# U.S. Department of Health and Human Services National Institutes of Health (NIH)

# 64th Meeting of the National Advisory Council on Minority Health and Health Disparities (NACHMD)

#### **Videocast**

NIH Building 31 31 Center Drive Bethesda, MD 20894

September 1, 2023 8:30 a.m. EST - Adjournment

## **Meeting Minutes**

#### **Council Members Present**

Eliseo J. Pérez-Stable, M.D.,
Director, National Institute on Minority Health and Health Disparities (NIMHD)
Samuel E. Adunyah, Ph.D., Meharry Medical College
Kendrick E. Curry, Ph.D., M.Div., The Pennsylvania Avenue Baptist Church
Mario Sims, Ph.D., University of California at Riverside
Chau Trinh-Shevrin, DrPH, New York University School of Medicine

## **Council Members Absent**

Emma Aguila, Ph.D., University of Southern California Valerie Blue Bird Jernigan, MPH, DrPH, Oklahoma State University

#### **Ad Hoc Members Present**

Jose Arturo Bauermeister, MPH, Ph.D. Lisa Marie Cacari Stone, Ph.D. Frank J. Penedo, Ph.D.

#### **Ex Officio Members Present**

Crystal Henderson, EDD, Veterans Health Administration, Department of Veterans Affairs Donald Shell, M.D., Office of the Assistant Secretary of Defense, Defense Health Headquarters Jane Simoni, Ph.D., Office of Behavioral Sciences Research, NIH

# **Representatives Present**

Monica Webb Hooper, Ph.D., Deputy Director, NIMHD
Rina Das, Ph.D., Division Director, Division of Integrative Biological and Behavioral Sciences, NIMHD
Nathan Stinson, Ph.D., M.D., MPH, Director, Division of Community Health and Population Science,
NIMHD

# **Executive Secretary**

Paul Cotton, Ph.D., RDN, Director, Office of Extramural Research Activities, NIMHD

# **Presenters**

Lisa L. Barnes, Ph.D., RUSH Medical College
Marie A. Bernard, M.D., Chief Officer for Scientific Workforce Diversity, NIH
Neil S. Calman, M.D., Icahn School of Medicine at Mount Sinai
Rada Dagher, Ph.D., MPH, NIMHD, NIH
Josh Denny, M.D., M.S., All of Us Research Program, NIH
Priscilla Grant, J.D., NIMHD, NIH
Gabriel Lai, NIMHD, NIH
Priscah Mujuru, DrPH, RN, NIMHD, NIH
Carolina Solis Sanabria, M.D., MPH, NIMHD, NIH

# **Call to Order and Welcome**

Dr. Pérez-Stable called the open session to order at 8:30 a.m.

#### **Roll Call, Minutes Review**

Dr. Cotton called the roll and invited members and staff to introduce themselves. The council unanimously approved the minutes of its May 2023 meeting and announced that the next session of NACMHD on February 2, 2024, will be virtual. The next in-person meeting dates are May 31, and September 6, 2024; the 2025 meeting dates are February 4, May 16, and September 5. Members were reminded that NIH policy allowed them no more than one absence per calendar year, and that they were prohibited from serving on NIH peer review panels while on the council.

#### **NIMHD Director's Report and Discussion**

https://videocast.nih.gov/watch=52195&start=590

Dr. Pérez-Stable greeted the council and provided a report on NIMHD-related activities since the May 2023 council meeting.

- The White House appointed Mandy Cohen, M.D., M.P.H., an internal medicine physician who led the North Carolina Department of Health and Human Services, as Director of the Centers for Disease Control and Prevention (CDC).
- <u>Jeanne Marazzo, M.D.</u>, the Director of the Division of Infectious Diseases at the University of Alabama at Birmingham was selected as the Director of the National Institute of Allergy and Infectious Diseases.
- <u>Jane M. Simoni, Ph.D.</u>, was selected as the new NIH Associate Director for Office of Behavioral and Social Sciences Research, and Director of the NIH Office of Behavioral and Social Sciences Research. She brings more than 25 years of experience in research focused on health disparities and resilience among populations that have been socially marginalized.
- <u>Patricia Flatley Brennan, R.N., Ph.D.</u>, will retire from federal service and her position as the Director of the National Library of Medicine on September 30, 2023.
- Dr. Pérez-Stable welcomed six new council members to NACMHD.
- Since FY2018, the number of R01 applications has risen from 281 to 576, with the award success rate climbing from 13.9% to 17.4% in FY2022. Dr. Pérez-Stable hopes to have an award rate of 20% over the next five years.
- 80% of R01 applications to NIMHD in FY2022 were in response to Program Announcements compared to 40% in FY2019. We need NIMHD scientists to send us their best ideas and not just adapt to Program Announcements
- Dr. Pérez-Stable discussed presentations and addresses he has made since the previous council
  meeting in May, including to the American Thoracic Society, the NIMHD Health Disparities
  Research Institute, and the NIH Tribal Advisory Committee.
- The John Lewis NIMHD Research Endowment Program awards were announced on August 1, 2023, and will support minority health and health disparities research capacity and infrastructure at six institutions:
  - o Florida International University, Miami, Florida
  - University of North Texas Health Science Center, Fort Worth, Texas
  - o SUNY Downstate Medical Center, Brooklyn, New York
  - o Charles R. Drew University of Medicine and Science, Los Angeles, California
  - o Meharry Medical College, Nashville, Tennessee
  - o Xavier University of Louisiana, New Orleans, Louisiana
- NIMHD participated with several other NIH institutes in the 2023 Design by Biomedical
  Undergraduate Team (DEBUT) Challenge, an annual contest for undergraduate teams not in the
  medical field to design creative new solutions to emerging healthcare problems, led by the
  National Institute of Biomedical Imaging and Bioengineering (NIBIB), and VentureWell. NIMHD
  sponsored a \$15,000 award for the Healthcare Technologies for Low-Resource Settings leading
  to the development of a point of care internal hemorrhage diagnostic tool.
- A Commentary published in Health Psychology co-authored by Drs. Webb Hooper and Pérez-Stable focused on the meaning of health equity and on the scientific pillars of health disparities

research. NIMHD prioritizes its research under the conception that race and ethnicity and socioeconomic status (SES) are the fundamental pillars of health disparities science and must continue to make these factors primary in its research and funding priorities, along with their intersectionality in rural populations, sex and gender minority (SGM) individuals, and other demographic factors and conditions. There will also be an effort to re-evaluate the default selection of White persons as the reference population in health disparities science, as the 60% of population that self-identifies as White do not always have the best health outcomes of all racial and ethnic groups.

- The 2023 NIMHD Health Disparities Research Institute comprised 52 early-stage career scientists representing 24 states, the District of Columbia, and Guam. Of the 52 scholars, 34 were of African American/Black or Latino/Hispanic identity, and 81 percent were identified as female.
- HDPulse was recognized as a resource for improving minority health and reducing health disparities. The Office of Minority Health highlighted HDPulse in its Health Resources Digest and it received an honorable mention in Academy Health's 2023 Health Equity DataJam.
- <u>Dorothy Castille, PhD</u> received the U.S. Department of Health and Human Services (HHS)
   Secretary's Commendation for exceptional service and leadership during the Public Health
   Emergency phase of the COVID-19 pandemic.
- The Rapid Acceleration of Diagnostics for Underserved Populations (RADx-UP) program produced the reference guide *Advocating for Racial Equity in the U.S. Health Care System* with the goal of helping patients and clinicians better navigate the barriers related to structural racism in U.S. healthcare.
- The Florida Community Engagement Alliance (CEAL) Against COVID-19 Disparities developed a
  community outreach project focused on recruiting and training barbers and beauty salons to
  spread accurate information about the virus and vaccination, particularly to the African
  American and Latino populations.
- The 2023 NIMHD Structural Racism and Discrimination Grantee Meeting took place in July. The 2021 RFA "Understanding and Addressing the Impact of Structural Racism and Discrimination in Minority Health and Health Disparities," funded 34 R01 grants across 14 different institutes committing \$38 million in the first year of funding. The meeting brought together NIH leaders along with 150 participants, including more than 80 grantees and study teams.
- A July 2023 study in the *Annals of Internal Medicine* measured the disparities in <u>Guideline-Recommended Statin Use for Prevention of Cardiovascular Disease</u>. Statins prevent cardiovascular disease by lowering LDL cholesterol and decreasing the incidence of cardiovascular events and their mortality. The study found statin use to be lower for secondary prevention in Black men and women (19% to 25%), Mexican American (64%) and other Latina women (43%), and White women (31%).
- A National Health and Nutrition Examination Survey (NHANES) <u>study</u> evaluated risk factors and racial and ethnic disparities in cardiovascular disease mortality with death rates per 100,000 person-years varying from 485 for Black, to 385 for White, and to 292 for Latino populations. It primarily focused on Black-White differences and found that disparity is reduced when adjusted for metabolic or behavioral risk factors and eliminated when adjusted for social factors, like unemployment, low family income, and food insecurity.
- <u>Data</u> from the Indian Health Service revealed that the age-adjusted Alzheimer Disease (AD) mortality rate among American Indian/Alaska Native (AI/AN) people increased by 22% between 2011 and 2019. The AD mortality risk was 14% lower as AI/AN population density increased, was 34% higher in more deprived counties, and was 20% lower in non-metro counties compared to metro counties.
- A <u>study</u> was published in the *Journal of Racial and Ethnic Health Disparities* to measure the implicit bias of the term "People of Color" (POC), which was introduced in the late 20th century to replace condescending terms like "non-White" and "minority." In contrast to when specific racial and ethnic groups were specified, when the general category POC was used, they observed a discrimination towards POC only for Black non-Hispanic participants; White NH participants showed no discrimination. This suggests that using the category POC in implicit measures may be inappropriate when evaluating discrimination and attitudes towards Black and Hispanic individuals as it may not capture specific discrimination towards these groups.

- Oregon increased the span of emergency Medicaid for new mothers to 1 year as a policy intervention for morbidity and mortality arising from postpartum symptoms and complications.
   Recipients increased their receipt of recommended glycemic screening and care as compared to South Carolina, which was considered a comparison state in this analysis.
- <u>Communication research</u> on patient-clinician medical decision-making in 25 Black adults hospitalized with serious illnesses demonstrated perceptions of racism in healthcare settings, and they reported a silencing of their knowledge and lived experiences about their bodies and illness by healthcare workers. Intersecting marginalized identities magnified these concerns.
- Percutaneous coronary intervention (PCI) within 15 minutes of acute myocardial infarction
  presentation is associated with better outcomes. <u>Data</u> from the *Journal of the American Heart*Association shows that more deprived areas produce worse health outcomes following PCI than
  more advantaged communities because of differences in PCI access.
- The Periodontal Disease Treatment After Stroke or Transient Ischemic Attack: The PREMIERS Study, a Randomized Clinical Trial tested whether intensive Periodontal Disease (PD) treatment reduces the risk of recurrent vascular events among persons hospitalized with an ischemic stroke or high-risk transient ischemic attack and with at least 5 natural teeth. Five sessions of full mouth intensive PD treatment was compared to standard PD treatment and secondary-outcome measures showed a trend toward improvement, with significant changes noted in diastolic blood pressure and high-density lipoprotein in both the treatment arms. Quality of Life, including family functioning and cohesion, was determined to strongly impact anxiety, depression, and hopelessness for Latino patients coping with advanced cancer in a study published in Palliative & Supportive Care.
- Endocrine-disrupting chemicals in plastics and personal care products are associated with poor
  developmental outcomes, but the impact of these chemicals on aging biomarkers in children
  remains unexplored. The Center for the Health Assessment of Mothers and Children of Salinas
  (CHAMACOS) <u>study</u> of primarily Mexican American mother-child pairs suggested that prenatal
  exposures on epigenetic age may only manifest during specific periods of child development,
  such as menarche, and may be biological sex-dependent.
- The <u>NIH-funded analysis</u> of U.S. cause-specific mortality, the most comprehensive peer-reviewed study to date of on how racial and ethnic disparities vary by location and cause of death has produced several findings:
  - Mortality is higher in AI/AN and Black population for most causes of death.
  - Geographical variation in mortality within and across racial and ethnic groups exists for all causes of death.
  - Cardiovascular diseases and neoplasms were the first and second leading causes of death, respectively, within and across all racial and ethnic groups; diabetes and kidney diseases ranked among the top five causes of death in every racial and ethnic group.
- The Incorporating the Effects of Structural Racism in Simulation Models of Cancer Mortality study, making use of NIMHD's PhenX Toolkit, has identified 150 measures of structural racism including measures of racial residential segregation. The study proposes a set of recommendations for best practices for modelers to consider when incorporating the effects of structural racism into simulation models.
- In a financial hardship <u>study</u> during COVID-19 (January to February 2021), a nationally representative sample of adults who used commercial tobacco products -- cigarettes, vaping products, cigars and cigarillos, other combustibles, and smokeless tobacco-- reported an increased receipt of tobacco discount coupons among people experiencing financial hardship, signaling that the tobacco industry continues to use marketing strategies to target individuals who are financially vulnerable.
- Captain Anthony Johnson, Scientific Advisor and Training Director for NIMHD's Division of Intramural Research (DIR), attended the 2023 Society for Epidemiologic Research Annual Conference in Portland, Oregon to conduct outreach to over 2,000 scientific professionals and young investigators in attendance, with the goal of increasing collaboration and to expand the scientific workforce.
- Dr. Pérez-Stable highlighted the NIH-wide <u>Stadtman Investigator Search</u>, which is an annual search open to all doctoral-level, biomedical and behavioral researchers interested in NIH

intramural tenure-track positions, noting that all current tenure-track investigators were found through a Stadtman search.

• Eight NIMHD-supported summer interns participated in the NIH Poster Presentation Day

#### **Presentations**

All of Us Research Program: Improving Health Through Diverse Technology, Huge Cohorts, and Precision Medicine,

Joshua Denny, M.D., M.S., Chief Executive Officer, All of Us Research Program, NIH <a href="https://videocast.nih.gov/watch=52195&start=4680">https://videocast.nih.gov/watch=52195&start=4680</a>

Dr. Joshua Denny presented on the All of Us research program. The mission of the All of Us program is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment and care for all. Dr. Denny explained that to achieve this mission, the All of Us team has nurtured partnerships for decades, seeking to enroll at least one million diverse participants, it delivers one of the largest and richest biomedical datasets that is broadly available and secure, and has catalyzed an ecosystem of communities, researchers, and funders who make All of Us an indispensable part of health research.

The program's core values include:

- Participation is open to all.
- Participants are partners and reflect the rich diversity of the U.S.
- Trust will be earned through transparency.
- Participants have access to their information.
- Data will be accessed broadly for research purposes.
- Security and privacy will be of the highest importance.
- The program will be a catalyst for positive change in research.

The All of Us program launched nationally in May of 2018 and now has nearly 700,000 participants, with more than 395,000 electronic health records and 498,000 bio samples. About 50% of participants are from race and ethnic minoritized populations in addition to persons who identify as SGM, low SES, or people with disabilities. The Division of Engagement and Outreach (DEO), led by Karriem Watson, PhD and with more than 100 awardees, is focusing on a more robust tribal engagement through trusted national and local partners.

Data collected from the program include:

- Electronic Health Records (demographics, vital signs, diagnoses, procedures, medications)
- Participant surveys on subjects such as lifestyle, personal and family medical history
- Physical measurements (height, weight, blood pressure, heart rate, BMI)
- Bio samples (blood, saliva, urine)
- Wearable data (Fitbit data for daily activity, sleep quality)

In turn, participants receive genetic information, comparative survey data, aggregate study results and ongoing study updates, scientific findings, and opportunities to be contacted for other research opportunities. Genomic health-related results inform participants through genetic counselors about hereditary disease risk, interactions between medicines and their DNA, and their genetic ancestry and traits. The overall frequency of actionable pharmacogenomics results among genetic ancestry groups was 97-99% across all ancestry groups, despite varying significantly for individual genes. For example, nearly a third of participants were exposed to a drug or medication that their genetics indicated could be avoided.

As of April 20, 2023, the All of Us Researcher Workbench, available to academic healthcare and not-for-profit organizations, contains the largest set of whole genome sequences widely available for research, with nearly 250,000 whole genome sequences available to advance precision medicine. The All of Us

program is creating an updated genomic data set that is more diverse and contains more underrepresented populations than other sources. The Researcher Workbench is currently utilized by more than 6,500 registered researchers (74% of which are underrepresented in the biomedical workforce) at nearly 600 institutions, including 39 Historically Black Colleges & Universities and 54 Hispanic Serving Institutions. Thus far, there have been over 230 All of Us publications and Dr. Denny expects that number to increase as research returns and studies mature over the course of time.

Council members raised several questions including:

- The possibility of participants being identified, the process of self-reporting, and the possibility of placing advertisements in under resourced institutions?
  - Response: All of Us has an Ambassador program and we encourage all institutions to come aboard. If your institution does not have an agreement, we encourage you to contact us to see if one can be developed.
- How were papers proposed by investigators prioritized?
  - Response: All of Us is an open resource platform so the program does not prioritize specific papers.
- What is the geographic link of data in terms of resource and health interventions?
  - There are limited geospatial data currently, along with the American Community Survey (ACS).
- What about community access to the data from various interested parties?
  - o Response: A non-profit patient advocacy institution was its largest user.
- What are some of the challenges of harmonization of data of electronic health records
  - Response: They generally use the Observational Medical Outcomes Partnership (OMOP)
     Common Data Model (CDM), and vendors of EHR are fewer, noting that there is a long journey to get where they want to be when it comes to data harmonization.
- What about the review process and process to support dissemination of data back to community?
  - Response: Projects are identifiable and can be flagged, and All of Us puts disseminates a newsletter including summaries available at a fifth-grade reading level in English and Spanish.

Diversity, Equity, and Inclusion at NIH from the COSWD Perspective

Marie A. Bernard, M.D., Chief Officer for Scientific Workforce Diversity, Office of the Director, NIH

<a href="https://videocast.nih.gov/watch=52195&start=7450">https://videocast.nih.gov/watch=52195&start=7450</a>

Dr. Marie Bernard, Chief Officer for Scientific Workforce Diversity (COSWD), explained the critical need for diverse perspectives to produce the best science. A study from <a href="Nature Medicine">Nature Medicine</a> that examined 2.5 million scientific articles found that homophily -- researchers publishing with co-authors of the same ethnicity -- was associated with publication in lower-impact journals with fewer citations, and this trend held when applied to geographic diversity and the number of homogeneous references in the paper. Assuring full inclusion of the variety of individuals who can contribute to scientific excellence, including those systematically disadvantaged based on race and ethnicity, involves implementing comprehensive, institutional-level strategies and approaches informed by research

Taking the Alzheimer's disease (AD) drug Aduhelm as an example, Dr. Bernard noted that underrepresented groups more often experience missed or delayed diagnosis of dementia than White persons. Additionally, in drugmaker Biogen's phase 3 trials, 89% of participants were White and 9% were Asian, leaving only 2% of trials in other populations, despite AD being more prevalent in the Black/African American and Latino/Hispanic communities. One of the reasons for this disparity is that Black/African American, Latino/Hispanic, and American Indian/Alaska Native physicians are more likely than White physicians to practice in underserved communities, and Dr. Bernard called for more Inclusive clinical and community-based research.

On March 20, 2023, NIH released its Strategic Plan for Diversity, Equity, Inclusion, and Accessibility (DEIA), laying out the framework for what NIH envisions doing from 2023-2027 to address issues

regarding inclusion. The mission is for NIH to embrace, integrate and strengthen DEIA across all NIH activities in service of the NIH mission with the vision that NIH will be a people-centered organization, representative of our nation's diversity, where all people feel a sense of belonging as they advance that mission.

The DEIA Strategic Plan Framework consists of three objectives:

- Grow and sustain DEIA through structural and cultural change
- Implement organizational practices to center and prioritize DEIA in the workforce
- Advance DEIA through research

NIH has several other strategic plans for different areas of focus, including Minority Health and Health Disparities, Tribal Health, Woman's Health, Health and Well-Being of SGMs, and the COSWD strategic plan, and it is conducting DEIA activities with partners like the Native American Research Centers for Health (NARCH) and the Community Engagement Alliance (CEAL) Against COVID-19 Disparities.

Dr. Bernard's vision for COSWD is to enable NIH and NIH-funded institutions to benefit from the nation's full range of talent and foster creativity and innovation in science with the mission of making NIH the thought leader in scientific workforce diversity, using evidence-based approaches to catalyze cultures of inclusive excellence. This mission can be achieved by building the evidence using NIH as a test bed, disseminating the evidence across the biomedical research workforce ecosystem, and acting on the evidence by advancing integrated, institution-wide systems. This process manifests in the form of the 21st Century Scholars Program, mentorship programs, and Notices of Special Interest (NOSIs) or administrative supplements to recognize excellence in DEIA.

The NIH UNITE Initiative arose due to the events of 2020, including the disparate morbidity and mortality of COVID-19 along with the murder of George Floyd, bringing into sharp relief the ongoing reality of racial and ethnic injustice in the U.S. It compelled NIH to examine itself internally and externally with a racial and ethnic equity lens and led to the development of new initiatives that are broadly applicable. UNITE is a people-focused and data-driven initiative to look at health disparities and minority health research, complementary to NIMHD's work. The effect of these initiatives and other efforts by COSWD can be seen in the number of Notices of Funding Opportunities (NOFOs) related to minority health and health disparities rising from 18 in 2018 to 115 in 2022, changing performance standards for institutes and center directors that requires that they address DEIA, and in a review of NIH Director's Awards to make them more inclusive of nonscientists at lower pay levels that help push the science forward.

The Distinguished Scholars Program (DSP) is built upon the Stadtman and Lasker investigator programs and provides a self-reinforcing community of Principal Investigators (PIs) devoted to diversity and inclusion. Since its implementation, underrepresented minority and female intramural tenure-track investigators have risen at a dramatic rate. The Faculty Institutional Recruitment for Sustainable Transformation (FIRST) program is modeled after the DSP, with funding being given to academic institutions to bring in cohorts of scientists and provide them with increased mentoring, lab resources, and other assistance. Dr. Bernard concluded by mentioning several new and enhanced NOFOs, as well as COSWD's \$1 million prize competition for institutional excellence in DEIA.

# Statement of Understanding Priscilla Grant, J.D., Chief Grants Management Officer <a href="https://videocast.nih.gov/watch=52195&start=10170">https://videocast.nih.gov/watch=52195&start=10170</a>

Priscilla Grant provided an overview of the statement of understanding that directs the council. NACMHD is responsible for advising, consulting with, and making recommendations to the director of NIMHD on matters relating to the research activities and functions of NIMHD. Council members serve as a national resource in developing, recommending, and setting the Institute's policy and research priorities. On occasion, special working groups may be formed by or at the request of council to examine and address critical scientific or policy issues of importance to the institute and its constituencies, and

NIMHD will inform the council of current scientific, budgetary, legislative or other issues that may have an impact on NIMHD and its constituencies.

There are two council sessions, one open to the public and the other closed. In the open session, there is discussion of scientific and policy issues and concept clearance of the special initiatives. In the closed session, there is secondary review of grant applications. Actions considered individually include:

- Plans for funding under RFAs
- Applications of high or low program priority
- · Applications from foreign institutions within a fundable range
- Summary statements of special interest or needing discussion/action
- Some investigator-initiated applications of PIs receiving over \$2 million total costs per year from active NIH awards

NIH-published RFAs do not allow appeals of initial peer review. If there are any appeals of the review of unsolicited applications, the council will be informed. The statement of understanding has a section that lists administrative decisions and actions that do not require council recommendation, such as the change of a PI, the change of domestic institution, or administrative supplements for increased costs within the previously peer reviewed and approved scope of a funded grant.

When reviewing grant applications during the closed session, the council may not change the scores assigned by the Scientific Review Group (SRG); however, available options include concurrence with the SRG's recommendation, nonconcurrence based on scientific or technical merit or policy considerations, or recommendation of high or low program priority or deferral to obtain additional information for consideration at another meeting. The statement of understanding also presents a report of the en bloc recommendations. Summary statements not requiring individual discussion are treated en bloc, but any council member may request that an individual summary statement be discussed individually by the council. When reviewing new concepts for clearance during the open session, the council may approve, disapprove, or defer approval with recommendations for specific modifications.

# **Approval of Concepts**

Spirituality and Religiosity as Psychosocial Determinants for Health in Populations Experiencing Health Disparities

Presenter: Carolina Solis Sanabria, MD

https://videocast.nih.gov/watch=52195&start=10660

The objective of the concept is to support multi-level, multi-domain intervention and observational research that addresses and investigates the role of spirituality and/or religiosity (S/R) on health and well-being among populations experiencing health disparities with the goal of reducing those disparities. The aim is also to understand how S/R can best be integrated into comprehensive models of health and health care delivery among populations experiencing health disparities. Religiosity and spirituality are two distinct but overlapping constructs that are important cultural elements across various cultures and in some places and communities they are an integral part of people's identities. Religiosity has certain behavioral, social, doctrinal, and denominational characteristics involving a system of worship that is shared in a group, whereas spirituality is concerned with the sacred transcendent and addresses questions about life's meaning. It can encompass but also extends beyond religion and includes diverse self-definitions of the source of meaning in one's personal search for the sacred.

Benefits of religiosity have been noted in the literature; religious attendance has been associated with improved health behaviors, such as less smoking, less drinking, greater physical activity, better sleep, and decreased mortality and cancer risk. Negative health outcomes have also been reported, but the literature also states that context plays an important role. According to the Pew Religious Landscape Study, 91% of African Americans and 84% of Latinos described religion as very or somewhat important to them, with 82% of those earning less than \$30,000 a year noting the same with 70 to 80 percent of rural populations of the U.S. estimated to be religious. As such, S/R are accessible, immaterial resources

that can provide social capital and emotional coping, promote health behaviors, and facilitate the provision of resources to help reduce health disparities.

It is important, therefore, to better understand the implications of S/R in improving the health of populations experiencing health disparities. However there is a limited amount of research on the role or integration of S/R in healthcare settings, or on the mechanisms by which S/R improve health outcomes and influence resilience and health behavior. Dr. Sanabria and her team conducted an NIH portfolio analysis looking at the past ten years to see what NIH had funded pertaining to S/R in populations experiencing health disparities and found that very few grants were mechanistic, none involved a healthcare setting, and many of the grants involving interventions were community-based and did not integrate spirituality. What is proposed is an initiative to support both observational and intervention studies, including longitudinal studies, mixed method studies, and other methodologies to assess the role of S/R on the health and well-being of populations experiencing health disparities, integrating different settings, practices, cultures, and measures.

## Research priorities:

- Understanding the mechanisms by which S/R can influence resilience, well-being, and improve health outcomes.
- Examining the role of ethics related to S/R and its impact on healthcare decisions, healthcare seeking, and health-related behavior (e.g., sexual and reproductive health services, end of life care).
- Understanding the impact of different spiritual practices and religious traditions (such as meditation, prayer, scriptural reading, chanting) on health promotion, well-being and health outcomes.
- Evaluating faith-based interventions at the community level and how faith engenders trust and sustainability to promote health, well-being and resilience through social support, and 12-step recovery programs.
- Assessing how best to measure S/R in clinical settings and how to harmonize these measures across studies and for different populations.

Dr. Curry commended the focus on the whole person in this concept, as well as the understanding of S/R as relational and based in community. He recommended expanding the scope of spiritual practices to include other activities like labyrinth walking and other contemplative behavior. Dr. Sims emphasized the incorporation of different S/R modalities outside of the Western tradition for different populations, and the interaction of S/R with other psychosocial factors. The motion to approve the concept was carried unanimously.

Research to Understand and Address Health Disparities in Native Hawaiian and Pacific Islander Populations

Presenter: Gabriel Lai, PhD

https://videocast.nih.gov/watch=52195&start=12100

The purposes of the proposed initiative are to support research that will help understand and address the factors and underlying pathways that cause health disparities among Native Hawaiian and Pacific Islander (NHPI) populations, defined as having origins in any of the original peoples of Hawaii, Guam, Samoa or other Pacific Islands that are part of the three major subregions of Oceania, those being Melanesia, Micronesia, and Polynesia. Asian Americans and NHPIs were separated into distinct groups for the 2000 census. NHPIs experience some of the worst health outcomes for diseases like cancer when compared to Asian Americans and other subgroups. NHPIs have 2 to more than 3.6 times higher rates of death compared to all racial groups following events like strokes, congestive heart failure, or the onset of diabetes, with a higher burden for chronic disease compared to Asian and other subgroups. In Hawaii, Native Hawaiians have the lowest life expectancy among all racial groups, and the causes of these health disparities have not been extensively examined, and a 2019 study reported that the proportion of total

NIH funding between 2000 and 2018 that focused on Asian Americans and NHPIs was only 0.18%, in sharp contrast to their share of the U.S. populations, which was between 4-6% at the time.

Among studies, reviews, workshop reports, or summaries on NHPI health, a number of gaps have been identified:

- Consideration of historical/political/social context
- Migration/structural factors
- Multilevel factors
- Behavioral/mental health
- Culturally relevant interventions
- Youth, families, communities

A Request for Information (RFI) recommended culturally responsive interventions, community collaborations, and traditional indigenous practices.

The initiative seeks to support multidisciplinary research to understand risk and protective factors, especially upstream factors like socioeconomic and political structures or social circumstances, which affect the health of NHPI populations. It will also help to develop and test interventions and prevention strategies to reduce these health disparities with the hope that observational and intervention researchers will collaborate with NHPI communities and other partners to consider cultural and traditional factors.

# Research priorities:

- Historical trauma and other structural factors that lead to suicide, substance abuse, and decreased mental health.
- Influence of traditional indigenous practices on health and quality of life.
- Interplay of social, cultural, environmental, and biological factors on cancer, diabetes, and other chronic diseases.
- The effect of intergenerational families and communities on health, resilience, and well-being
- Interaction of health care practices and policies with traditional healing practices, noting the geographic, cultural, and linguistic diversity of NHPI populations.
- Culturally tailored or adapted strategies for early detection, control, and/or prevention of chronic diseases.
- Community level and culturally informed health promotion strategies to improve access and use of mental health services.
- Strategies to address social determinants of health that may increase reach and access to health care in low resource settings.

Dr. Trinh-Severn underscored the significance of the diversity of NHPI populations and the importance of community-based treatments and access to research. She also spoke about the role of intergenerational family structures and kinship relations. Dr. Sims spoke on the variegated factors that lead to chronic diseases and epigenetic research, and the need to disaggregate NHPI subgroups. The motion to approve the concept was carried unanimously.

Examining Understudied Health Care System and Clinician Factors and Their Impact on Disparities in Maternal Mortality and Morbidity

Presenter: Rada Dagher, PhD

https://videocast.nih.gov/watch=52195&start=13260

The U.S. maternal mortality rate (MMR) is an urgent public health problem with approximately 1,200 U.S. women dying from pregnancy and attendant complications every year, with Black/African American patients having three times and AI/AN patients having two times the MMR of White patients. While maternal mortality is a relatively rare event, severe maternal morbidity (SMM) affects around 50,000 U.S. women per year with similar racial and ethnic disparities as maternal mortality. Adverse social

determinants of health such as lack of access to quality and affordable care may increase SMM and maternal mortality risk, especially among Black/African American and Al/AN women. According to the CDC, more than 80% of pregnancy-related deaths are preventable; as an example, 93% of deaths among Al/AN women are preventable.

Women delivering their babies in hospitals serving a predominantly Black/African American population are more likely to experience SMM but it's not clear if quality of care including clinician factors such as implicit bias, delays in diagnosis and poor communication are implicated, and initiatives to improve quality of care for maternal outcomes have not been adequately evaluated. Additionally, racial and ethnic minority women's access to care is often limited by factors like insurance coverage, socioeconomic status, access to community resources, and site of care. A recent study showed that Medicaid expansion under the Affordable Care Act was associated with a lower total MMR relative to non-expansion states.

In examining research gaps, this concept recommends studies that investigate the role of clinician factors in racial and ethnic disparities in maternal morbidity and mortality (MMM), as well as studies that evaluate the impact of patient safety bundles and initiatives on coordination of perinatal care between specialists, primary care providers, hospital-based clinicians and community-based service providers such as doulas and midwives. These and other existing interventions need to be evaluated to improve access to high quality care, through an examination of health policies beyond insurance coverage expansions and a promotion of culturally responsive and clinically appropriate care in healthcare settings and among clinicians.

#### Research priorities:

- Evaluation of strategies to improve the quality of maternal health care for racial and ethnic minority women, including emerging innovative strategies.
- Investigation of the mechanisms through which health insurance expansions impact racial and ethnic disparities in MMM.
- Investigation of care coordination challenges or breakdowns in the diagnostic or care pathways between primary care and specialists.
- Examination of clinician-level factors like implicit bias, patient-clinician communication, racial concordance between clinician and patient, and strategies to improve cultural competence.
- Investigation of the contribution of differential access to and quality of obstetric and perinatal care to rural and urban disparities in MMM.

Following feedback from members of the Council, the concept was approved unanimously after being duly moved and seconded.

Minority Health and Health Disparities Research Training (MHRT) Presenter: Priscah Mujuru, PhD

https://videocast.nih.gov/watch=52195&start=15438

The objectives of the RFA are to develop and enhance research training opportunities for individuals who are from groups underrepresented in the biomedical, behavioral, and clinical research workforce, and to support creative educational and training activities to provide research experiences at the undergraduate, graduate, post-doctoral, medical resident, and fellow levels. There is a need for a MHRT program renewal because the U.S. population is increasingly diverse but the biomedical workforce in not keeping up with this transformation. Published reports from Association of American Medical Colleges, the National Science Foundation, the National Academy of Sciences and others provide evidence that there is a need to diversify the U.S. workforce in the biomedical, clinical and behavioral health sciences. There remains a critical need for trained racial and ethnic groups underrepresented in biomedical research to contribute to the body of science and serve in their communities.

The current MHRT program, using data from 2019-2021, 42.1% of its participants identified as Black/African American, 22% as Latino/Hispanic, and 15.7% as Asian American, with smaller percentages

from NHPI, AI/AN, and White populations. There was a different distribution of MHRT participant by' race and ethnicity in regard to the educational level at recruitment; Asian American and NHPI trainees were primarily recruited as undergraduates, whereas Black/African American and Latino participants were recruited more often while pursuing graduate level degrees. These participants published over 55 papers in that same period of 2019-2021 in journals like the *American Journal of Public Health*, the *Journal of the American Medical Association*, and *Population Research and Policy*.

The proposed renewed MHRT program would prioritize cohorts that are advanced in educational level, with 80% of the trainees at the graduate level and higher, and prioritize opportunities for trainee growth through enhanced education at domestic sites in lower- and middle-income countries in Latin America, the Caribbean, and Sub-Saharan Africa, emphasizing cultural learning both for the trainee and their mentor(s).

#### Research priorities:

- Development of screening, preventive, and therapeutic health care interventions that contribute to reducing health disparities.
- Research in clinical settings that address access to healthcare.
- Behavioral, sociocultural, and environmental influences on disease risks and outcomes
- Epidemiological, behavioral, social, applied and surveillance research to understand the impact of social determinants on population well-being.
- Research integrating multiple determinants of health at the biologic, behavioral, and contextual levels, and their interactions.

Dr. Sims lauded the presentation but suggested there be a clearer description of how the research experience for each trainee would be tailored to the individual, and asked whether there was a structured curriculum across the sites or if each site or mentorship programs were unique at each site. Dr. Trinh-Shevrin encouraged applicants to collect demographic data that are disaggregated by ethnic subgroup, immigration status, and whether they are the first generation in college or university to ensure reach and representation of the program. Dr. Sims moved to approve the concept with Dr. Adunyah seconding, and the motion was carried unanimously.

# Council Working Group Report - People Living with Disabilities and Health Disparities Presenters Dr. Lisa Barnes and Dr. Neil Calman

https://videocast.nih.gov/watch=52195&start=14250

NIMHD was asked by the National Council on Disabilities and other organizational advocates to declare persons living with disabilities as a population facing health disparities and to include research on disabilities in the same manner that research on racial and ethnic disparities, SES, SGM, and rural health disparities are covered by NIMHD. The working group assembled in response was charged with:

- Reviewing the state of the science on health disparities among people living with disabilities
- Providing input on gaps, research needs, and strategic opportunities for health disparities research using an intersectional lens
- Advising on the benefits and risks of expanding the NIH-designated health disparity populations to include people living with disabilities
- Providing a recommendation and draft report to NACMHD and the NIMHD Director at the Open Session of Council on September 1, 2023

The working group conducted a series of meetings from November 2022 to August 2023 with special presentations (e.g., National Council on Disabilities, HHS Administration for Community Living) and committee discussions. It shared an interim report during the closed session of the NACMHD in May 2023 and met with the Director and Deputy Director of NIMHD to discuss the report, with the final report to be submitted by the end of September 2023.

The bulk of the working group's activity was reviewing the state of the science. The CDC defines health disparities as preventable differences in the burden of disease, injury, violence, or in opportunities to achieve optimal health experienced by socially disadvantaged racial, ethnic, and other population

groups and communities. Working from this definition, the working group sought to better understand what had been published on various aspects of disparities in the disability literature. NIMHD staff members conducted several PubMed searched on various topics and search terms yielding more than 1,300 publications, along with presentations by disabilities researchers and advocates.

Three key points emerged. First, not all health differences among individuals with disabilities meet the criteria of a health disparity. Second, people with a disability may have a higher prevalence of morbidity and all-cause mortality, and they may experience accessibility barriers to high quality care. And finally, people with a disability may experience stigma, bias, and discrimination in the form of ableism. A key gap in the literature was that currently there are several definitions of disability -whether it is related to conditions present at birth, a developmental condition, or the result of an injury. Therefore, there was a lack of clarity regarding which persons with disabilities would be impacted by this designation.

The working group found a need for research to enhance the understanding of whether all populations with disabilities experience health disparities or if some populations with disabilities are more at risk of experiencing health disparities. The working group also highlighted a need to examine the intersection between disability and health outcomes of other groups experiencing health disparities, and the etiology and impact of disparities and how to mitigate their negative effects in people with disabilities.

NIMHD actions to date included an approval of the concept "health disparities experienced among persons living with disabilities," an NIH-wide NOFO announcement currently underway, and the establishment of the working group. There was also a summary of NIH investment, which estimated that for FY18-22, NIH funding for disability-related research ranged from \$6.6 to \$11.8 billion. The conditions that were most prevalent in this portfolio included brain disorders, aging, neurodegenerative conditions, rare diseases, and cerebrovascular conditions. The working group then reported the benefits and risks of making this designation:

#### Benefits

- Could increase research related to disparities among people with at least one disability.
- Could lead to greater inclusion of researchers with disabilities and people with disabilities as participants in research studies.

# Risks

- $\circ\quad$  High potential for mission "creep" and loss of focus at NIMHD science
- Limited budget and staff members could be overwhelmed by influx of applications for a broad and heterogeneous population
- Could dilute efforts to train scholars from underrepresented groups in medicine backgrounds
- o Could reduce accountability of other Institutes and Centers to fund disability research
- Could divert attention from establishing and Office or Institute focused on disability research

Acknowledging that certain individuals with disabilities experience health disparities and that further information and action are needed, the working group committee recommended that the entire disabilities population not be categorized as an NIH-designated health disparity population at this point, but that further research be conducted to establish those populations with disabilities are in fact affected by health disparities. The committee also recommended the establishment of an Office of Disability Research to coordinate NIH disabilities research equipped with a budget for research on disparities experienced by people with disabilities, incorporating a greater emphasis on the intersection of disability and existing populations with health disparities. Next steps included issuing RFAs to study the intersectionality of persons with disabilities who are also members of a health disparity population and completing and submitting the final report to the NIMHD Director. Dr. Sims made a motion to accept the working group's recommendations which was seconded by Dr. Penedo and it passed unanimously.

# **Closing Remarks and Adjournment**

After ascertaining that there were no public comments forthcoming, Dr. Pérez-Stable adjourned the meeting at 2:25 p.m.

END NOTE: REVIEW OF GRANT APPLICATIONS\_ CLOSED SESSON A portion of the meeting was closed to the public in accordance with the provisions set forth in Sections 552b(c)4 and 552b(c)6, Title 5 U.S.C. and 10(d) of the Federal Advisory Committee Act as amended (5 U.S.C. appendix 2). Dr. Pérez-Stable called the Closed Session to order at 1:00 pm, May 22, 2023. Dr. Cotton led the second level review of grant applications submitted to NIMHD programs. Council members and NIMHD staff members were instructed on conflict of interest and confidentiality regulations. Council members and staff absented themselves from the meeting room and discussions for which there was a potential conflict of interest, real or apparent. The Council considered 532 competing applications requesting an estimated \$448,851,427 in requested total costs for year 1 for non-fellowship grants. Funding recommendations for all applications submitted in response to funding opportunity announcements were reviewed. Applications submitted in response to program announcements and special program review announcements were considered by the Council through En Bloc voting.

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Eliseo J. Pérez Stable, M.D. Date Director

National Institute on Minority Health and Health Disparities, NIH

Paul Cotton, Ph.D. Date
Designated Federal Official
National Institute on Minority Health and Health Disparities, NIH