

**U.S. Department of Health and Human Services (HHS)  
National Institutes of Health (NIH)  
National Institute on Minority Health and Health Disparities (NIMHD)  
National Advisory Council on Minority Health and Health Disparities (NACMHD)**

9000 Rockville Pike, Bethesda, MD  
Building 31, 6<sup>th</sup> Floor Conference Room 6 or 10(?)  
February 27, 2017 (Closed Session) 3:00PM-5:00PM  
February 28, 2017 (Open Session) 8:00AM-2:00PM

**Meeting Minutes**

**Council Members Present**

Eliseo J. Pérez-Stable, MD, Chairperson; Director, NIMHD  
Linda T. Adams, PhD, RN, FAAN, West Chester University  
Margarita, Alegria, PhD, Massachusetts General Hospital  
Maria R. Araneta, PhD, University of California San Diego  
Linda Burhansstipanov, MSPH, DrPH, Native American Cancer Initiatives  
Eddie L. Greene, MD, Mayo Clinic Rochester  
Linda S. Greene, JD, University of Wisconsin  
Hilton M. Hudson, II, MD, FACS, FCCP, University of Chicago  
Fernando Sanchez Mendoza, MD, MPH, Stanford University  
Valerie Montgomery-Rice, MD, Morehouse School of Medicine  
Brian Rivers, PhD, MPH, Morehouse School of Medicine  
Gregory A. Talavera, MD, MPH, San Diego State University

**Ex Officio Members Present**

Said A. Ibrahim, MD, MPH, University of Medicine  
Cara Krulewicz, CNM, PhD, FACNM, Department of Defense  
William Riley, PhD, Office of Behavioral and Social Sciences Research, NIH

**Council Members Absent**

Sandro Galea, MD, MPH, DrPH, Boston University  
Ross Hammond, PhD, The Brookings Institute  
Lisa Newman, MD, MPH, FACS, FASCO, Henry Ford Health System  
Michael Rashid, MBA, AmeriHealth Mercy (Retired)

**Executive Secretary**

Joyce A. Hunter, Ph.D.

**Presenters**

Joseph Selby, MD, MPH, Director, Patient-Centered Outcomes Research Institute  
Linda Burhansstipanov, MSPH, DrPH, Native American Cancer Initiatives  
Meredith Temple-O'Connor, PhD, Eunice Kennedy Shriver National Institute of Child Health and Human Development

**CALL TO ORDER AND INTRODUCTORY REMARKS**

The 44th meeting of the National Advisory Council on Minority Health and Health Disparities (NACMHD) was held on Monday, February 27, 2017 and Tuesday, February 28, 2017 in Building 31, Conference Room 6. The closed session began at 3:00 pm on February 27<sup>th</sup>, and adjourned at 6:00 pm. The session was open to the public on February 28<sup>th</sup> from 8:00am until adjournment at 3:01 pm.

Dr. Eliseo J. Pérez-Stable, Director of the National Institute on Minority Health and Health Disparities (NIMHD), presided as Chair and called the meeting to order. Dr. Joyce Hunter, Deputy Director, and NACMHD Executive Secretary, reviewed the confidentiality and conflict of interest information with Council members. Dr. Pérez-Stable asked the Council members to introduce themselves, followed by NIMHD staff and invited guests.

### **COUNCIL MINUTES APPROVAL – September 2016**

The Council unanimously approved the minutes of the September 2016 Council meeting.

### **FUTURE MEETING DATES**

#### **2017 Council Dates**

June 5-6, 2017  
September 7-8, 2017

#### **2018 Council Dates**

February 26-27, 2018  
June 4-5, 2018  
September 10-11, 2018

### **NIMHD DIRECTOR'S REPORT AND DISCUSSION**

Dr. Dr. Pérez-Stable reported on current NIH and NIMHD activities.

#### *NIH News*

- Dr. Francis Collins has been held over as the NIH Director by the Trump administration until further notice. Dr. Larry Tabak will remain as the NIH Principal Deputy Director.
- Dr. David Wilson has been appointed the head of the new Tribal Health Research Office. The office will help coordinate all research related to American Indian and Alaskan Native health across the Institutes.
- Dr. Phil Bourne, former head of the Big Data to Knowledge program, announced his departure from NIH in January 2017 and will become a professor in biomedical engineering at the University of Virginia. Dr. Patty Brennan, Director, National Library of Medicine (NLM), will serve as the Interim Director of Data Science.
- The 21<sup>st</sup> Century Cures Act, signed in December 2016. Contained a provision that Directors of NIH Institutes and Centers will (ICs) will consult annually with the Director of NIMHD to discuss minority health and health disparities initiatives. The Common Rule, established in January 2017, aims to improve protections for human participants in research while also making research more efficacious.
- NIH has launched a multilateral effort to increase the quality and efficacy of clinical trials.
- The All of Us precision medicine initiative has not yet launched recruitment though it has been funded through the 21<sup>st</sup> Century Cures Act. NIMHD staff scientists are participating in program development.
- In October 2016, NIMHD announced that sexual and gender minorities (SGM) will be considered a health disparity group for research purposes.

- NIMHD is participating in a genomic medicine research fellowship that trains physicians on the management of genomic medicine programs
- On February 23, 2017, Dr. Joyce Hunter, Deputy Director, NIMHD attended a Tribal Consultation Advisory Committee meeting.

#### *NIMHD News*

- Dr. Judith Bradford, Advisory Council member, passed away in early February 2017. Dr. Pérez-Stable spoke highly of her participation in the Advisory Council and her work in support of health disparities research locally and nationally in her community. The Council observed a moment of silence to acknowledge her many contributions to NIMHD and to the field of minority health and health disparities research.
- Dr. Pérez-Stable participated in an NIH meeting with Congressman Tom Cole and his fellow subcommittee members from the House Appropriations Subcommittee on Labor.
- Dr. Pérez-Stable briefly discussed plans regarding the NIMHD intramural program. A search for a possible scientific director is being finalized. The program will have a population science emphasis with a clinical component.

#### *NIMHD Activities*

- In September, Dr. Pérez-Stable attended the VA's Health Services Research and Development's field meeting in Philadelphia, PA, and gave a keynote address at the American Association for Cancer Research's Cancer Health Disparities Conference in Fort Lauderdale, FL
- In October, Dr. Pérez-Stable returned to the University of California San Francisco's (UCSF) 10<sup>th</sup> Annual Health Disparities Research Symposium, an event he established in 2006, attended the Mayo Clinic's Health Disparities Research Annual Retreat with Dr. Greene, gave the keynote address at the Meharry Medical College's convocation and met with Dr. Louis Sullivan, former HHS Secretary in October.
- On Oct 24-25, 2016, NIMHD hosted a scientific workshop in conjunction with the National Human Genome Research Institute (NHGRI) on the use of race, ethnicity, and gender in genomic research.
- The NIMHD Worklife committee organized an event to provide and serve dinner to the Children's Inn families.

#### *NIMHD Staff News*

- Donna Brooks, the inaugural executive officer of NIMHD, retired from her position on October 31, 2016.
- Kimberly Allen, the previous NIMHD Deputy Executive Officer, has been appointed as the NIMHD Executive Officer after a search process.
- Dr. Pérez-Stable welcomed the following new staff members to NIMHD: Drs. Benyam Hailu, Beda Jean-Francois, Andrew Loudon, Meryl Sufian and Priscah Mujuru to the Division of Extramural Scientific Programs; Dr. Richard Palmer and Janet Mfon to the Office of Extramural Research Administration; Dr. Carole Christian, Dr. Steve Newell, Kester Williams-Parry, and Barbara Wojciechowsk to the Office of Strategic Planning, Legislation and Scientific Policy; Carlene Neil-Allman and Brenda Parker to the Office of Administrative Management; Kyan Chong, Shelly Pollard, and Rebecca Newton to the Office of Communication and Public Liaison, and Mary Andrews to the Division of Intramural Research. Aaron Credle has moved to the legislative affairs in the OD.
- Dr Erik Rodriquez joined Dr. Pérez-Stable's intramural program at NHLBI as a staff scientist.

### *Noteworthy Publications*

- NIMHD's Mid-South Transdisciplinary Coordinating Center (TCC) has published a journal supplement in the American Journal of Preventive Medicine discussing their research projects on the various socioeconomic, cultural, and environmental factors affecting obesity and nutritional issues in the region.
- Dr. Esteban Burchard co-authored a paper with Dr. Josh Galanter on methylation for different racial groups, reflecting differential contributions of genetic ancestry and environmental exposures to health in the open journal eLIFE.

### *NIMHD-Funded Science Activities*

- Dr. Pérez-Stable discussed a summary of his work in the intramural program at the National Heart, Lung and Blood Institute (NHLBI). Along with Dr. Erik Rodriguez, Dr. Pérez-Stable conducted an analysis of the National Health Interview Survey, which suggested that among Mexican Americans, gender, acculturation, and educational level correlate with smoking rates, with greater levels of education reducing these rates.
- NIMHD is funding two scientific workshops. The first focuses on the use of IT in minority health and health disparities and the second examines how structural racism and cultural competence affect minority health and health disparities.
- NIMHD will work with the National Institute on Aging (NIA) and the Eunice Kennedy Shriver National Institute on Child Health and Development (NICHD) on a workshop exploring inclusion through life course in June.

### **The Intersection of Comparative Effectiveness and Disparities Research**

Dr. Joseph Selby, Executive Director, Patient-Centered Outcomes Research Institute (PCORI) made a presentation focused on PCORI's goal to involve patients and other stakeholders in the research process, giving them a voice in the design, review, and dissemination of studies, to improve the research process. Research scientists at PCORI have found that involving patients in every stage of the research life cycle positively affects what decisions are made. The Affordable Care Act (ACA) charged PCORI with, among other things, investigating practice variations for some procedures as well as health disparities among certain populations. This charge has led to the development of five priorities: 1) the assessment of prevention, diagnosis, and treatment options; 2) improving healthcare systems; 3) communication and dissemination of research; 4) addressing disparities; and 5) accelerating patient-centered outcomes research through building research infrastructure. The Addressing Disparities program takes its mission from the overall goals of PCORI and aims to use clinical comparative effectiveness research (CER) to identify the best methods of reducing health disparities. Dr. Selby pointed out that PCORI does not fund studies that identify new disparities, but rather funds studies that compare the effectiveness of interventions that have already been implemented.

### **Retiring Members Appreciation**

Dr. Pérez-Stable acknowledged retiring members Dr. Eddie Greene and Dr. Linda Adams for their substantial contributions to the NACMHD. Dr. Greene thanked Dr. Pérez-Stable and NIMHD staff for all the support they've provided the Council. He noted the progress that health disparities research has made over his years. Dr. Adams praised the Council members for their hard work and took a moment to commemorate the late Dr. Bradford for her work in the care of LGBT children and adolescents.

### **Overview of Native American Cancer Research Corporation (NACR) with focus on the mHealth Northern Plains American Indian Tobacco Cessation Study**

Dr. Linda Burhansstipanov, Executive Director and President, Native American Cancer Initiatives, NACMHD Council Member, gave an overview of the Indian Health Service (IHS) regions, pointing out that in the Alaskan, Northern Plains, and Southern Plains regions, there is a statistically significant difference in rates of cancer in terms of mortality. Delays in healthcare delivery mean that American Indians tend to be treated later in the progression of the disease and therefore at much greater cost. The Native American Cancer Education for Survivors (NACES) network, the largest indigenous survivorship network in the country, aims to address some of these issues. The network began as a research grant designed for breast cancer patients but expanded into an autonomous, web-based source of information. It addresses issues unique to the native community, including spiritual practices. Dr. Burhansstipanov also discussed the mHealth Northern Plains American Indian Tobacco Cessation Study. The study had three aims: 1) measure the factors correlated with smoking among Northern Plains American Indians; 2) identify risk factors related to smoking persistence regardless of education about the dangers of smoking; and 3) develop and adapt tobacco cessation interventions. Researchers have just begun to dissect the outcome data, but preliminary results are positive.

### **Centers Program Working Group: Dr. Joyce Hunter, Deputy Director NIMHD**

The Centers Program Working Group was established in April 2016 to make recommendations to the NIMHD Director on the Centers program. The Research Centers in Minority Institutions (RCMI) and the Environmental Health Disparity Centers did not fall under the purview of the Working Group. The priorities focus areas for this working group were as follows: 1) advancing the science of minority health disparities, 2) adequately leveraging funding in service of this agenda, and 3) advancing other funding mechanisms to recruit and develop future minority health disparities researchers.

The working group examined data from 114 Centers grants, totaling \$857 million dollars, from 2002-2015. The group stratified grant awards along general topic areas, such as disease focus. A plurality of P20s, for example, studied diabetes. There were about 25 consistent diseases studied across the programs. Generally, there was a good variety of health disparities populations studied, with African Americans being the most examined across all three grant types. Dr. Hunter noted that there were an unexpected number of grants that did not specify a specific health disparity population as the focus of their study. As far as methodologies were concerned, interventional and epidemiological studies were most common. Some grants sponsored more than one type of study during their lifespan. Dr. Hunter noted there were no standard metrics for reviewing the success or output of the grants that had been awarded.

The Working Group recommended that the U54 mechanism be used as an alternative to the P20 and P60 mechanisms. Members concluded that cooperative agreements would more effectively promote innovation, and would better leverage program staff and other NIH resources. By using only U54s, program staff would have the responsibility of ensuring that under-resourced institutions were appropriately linked with research intensive institutions. Part of the greater linkage between NIMHD and staff would be cemented by making site visits by staff an option within the cooperative agreement. Regular meetings would also help ensure that the Institute was seeing a return on its investment. Additionally, they advised that the criteria for program evaluation be communicated in the FOA as a first step towards a standardization of review.

Given the limited funding for NIMHD each year, the Working Group recommended that the Institute be cognizant of other funding opportunities that exist both within and without

government. Foundations, medical societies, local community organizations, as well as federal and state agencies are all viable candidates for partnerships. These synergies do not have to be limited to funding and research; the group recommended that NIMHD look to leverage existing data resources as well through agencies such as CMS, PCORI, SAMHSA, AHRQ, among others.

For Priority 3, the Working Group recommended that the Institute keep better track of projects and project personnel to provide as much support as possible to outstanding researchers and investigators. This means collecting granular data on these researchers to forge specific partnerships with them. This data can also be used to assist researchers in forging partnerships with each other by establishing networks of funded investigators. New and early stage career researchers can be coached by senior mentors to support their development in the minority health and health disparities research sphere. The Network of Minority Health Research Investigators (NMRI) was cited as a successful example within National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The standardization of review should be extended to this priority as well and, accordingly, the Institute should develop evaluation criteria for these training and recruitment activities

### **Inclusion in Clinical Research at NIH**

Meredith Temple-O'Connor, Ph.D., Senior Policy Advisor for Clinical Research, Eunice Kennedy Shriver National Institute of Child Health and Human Development (formerly Senior Scientific Advisor to the NIH Deputy Director for Extramural Research)

Dr. Temple-O'Connor began with an overview of inclusion policies. Almost all human subjects' research conducted per the Common Rule is subject to inclusion policy. The idea behind examining inclusion policy is to ask, "does the study include the right participants for the scientific questions driving the research?"

In 2011, NIH undertook an Inclusion Re-Engineering project. Dr. Temple-O'Connor explained that in her capacity at the Office of Extramural Research (OER) she was focused on the business process side of reconfiguring inclusion at NIH. This meant developing new data system functionality, strengthening scientific oversight, and streamlining data entry among other tasks. Changes were made because of the Inclusion Re-Engineering project that led to enhanced data accuracy and accountability for NIH grant awards.

### **CONCEPT CLEARANCES**

Dr. Nathaniel Stinson, Director of the NIMHD Division of Extramural Scientific Programs led the discussion of two new initiatives presented by NIMHD program officials. Council engaged in detailed discussions. While generally supportive, members had some questions and recommendations for consideration prior to their approval. The NIMHD will consider the recommendations as well as other budgetary and programmatic issues in determining which of the proposed initiatives, if any, to implement.

**Title: Collaborative Minority Health and Health Disparities Research with Tribal Epidemiology Centers (TECs) Dr. Jennifer Alvidrez**

Purpose: This trans-NIH initiative seeks to foster relationships between TECs and external researchers to better study American Indian/Alaskan Native (AI/AN) populations.

**Title: NIMHD Centers of Excellence-** Dr. Derrick Tabor

Purpose: This initiative seeks to support specialized research centers to conduct transdisciplinary research, training and community engagement aimed at improving minority health. In 2016, NIMHD modified the scope of this program to include sex and gender minorities as a health disparity population. A motion to approve the two concepts was made, seconded, and passed unanimously.

**Agenda Item: Public Comment**

Dr. Pérez-Stable opened the floor to public comments and questions. There were no public comments.

**Closing Remarks and Adjournment**

Dr. Pérez-Stable thanked members for their contributions and adjourned the meeting at 3:01 pm.

**CLOSED SESSION**

*A portion of the meeting was closed to the public in accordance with provisions set forth in Sections 552b(c)(4) and 552b(c)(6), Title 5, U.S.C., and Section 10(d) of the Federal Advisory Committee Act, as amended, U.S.C. Appendix 2.*

**REVIEW OF GRANT APPLICATIONS**

Dr. Pérez-Stable called the Closed Session to order at 3:00PM. Dr. Hunter led the second level review of grant applications submitted to NIMHD programs. The Council considered 286 applications requesting an estimated \$168,671,452 in total costs. Funding recommendations for all applications submitted in response to program announcements and special program review announcements were made by the Council through *en bloc* voting.

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