hispanic Black women compared with non-Hispanic Whites[21].

As discussed during a number of NICHD-sponsored workshops[3, 4, 5, 6], differential access to care, especially high-quality care, is a critical factor affecting disparities in maternal mortality. In research findings

[†] Non-transfusion SMM includes SMM cases in which blood transfusion was not the sole indicator of a severe complication

published October 2020, Dr. Wallace and her team found that in Louisiana the risk of pregnancy associated death and the risk of pregnancy related death were, as expected, significantly higher among women residing in maternity care deserts‡ compared to women in areas with greater access to care. However, racial disparities in the risk of pregnancy related and associated death persisted beyond differences in geographic access to maternity care[22]. Even when accounting for access to care, Black-White racial disparities in maternal mortality persist.

Additional Initiatives

The **I**mplementing a **M**aternal health and **PR**egnancy **O**utcomes **V**ision for **E**veryone (IMPROVE) Initiative supports research to reduce preventable causes of maternal deaths and improve health for women before, during, and after delivery. The initiative is supported by multiple NIH Institutes and is led by NICHD, the NIH Office of the Director (OD), and ORWH. Under IMPROVE, approximately $7.2 million in grants was awarded through a Notice of Special Interest on Maternal Mortality. Areas of research include heart disease, hemorrhage or bleeding, and infection (the leading causes of U.S. maternal deaths); contributing conditions, such as diabetes, obesity, mental health disorders, and substance use disorders; and structural and healthcare system factors that may contribute to delays or disruptions in maternal care. NICHD is supporting four of these awards, totaling about $1 million[23, 24].

In fiscal year 2020, NIMHD lead a group of NIH institutes and offices (the National Heart, Lung, and Blood Institute, NINR, and OD) that issued a Funding Opportunity Announcement on *Addressing Racial Disparities in Maternal Mortality and Morbidity.* This initiative supports multidisciplinary research examining mechanisms underlying racial and ethnic disparities in maternal mortality and morbidity, testing the efficacy and/or effectiveness of multi-level interventions, and/or research strategies to optimally and sustainably deliver proven-effective prevention and treatment interventions to reduce these disparities[25].

Closing

Current CDC estimates of *pregnancy-related mortality rates* show disparities that are stark. Pregnancy related mortality rates among non-Hispanic Black (30.8 percent) and non-Hispanic American Indian/Alaska Native or Indigenous women (29.7 percent) exceed rates for all other racial/ethnic populations, exceeding rates for white women by 320 percent and 230 percent (respectively). Disparities are even more pronounced among older age groups[26].

Research is critical in developing an evidence base on how institutional policies impact the racial and socioeconomic disparities observed in maternal mortality. It is one thing to know anecdotally (or suspect) that racism, as demonstrated through individual level experiences of everyday discrimination or through institutional level practices and policies that disproportionally impact marginalized populations

‡ Counties with no hospitals offering obstetric care and no OB/GYN or certified nurse midwife providers.

negatively, is a fundamental cause of maternal mortality. It is another thing to create the evidence base. The narratives should not be silenced, they fuel the scientific investigation. Research is an iterative and cumulative process. Creating the evidence-base documents the pervasive disparities and identifies opportunities for informed intervention and prevention.

Maternal mortality does not exist outside of the social context in which it takes place, nor does it exist outside of the greater context of young adult mortality. Understanding the social determinants of maternal mortality will have broader impacts on what is known about young adult mortality and any knowledge gained on young adult mortality will impact what is known regarding maternal mortality.

Glossary

Maternal death: death of women while pregnant or within 42 days of being pregnant, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes

Pregnancy-related death: death of a woman while pregnant or within 1 year of the end of a pregnancy, regardless of the outcome, duration or site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes

Pregnancy-associated death: death of a woman while pregnant or within 1 year of the termination of pregnancy, regardless of the cause

Severe maternal morbidity: unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman's health

Other NIH Resources on Maternal Mortality (non-Exhaustive List)

NICHD Maternal Mortality Health Topic: https://www.nichd.nih.gov/health/topics/maternal-mortality

NIH Office for Research on Women's Health Maternal Morbidity and Mortality Web Portal: https://orwh.od.nih.gov/research/maternal-morbidity-and-mortality

NICHD Maternal Fetal Medicine Units Network: https://www.nichd.nih.gov/research/supported/mfmu

Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC): https://www.nichd.nih.gov/about/advisory/PRGLAC

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