U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES NATIONAL INSTITUTES OF HEALTH NATIONAL ADVISORY COUNCIL ON MINORITY HEALTH AND HEALTH DISPARITIES

SUMMARY MINUTES

TUESDAY MAY 24, 2022

The National Advisory Council on Minority Health and Health Disparities met via Video Teleconference, at 11:00 a.m. EDT, Eliseo J. Pérez-Stable, Chair, presiding.

COUNCIL MEMBERS PRESENT

Eliseo J. Pérez-Stable, MD, Director, NIHMD; Chair Emma Aguila Vega, PhD, University of Southern California Lisa L. Barnes, PhD, Rush University Medical Center Neil S. Calman, MD, Icahn School of Medicine at Mount Sinai Amy Elliot, PhD, Avera Research Institute Nitza Milagros Escalera, EdM, JD, MPA, MS, John Jay College of Criminal Justice Kimberly Johnson, MD, Duke University Medical Center Joseph Keawe'Amimoku Kaholokula, PhD, University of Hawaii at Manoa Brian Mustanski, PhD, Northwestern University Kenneth A. Resnicow, PhD, University of Michigan Mario Sims, PhD, University of Mississippi Medical Center William M. Southerland, PhD, Howard University Chau Trinh-Shevrin, DrPH, New York University Grossman School of Medicine Carmen D. Zorilla, MD, University of Puerto Rico School of Medicine

<u>COUNCIL MEMBERS ABSENT</u> Joan Y. Reede, MD, MS, MPH, MBA, Harvard Medical School

EX OFFICIO MEMBERS PRESENT

Judith A. Long, MD, VA Center for Health Equity Research and Promotion Donald Shell, MD, MA, Office of the Assistant Secretary of Defense for Health Affairs

PRESENTERS

Lindsey A. Criswell, MD, MPH, Dsc, Director, National Institute of Arthritis and Musculoskeletal and Skin Diseases
Robert Otto Valdez, PhD, MHSA, Director, Agency for Healthcare Research and Quality
Monica Webb Hooper, PhD, Designated Federal Official, Deputy Director, NIMHD
Nathaniel Stinson, PhD, MD, Division Director, Community Health and Population Sciences, NIMHD
Rina Das, PhD, MD, Division Director, Division of Integrative Biological and Behavioral Sciences, NIMHD
Rada K. Dagher, PhD, MPH, Program Official, Division of Clinical Sciences and Health Research

TUESDAY, MAY 24, 2022

Greetings, Introductions, Roll Call and Approval of Minutes:

- Chair Eliseo Pérez-Stable, Director of the National Institute on Minority Health and Health Disparities (NIMHD), called to order the 60th meeting of the National Advisory Council on Minority Health and Health Disparities (NACMHD) at 11:00 a.m.
- Dr. Eliseo Pérez-Stable welcomed viewers attending virtually and in person, and introduced Executive Secretary Dr. Monica Webb Hooper, Deputy Director of NIMHD, who advised council members on speaking parameters for the National Institute of Health (NIH) Video Cast Network and called the roll of the Council and the NIMHD staff, including brief introductions and explanations of their area of focus.
- The February 2022 Council minutes were reviewed, and Dr. Webb Hooper asked if there were any questions, concerns, or corrections. None being raised, the minutes were approved following a motion made by Dr. Resnicow and duly seconded.

<u>Retiring advisory council members were asked to reflect on their experiences of their time</u> <u>on the committee.</u>

- Dr. Kaholokula spoke about the privilege and honor of serving on the Council and advocating on behalf of Native Hawaiians and Pacific Islanders specifically and commended his colleagues and friends who are passionate about improving the health and well-being of the most vulnerable populations in the United States.
- Dr. Brian Mustanski joined the council shortly after Dr. Pérez-Stable had designated gender and sexual minorities as a health disparity population for research purposes at NIH, which he described as a game-changer in bringing attention to the disparities

experienced by those communities and the role that research and science can play in creating health equity.

- Dr. Webb Hooper also acknowledged and thanked Dr. Joan Reede for her years of service on NACMHD and directed the Council to the agenda for future meeting dates and stressed the importance of having a quorum for each meeting to conduct the business of the institute.
- The last council meeting in 2022 will be held on September 1-2. The 2023 council meeting dates are February 6-7, May 22-23, and August 31 through September 1. It is NIH policy that council members can only have one absence per calendar year and an individual cannot serve on any NIH peer-reviewed panel while serving as a council member.
- Dr. Webb Hooper then turned the meeting over to Dr. Pérez-Stable for the Director's Report.

Director's Report:

Dr. Pérez-Stable recounted some key events and major appointments that had transpired since the last council meeting, including the confirmations of Robert Califf as FDA Commissioner, Rob Valdez as the director of the Agency for Healthcare Research and Quality (AHRQ), Ashish Jha as Coronavirus Response Coordinator, and Francis Collins as Acting Science Director to the President. Dr. Norman E. Sharpless stepped down as the 15th Director of the National Cancer Institute and Dr. Doug Lowy will serve as the NCI Acting Director until a new director is appointed by the President.

Dr. Pérez-Stable then described a visit to the White House on March 18 where he and Dr. Tabak were invited to the signing of the John Lewis NIMHD Research Endowment Revitalization Act, which provides the Director the authority to make certain research endowments apply to the NIMHD Centers of Excellence (COE). He spoke briefly about the Advanced Research Projects Agency for Health (ARPA-H), a proposed Agency to benefit Americans by catalyzing breakthroughs and support high-risk, high-reward research on the model of the Defense Advanced Research Projects Agency (DARPA). The perspective was to go from the molecular research into medical conditions like Alzheimer's related dementias, diabetes, and cancer to the societal implementation of healthcare interventions and care in populations in a more closely managed structure with rigorous project milestones. It would be able to take advantage of the NIH expertise, knowledge, and administrative infrastructure, but remain distinct with its own culture and organization. ARPA-H received \$1 billion in appropriations in FY22, which is three-year money without the obligation to spend this fiscal year.

Turning to NIMHD, Dr. Pérez-Stable mentioned there was a second annual lecture series for public health leadership with Surgeon General Vivek Murthy in observation of Asian American and Pacific Islander (AAPI) History Month, involving a conversation with Boston Mayor Michelle Wu. NIMHD also graduated a sixth Rwandan physician in a program that was initiated in 2016 by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) with NIMHD, where she has a program on diabetes in African immigrants. The visiting Rwandan scholars have received training in clinical research, conducted research, contributed to publications, and led publications within the Intramural Research Programs.

The March omnibus bill gave NIMHD its biggest discretionary increase ever, going up by \$50 million for health disparity research without an earmark included. The number of R01 applications from 2016 to 2021 has increased almost fourfold. Unfortunately, the award rate has decreased by about half, but Dr. Pérez-Stable hopes that rate bottomed out in 2020 and will increase year to year, and he's optimistic the success rate for 2022 will be at least 13% and represent an increase from 2021. When comparing early stage success to established investigator success, in FY21, 18.4% of early stage investigators were successfully awarded for their R01 applications compared to about 21% of established investigators.

On the legislative front, there was a briefing with the four congressional appropriations committees to provide an update on ongoing COVID work, where Dr. Pérez-Stable presented on Rapid Acceleration of Diagnostics (RADx) for Underserved Populations and briefed the Senate Finance Committee majority staffer on data analytics and research on health disparities research and the minority staffer on inclusive participation in clinical research. Dr. Nathan Stinson briefed the Congressman David Price's staffer on Duke University's COE program, and they both briefed the Energy and Commerce Minority Committee on diversity in the workforce.

Dr. Pérez-Stable welcomed Paul Cotton, PhD to NIMHD leadership after 20 years of federal service, most recently at the National Heart, Lung, and Blood Institute. Dr. Cotton will be the future executive secretary of NACMHD. Other new staff members include Sundania Wonnum in Clinical and Health Services Research, Gina Roussos in the Office of the Director, and Krystale Lyons in the Office of Administrative Management. Many NIH staff members were recognized in different award settings in the past year, and Dr. Pérez-Stable particularly commended the staff for the departmental award received for the RADx Underserved Populations Initiative. NIMHD has funded 127 unique projects across the country from Hawaii to Puerto Rico in different formats and 112,000 unique participants have been consented as of early May, with over 222,000 unique tests done. Dr. Pérez-Stable went on to describe various grants, awards, projects, publications, and studies undertaken in the previous months and the Social Determinants of Health (SDoH) connected with structural racism, especially as they pertain to mental health, maternal morbidity, and cancer. He closed by noting that NIMHD is in a continuous recruitment mode with its rising budget and encouraged attendees to apply for open positions, followed by commendations for the Director's report and questions from members of the council.

NIAMS Commitment to Eliminating Health Disparities Through Research, the Workforce, and Engagement

Chair Pérez-Stable introduced Dr. Lindsey Criswell, Director of the National Institute of Arthritis, and Musculoskeletal, and Skin Disease (NIAMS) for her presentation.

Dr. Criswell's research has focused on the genetics and epidemiology of human autoimmune disease, particularly rheumatoid arthritis and systemic lupus, which disproportionately affect women of color.

She began by introducing NIAMS through its current budget and its strategic plan. Its current budget is \$656 million which represents a 3.4% increase compared to FY21, which supports both intramural and extramural research programs. NIAMS spends its budget in similar proportions to NIH as a whole, with 80.4% going to extramural research programs, 10.4% to Intramural research programs, and 5.5% to Research, Management, and Support (RMS).

NIAMS's current strategic plan continues to 2024, the ultimate goal of which is to develop patient-centered personalized ways to improve health outcomes in five core areas: systemic rheumatic and autoimmune diseases; skin biology and diseases; bone biology and diseases; muscle biology and diseases; and joint biology, diseases, and orthopedics research.

Several cross-cutting themes emerged in a NIAMS listening session engaged in by thought leaders of the five core areas of research, and it was clear that NIAMS-funded research must be applicable to health and disease in diverse populations to achieve the goal in improving health in all Americans.

• Several NACMHD members had questions about specific diseases that NIAMS focused its research on, with Dr. Southerland asking about scleroderma. Dr. Barnes asked why the myth persists that osteoporosis affects African American women at a lower rate, and Dr. Criswell proposed several historical, social, medical, and psychological explanations that may influence one another to a greater or lesser extent. Dr. Trinh-Shevrin asked about alternative healthcare models, such as integrating community health workers, especially in the contexts of Asian and Latino/a communities, as they tend to support engagement, adherence, and reducing stigma with certain health disparities.

Ending Inequitable Treatment

Chair Pérez-Stable introduced Dr. Robert Valdez, Director of AHRQ, for his presentation.

Dr. Valdez gave a presentation on confronting racial and ethnic disparities in health care, twenty years after a pivotal Institute of Medicine (IOM) Report entitled "*Unequal Treatment*." AHRQ is one of the four science-based organizations in HHS -- along with NIH, the Food and Drug Administration (FDA), and the Centers for Disease Control (CDC) -- that has Congressional responsibilities to produce scientific evidence that makes healthcare safer, higher quality, more accessible, equitable, and affordable.

In "*Unequal Treatment*," released March 20, 2002, AHRQ was singularly recognized for the work it had already started to understand how to eliminate disparities in healthcare, and it inspired a more ambitious agenda to disentangle the influences of process, structure, and outcomes. "*Unequal Treatment*" took all the studies available at the time and documented how persons of color experienced the healthcare system. The Committee that created the report sought to understand how the disparities in treatment arose and what aspects of the clinical encounter made themselves available for intervention and modification, including medical care financing, the allocation of care, availability of language translation, and others. Dr. Valdez lamented the creation of a care delivery system in the United States segregated along the fault

line of class and income.

Dr. Valdez stated that he has moved AHRQ from being only patient-focused and has now shifted to being focused on the well-being of the health professional, which is necessary to provide optimal care. AHRQ examines health systems research, issues around practice improvement, and the development of new analytics for understanding data and turning it into information. Dr. Valdez also discussed the Question Builder app, which is a tool for patients to choose questions they want to ask their doctor, starting with a list of common questions that can be customized to fit individual needs. Dr. Valdez concluded by describing potential collaborations between AHRQ and NIMHD for reducing disparities in health and healthcare.

- Dr. Perez-Stable asked about the diversity of the workforce that AHRQ funds, and what AHRQ does to fund less-resourced institutions, particularly minority-serving institutions or HBCUs. Dr. Valdez said there are improvements to be made and that he has worked to make those changes since became Director.
- Other subjects covered while Dr. Valdez answered questions included the effect of similarity in racial or ethnic background between patient and healthcare provider, funding opportunities for different languages in the provision of care, a deeper look at implementation science, and what an updated version of "*Unequal Treatment*" would look like.

Approval of Concepts:

Dr. Webb Hooper explained that the next section of the agenda would be a review and discussion of scientific concepts. Two council members were assigned to review each concept, and assigned reviewers were designed to incorporate input from other members into their own comments.

<u>Structured Institutional Needs Assessment and Action Plan Development for Minority</u> <u>Serving Institutions (MSIs)</u>

Dr. Rina Das presented this scientific concept on behalf of the NIH UNITE's E committee (Extramural Research Ecosystem) implementation team, with Dr. William Southerland and Dr. Emma Aguila Vega as council reviewers.

- The goal of the concept is to support research active MSIs in constructing a structured needs assessment and developing a short-term and long-term action plan based on the results. The charge of the E Committee is to perform a broad systematic evaluation of NIH extramural policies and processes to identify and change practices and structures that perpetuate a lack of inclusivity or diversity within the extramural research ecosystem. This includes developing strategies to address funding health disparities research and increase applications to support individuals from underrepresented groups.
- NIH institutes and centers interested in supporting the effort will sign on to a funding opportunity announcement, with one lead institute that will coordinate efforts across the NIH. Looking at the data, Dr. Das and the committee noticed a notable diversity among

academic institutions,

- Dr. Southerland emphasized the importance of this concept for MSIs, and of methodically improving MSIs' effectiveness. He pointed out that one of the positive impacts of this plan is that it invites MSIs to look critically at the current state of biomedical research at their institution, compare their present state with where they want to be, and chart a path to get there.
- Dr. Aguila Vega raised issues that exist among MSIs, including lack of research support, lack of an appropriate research environment, and lack of high performing staff development, but that as MSIs serve nearly 30% of undergraduates and growing, it's important to address their most pressing needs.
- After a brief discussion and some questions from council members, Dr. Carmen Zorilla made a motion to approve this concept and move it forward, which was seconded by Dr. Southerland and approved by the council.

Addressing Health and Healthcare Disparities in Sexual and Gender Minority (SGM) Populations

Dr. Rada Dagher presented this scientific concept with Dr. Mustanski and Dr. Resnicow as council reviewers.

- The purpose of the concept is to solicit research to address and understand health and healthcare disparities in SGM populations using an intersectional lens, whenever feasible. There is a need for studies that test interventions, observational studies, and secondary data analyses.
- Dr. Dagher began by pointing out the scope of the issue. There are 11 million lesbian, gay, bisexual, and transgender (LGBT) individuals living in the United States, or approximately the population of Ohio. In addition to the LGBT community, SGM individuals include asexual, Two-Spirit, queer, and intersex people, those with a difference in sex development, and those who do not self-identify with one of the terms but whose sexual orientation, gender identity or expression, or reproductive development is characterized by non-binary constructs of sexual orientation, gender and/or sex. SGM populations have been shown to have an increased risk for health disparities in specific illnesses, including cardiovascular disease (CVD), cancer, and HIV, as well as violence. They also experience disparities in mental health, substance use, and behavioral health, with heightened anxiety and depressive symptoms and greater suicidality when compared with straight and cisgender populations.
- There are key research gaps for SGM populations, including a scarcity of evidence-based intervention and longitudinal studies. There is also a need for studies on how structural stigma develops and evolves across the lifespan to impact health and healthcare disparities.

- Interventions are also needed to address disparities of SGM populations that live in rural areas or who are persons of color or socioeconomically disadvantaged, and to improve access to and quality of care.
- There is a lack of studies examining SDoH and how differential access to opportunities and resources impacts health and health care disparities.
- One potential research area inviting more attention is examining the intersection of SGM and other populations that experience health disparities, such as racial and ethnic minority groups, underserved rural populations, and socioeconomically disadvantaged individuals. Additionally, it is important to test interventions to reduce SGM health and healthcare disparities, along with an evaluation of policies that affect SGM populations, including those that are SDoH-based.
- Finally, conducting secondary data analyses of disparities in healthcare and health outcomes using national and cohort studies that include sexual orientation and gender identity measures would yield important information.
- Dr. Mustanski commented that certain health disparities have been known for decades, such as HIV and substance use, but that some like CVD are just beginning to be understood. He commended the broadening of subject matter being studied in SGM populations and shift from merely documenting the existence of health disparities to an attempt to understand the mechanisms that drive them and link SDoH to these health outcomes.
- Dr. Resnicow concurred with Dr. Mustanski that although intersectionality is a wonderful opportunity for novel research, it shouldn't be a requirement. He did think that the concept could use a stronger rationale about the benefits of expanding SGM research beyond HIV and the need for a unique request for applications (RFA), given that SGM populations are already an established disparity group. He also hoped to encourage specific research to look the psychological and medical effect of anti-SGM legislation on those populations.
- Dr. Mustanski made a motion to move the concept forward and it was seconded by Dr. Zorilla and approved by the council.

Closing Remarks and Adjournment

Dr. Webb Hooper turned the meeting over to Chair, Dr. Pérez-Stable for closing remarks. He thanked the staff and presenters for supporting the meeting, as well as the council members for their participation. He adjourned the meeting at 3:41 p.m.

REVIEW OF GRANT APPLICATIONS: CLOSED SESSION

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 9:00 am on May 23, 2022.

Dr. Webb Hooper led the second level review of grant applications submitted to NIMHD programs. Council Members and Staff were instructed on conflict of interest and confidentiality regulations. Members and staff were removed from the meeting room and discussions for which there was a potential conflict of interest, real or apparent.

The Council considered 433 competing applications requesting an estimated \$269,900,466 in requested total costs for year 1. 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.

Eliseo J. Pérez Stable, M.D. Date Director National Institute on Minority Health and Health Disparities, NIH

Monica Webb Hooper, Ph.D.DateDesignated Federal OfficialNational Institute on Minority Health and Health Disparities, NIH