

**U.S. Department of Health and Human Services (HHS)
National Institutes of Health (NIH)
National Institute on Minority Health and Health Disparities (NIMHD)
51st Meeting of the National Advisory Council on Minority Health and Health Disparities (NACMHD)**

6710 B Rockledge Drive, Conference Rooms, 1425 and 1427
Bethesda, MD 20892

Tuesday, May 21, 2019
8:00 a.m. – 1:00 p.m.

Meeting Minutes

Council Members Present

Eliseo J. Pérez-Stable, MD, Chairperson; Director, NIMHD
Maria R. Araneta, PhD, University of California San Diego
Marshall Chin, MD, MPH, FACP, University of Chicago
Giselle M. Corbie-Smith, MD, MS, University of North Carolina at Chapel Hill
Sandro Galea, MD, MPH, DrPH, Boston University
Ross Hammond, PhD, The Brookings Institute
Joseph Keawe'aimoku Kaholokula, University of Hawai'i at Manoa
Spero Manson, PhD, University of Colorado
Fernando Sanchez Mendoza, MD, MPH, Stanford University
Brian Mustanski, PhD, Northwestern University
Amelie G. Ramirez, DrPH, MPH, BS, University of Texas Health Sciences Center
Joan Reede, MD, Harvard Medical School
Brian Rivers, PhD, MPH, Morehouse School of Medicine
Gregory A. Talavera, MD, MPH, San Diego State University
Carmen Zorrilla, MD, University of Puerto Rico, Medical Sciences Campus

Ex-Officio Members Present

Judith Long, MD, University of Pennsylvania Perelman School of Medicine

Ex-Officio Members Absent

Cara Krulewicz, CNM, PhD, FACNM, Department of Defense

Representative

William Riley, PhD, Office of Behavioral and Social Sciences Research

Executive Secretary

Joyce A. Hunter, PhD, NIMHD

Presenters

Matthew W. Gillman, MD, Program Director for the Environmental Influences on Child Health Outcomes (ECHO) Study, Office of the Director (OD), NIH
Helene Langevin, MD Director, National Center for Complementary and Integrative Health (NCCIH)
Marcella Nunez-Smith, MD Director, Equity Research and Innovation Center, Yale University

CALL TO ORDER AND INTRODUCTORY REMARKS

Dr. Eliseo Pérez-Stable, Director of the National Institute on Minority Health and Health Disparities (NIMHD), called to order the Open Session of the 51st meeting of the National Advisory Council on Minority Health and Health Disparities (NACMHD) at 8:14 a.m.

INTRODUCTION OF MEMBERS

Council members and others present introduced themselves and stated their affiliations.

COUNCIL MINUTES REVIEW – February 2019

Dr. Joyce Hunter brought the minutes before the Council and called for a motion to approve the minutes. The Council unanimously approved the minutes of the February 2019 Council meeting. Dr. Hunter reminded members that future meeting dates could be found in the agenda and added that the location for NACMHD meetings occasionally changed. She reminded members that they were only allowed to miss one meeting per year.

NIMHD DIRECTOR'S REPORT AND DISCUSSION

Dr. Pérez-Stable provided the report on activities relevant to NIMHD since the February 2019 meeting.

HHS/NIH News

- Dr. Noni Byrnes was appointed Director of the NIH Center for Scientific Review (CSR). Dr. Pérez-Stable noted that Dr. Byrnes, who served as Acting Director since the retirement of Dr. Richard Nakamura in May 2018, was an outstanding applicant. She will oversee the CSR annual budget of \$130 million and the review of grant proposals for the NIH and other federal agencies.
- Dr. Ned Sharpless became Acting Commissioner of the Food and Drug Administration (FDA) on April 5th, after serving as the 15th Director of the National Cancer Institute (NCI) in 2017. Dr. Sharpless took the position after Dr. Scott Gottlieb stepped down. Dr. Sharpless came to the NIH from the University of North Carolina (UNC). Dr. Douglas Lowy will serve as Acting NCI Director until a new presidential appointment is made.
- Dr. Debra Tucci was appointed as Director of the National Institute on Deafness and Other Communication Disorders (NIDCD). Taking over for Dr. Jim Battey, Dr. Tucci will oversee the NIDCD annual budget of \$459 million as well as the Institute's (IC) research and training programs. She comes from Duke University Medical Center, where she led the Duke Hearing Center focused on cochlear implants. Dr. Tucci is an oral, head and neck surgeon and has a research track record in hearing disorders. She will join NIH in September 2019.
- On June 19-20, 2019, NIMHD will host the Pathways to Prevention Workshop at the Natcher Conference Center. Headed by Dr. Rick Berzon, the genesis of the Workshop was to focus on prevention recommendations (like mammography or prostate cancer screenings) by demographic categories and consider recommendations based on new data.
- Dr. Larry Tabak recently announced the signing of a first-time data-sharing agreement with the Navajo Birth Cohort Study (NCBS). The agreement was signed by the Navajo Nation, Johns Hopkins University, and RTI International. It will enable the NCBS to continue as part of the Environmental Influences on Child Health Outcomes (ECHO) program and allow NCBS individual participant data to be shared with ECHO consortium members. The agreement does not cover genetic or biospecimens. The agreement respects the Navajo Nation's cultural beliefs, Tribal sovereignty, and community values. David Wilson, PhD was instrumental in facilitating the agreement, which was in development for over a year. It represents the first Tribal data-sharing agreement for a nationwide research consortium creating a large-scale database. It also lays the groundwork for discussions with other Tribal Nations.

NIMHD News

- Dr. Rada Dagher was appointed Health Science Administrator in Clinical and Health Services Research. She had previously been an American Association for the Advancement of Science (AAAS) fellow with NIMHD.
- Vincent Thomas, Jr., received an HHS Honor Award for 50-plus years of federal service at the Humphrey Building on May 8th.
- Kina Hendrick and Dr. Juliet Pena departed from NIMHD. Dr. Pérez-Stable shared that Dr. Pena played the harp and was able to showcase her skills at a combined federal campaign event in the fall of 2018.

- NIMHD's Intramural program made three new hires, specifically Charmaine Chan (Post Baccalaureate), Collins Perryman (Predoctoral Fellow), and Dr. Calais Prince (Postdoctoral Fellow).
- On April 2nd, the House Appropriation Subcommittee on Labor, Health and Human Services, Education, and Related Agencies held a hearing on the President's proposed 2020 budget. Director Collins testified, as did several IC Directors (NCI, NICHD, NIAID, NHLBI, and NIDA). A similar hearing was held in a Senate Appropriation Subcommittee on Labor on April 11th. Dr. Collins testified along with several IC Directors (NCI, NIAID, NIGMS, NIDDK, NIA, and NIDA). Pérez-Stable noted that the House Members had questions about health disparities and added there was ample NIH support on this in Congress.
- On February 26th, Dr. Pérez-Stable attended the Children's Inn's congressional reception on Capitol Hill.
- On March 12th Dr. Pérez-Stable met with Senator Bill Cassidy to discuss health disparities. Dr. Pérez-Stable said that Dr. Thomas LaVeist—who serves as Dean of the Tulane University School of Public Health and Tropical Medicine—was also in attendance.
- On March 14th, Dr. Pérez-Stable gave a presentation to the Congressional Hispanic Caucus Institute (CHCI) on the importance of diversity in clinical trials. Dr. Pérez-Stable noted that most of the panel members worked on FDA drug approvals.
- On April 15th, Dr. Pérez-Stable participated in a congressional briefing sponsored by the Friends of NIMHD and hosted by Representative Jamie Raskin (D-MD), titled: Health Disparities - A National Crisis that impacts Us All

NIMHD Director Activities

- On February 7th, Dr. Pérez-Stable spoke at the Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC). Sponsored by the National Human Genome Research Institute (NHGRI).
- On February 14th, Dr. Pérez-Stable spoke and gave medical grand rounds at the Medical College of Wisconsin Department of Medicine.
- On February 21st, Dr. Pérez-Stable gave a keynote address on Public Health Science at the Society for Research on Nicotine & Tobacco. Dr. Pérez-Stable noted that NIMHD's Dr. Kelvin Choi also spoke at the meeting.
- On March 1st, Dr. Pérez-Stable visited the 3rd Annual Cancer Disparities Symposium at Case Western Reserve's Comprehensive Cancer Center (CCC). Dr. Pérez-Stable said of the four cancer centers he visited this year Case Western was the only institution in which he spoke to the CCC Director.
- On March 11th, Dr. Pérez-Stable visited Marshall University's medical school in Huntington, West Virginia. Bordering Kentucky and Ohio, Huntington is an epicenter of the opioid epidemic.
- On March 18th, Dr. Pérez-Stable spoke to the Lupus Research Alliance in Washington, DC.
- On March 20th, Dr. Pérez-Stable spoke on a panel at the Society for Research in Child Development (SRCD) Biennial Meeting in Baltimore, MD on maternal morbidity and infant mortality.
- On April 8th, Dr. Pérez-Stable spoke at Xavier University's (New Orleans) College of Pharmacy 12th Health Disparities Conference.
- On April 23rd, Dr. Pérez-Stable spoke at SciEd 2019, the Annual Conference for NIH Science Education Projects in Washington, DC.
- On April 28th, Dr. Pérez-Stable spoke on another panel in Baltimore on racism at the 2019 Pediatric Academic Societies Annual Meeting.
- On May 16th, Dr. Pérez-Stable gave the commencement address for George Mason University's College of Health and Human Services in Fairfax, VA.

NIMHD Activities

- NIMHD published Supplement 2, 2019, Volume 57, No. 6, which include peer-reviewed articles on the potential application of health information technology (IT) and ways to promote health

equity in clinical settings. The supplement featured commentaries and research on potential application of Health IT in reducing disparities via access to care, higher quality of care and patient-clinician communication (12 original research articles, 5 editorials and perspectives). The publication was spearheaded by Dr. Pérez-Stable, along with Drs. Beda Jean-Francois, Xinzhi Zhang, and Courtney Aklin.

- NIMHD is continuing their successful collaboration with NIDDK on the NIH Rwanda Fellowship Program. Dr. Pérez-Stable said Dr. Regine Mugeni—who studies diabetes—is the third Rwanda Fellow. Dr. Mugeni is working to develop a cost-effective and reliable model to diagnose diabetes in Africans. She has found a combination of two test to help capture at risk Africans that are often undiagnosed due to different thresholds for the standard diabetes test.
- Dr. Marshall Chin wrote a piece for the NIMHD Insights Blog called “Addressing Social Needs and Structural Inequities to Reduce Health Disparities: A Call to Action for Asian American and Pacific Islander Heritage Month.”
- On April 17th, NIMHD partnered with HHS’ Office of Minority Health (OMH) and the Office of Disease Prevention and Health Promotion in the “Active and Healthy Bilingual Twitter Chat” as part of the National Minority Health Month activities. Dr. Felicia Collins (Director, OMH) participated in the Twitter chat.
- On April 24th, NIMHD hosted its 3rd Annual Minority Health 5k Walk/Run for National Minority Health Month. There were 400 registered participants. Dr. Pérez-Stable noted that the Surgeon General Dr. Jerome Adams—who happened to be on campus meeting with Dr. Tabak at the time—participated in the event. Dr. Adams did a Twitter video where he had people respond to his call-outs about an active and healthy life. He sent the Tweet to Dr. Collins, who responded. This was very positive for NIMHD.

Budget

- Dr. Pérez-Stable displayed a chart showing NIMHD’s budget projections based on the President’s proposed Fiscal Year (FY) 2020 budget. Dr. Pérez-Stable commented that they were hopeful the projected budget of \$270.87 million would not be the final funding amount, since it proposes a \$43.8 million reduction from the FY19 appropriation level. They hope that the both the House and Senate will continue to be supportive of the NIH and supportive of NIMHD’s research.
- Dr. Pérez-Stable displayed a slide showing how efficiently NIMHD dispenses awards and noted that some issues in the past have largely been resolved. There is not a problem getting lots of R01 applications that are very well reviewed. Now, NIMHD must make tough decisions about what to fund. Awards are also getting out at a more efficient pace.
- Dr. Pérez-Stable displayed a slide on the growth of various NIMHD research areas, which includes Research Project Grants (RPG), Intramural, Research Centers in Minority Institutions (RCMI), and Research and Development (R&D) Contracts, as well as the Jackson Heart Study (JHS) and the Hispanic Community Health Study (HCHS)/Study of Latinos (SOL). The largest projected growth in research areas has been in RPGs. The JHS and SOL should generate critical data for use by all in the scientific community.

NIMHD-Supported Grants and Programs

- On April 4, 2019, NIMHD hosted the Health Disparities Bioethics Scholars from Fordham HIV Prevention Research Ethics Training Institute. Dr. Celia Fisher (Fordham) brought four early-stage investigators who shared their bioethics research on minority health and health disparities research topics with NIMHD.
- In March, the Clinical Research Education and Career Development (CRECD) scholars held their annual meeting. CRECD R25s funded by NIMHD. Two of the three awards have been linked to RCMI programs. They focus on development of the pipeline with postdoctoral fellows and junior faculty, mostly minority investigators working in minority health and health disparities.
- Dr. Anna Napoles gave a moving talk for Women’s History Month that was included in a publication for NIH’s Office of Equity, Diversity, and Inclusion (EDI). Dr. Napoles discussed her personal journey, her career, and offered advice to young aspiring female scientists. She is the

first Latina Scientific Director at NIH. In just two years, she has been very impactful in her leadership role.

- Dr. Kelvin Choi was honored with the 2019 Jarvik-Russell New Investigator Award by the Society for Research on Nicotine and Tobacco. He was recognized as an early-career scientist who has made extraordinary contributions to the field of nicotine and tobacco research.
- Drs. Sherine El-Toukhy, Kristyn Kame, and Kelvin Choi presented at the 2019 Society for Behavioral Medicine (SBM)'s Annual Meeting in Washington, DC.
- Dr. Napoles' lab presented her work on transcreation at the 2019 American Association of Cancer Research (AACR) Annual Meeting. Christian Escalera and Dr. Jung Byun also presented.

Scientific Advancements.

- A recent study by Kaiser on time to follow-up after colorectal cancer screenings by health insurance type, showed that patients with Medicaid may have a longer wait time for follow-up after a positive fecal immunochemical test (FIT) than patients with other types of insurance. Dr. Pérez-Stable said that while many people will not have adverse consequences from follow-ups that take place within six months to a year rather than three months. The natural history of colon cancer is that on average it takes six years to go from polyp to an invasive cancer. A paper published in *Child Development* looked at racial disparities in sleep and explored whether discrimination translated to worse sleep for minority adolescents. Black adolescents slept 35 minutes less than Asian and 36 minutes less than Latino/a youth. Though sleeping is an essential human activity it has been largely overlooked as a risk or resilience factor, and Dr. Pérez-Stable said it could have significant effects on adolescent development. This study found an association between discrimination with disruptive sleep or dysfunctional sleep and higher daytime sleepiness in adolescence.
- Another study in *Addictive Behavior*, examined smoking prevalence among sexual and gender minorities (SGM), who tend to have higher rates. The study also looked at the "Put It Out Project" (POP), a Facebook smoking cessation intervention for SGM young adults. The study found that Lesbian women began smoking at an older age than "other" sexual orientation participants. Transgender participants smoked the most cigarettes per day. Smoking characteristics were mostly similar across sexual and gender identities.
- Dr. Pérez-Stable noted that a recently funded NIMHD study that appeared in the *Annals of Internal Medicine* confirmed a bias he has held for a long time that dietary supplements do not make an asymptomatic person feel better. The study looked at the association among dietary supplement use, nutrient intake, and mortality among U.S. Adults. NHANES data from 1999 to 2010 linked to National Death Index mortality data was used. The study showed that taking dietary supplements had little benefit on lifespan among U.S. adults. Further, the study also found that excess intake of calcium associated with increased risk for cancer death was likely related to increased calcium intake from supplements.
- Another study examined the effects of changes in the Earned Income Tax Credit (EITC) in Washington, DC compared to states with no EITC from 1990-2015. This was a time-series analysis reported in *Social Medicine Population Health*. The study found that there were significant improvements in pre-term birth, birth weight, gestational weeks as the size of the EITC increased. More work is needed though to identify the mechanisms linking more generous EITC benefits to improved birth outcomes.
- A paper in *BMC Cancer* reviewed archived pathology reports from 2000-2015 to determine the prevalence of cancer (CA) subtypes in Puerto Rico. The data reviewed was for participants 21 to 89 years of age. The study found that Breast CA diagnosed at an earlier age was more aggressive and had higher grade tumors. A significant number of CA cases had critical missing clinical and pathological information. Dr. Pérez-Stable commented that the missing data limited the overall results of the study and added that better data could benefit future research.
- A retrospective study in the *Journal of Immigrant and Minority Health* looked at asthma and chronic obstructive pulmonary disease (COPD) disparities in the diagnosis and basic care utilization among low-income patients in community health centers in Oregon. The study found

lower odds of obstructive lung disease diagnosis among Latinos than Whites. Among diagnosed patients, the uninsured had lower visit rates over 5 years than their insured racial/ethnic counterparts.

- A study in *Inquiry* looked at the effect of insurance coverage and having a regular clinician among childhood cancer survivors. Latinos were twice as likely to lack a regular source of care for cancer-related care compared to non-Latinos. The study also showed that the uninsured were more than twice as likely to report no regular source of care for follow-up compared to those with private insurance coverage. Dr. Pérez-Stable stated that more research is needed with Latinos and other racial/ethnic groups of childhood cancer survivors to understand the barriers to care.
- The *Journal of Immigrant and Minority Health* published a paper from an NIMHD funded study that looked at the effects of self-silencing and egalitarian attitudes on HIV prevention behaviors among Latina immigrant farmworker. The study cross-sectional study, using secondary, found that self-silencing behaviors were negatively associated with self-efficacy for HIV prevention, intentions to negotiate safe sex, and HIV-related knowledge. In contrast, egalitarian attitudes were positively associated with the preventive behaviors.
- A paper in *Alzheimer's & Dementia* by CRECD scholars out of the Morehouse School of Medicine looked at racial and ethnic estimates of Alzheimer's disease and related dementias (ADRD) in the United States. The study used claims data for population among Medicare Fee-for-Service beneficiaries in 2014. Blacks had the highest prevalence of ADRD, followed by Latinos. Women had a higher rate of ADRD than men in all race/ethnic groups. The study estimated that there will be 13.9 million Americans with ADRD by 2060. Dr. Pérez-Stable noted that Dr. Spero Manson has been working to get better American Indian data related to this topic.
- Another paper in the *Journal of Abnormal Child Psychology* looked at protective factors that buffer life stress and behavioral outcomes among high-risk African American youth. Behaviors such as internalizing problems, externalizing problems, and drug use is seen in high-poverty neighbors were considered. The study tested potential protective factors like religiosity, parental monitoring, and neighborhood collective energy on life stressors and behavior in 576 African American youth. The investigators found that internalizing problems were buffered by adolescent religiosity and neighborhood collective efficacy, while externalizing problems were buffered by parental monitoring and collective efficacy.
- One funded study worked with the National Health Interview Survey (NHIS) data from 2012-2015 linked with neighborhood data from the US Census American Community Survey and the National Center for Health Statistics Urban-Rural Classification Scheme to examine urban versus rural COPD prevalence patterns. COPD prevalence in poor, rural areas was almost twice that in the overall population. Rural residence and poverty appear to be indicators of household wealth. The study also showed that rural residence, poverty, and coal heating were risk factors for COPD even among never-smokers.
- A study in the *Journal of Immigrant and Minority Health* from Dr. Choi's lab examined tobacco-use behaviors among US-born blacks compared to immigrant blacks (US territories, Africa, West Indies, and Europe) living in the US. The study found that the US-born black smoking rate was 17%, compared to 4.7% in African-born blacks and 4.9% in West Indies-born blacks. Dr. Pérez-Stable said in his research he found Sub-Saharan blacks smoke very little. The study found that the rates of first cigarette after waking and menthol cigarette use are higher in U.S.-born blacks than other groups.
- Another paper from Dr. Choi's lab looked at online tobacco marketing among US adolescent SGM as well as racial/ethnic minorities. Using the Population Assessment of Tobacco and Health (PATH) Study Wave 1 survey youth sample, the study found that SGM and racial/ethnic minorities are more likely to engage with online tobacco marketing than heterosexual and non-Hispanic whites.
- Dr. Napoles' lab published a paper to *Community Mental Health* on pre and post-intervention incomes with 50 Spanish-speaking Latino immigrants. While the intervention had little effect on the stress of immigration, there was a marked improvement in depressive symptoms post-intervention.

- A Morbidity and Mortality Weekly Report (MMWR) on the National Youth Tobacco Survey (NYTS) found that the youth cigarette smoking rate—for both combustible and e-cigarette smoking, respectively— was 14.7% and 26.8% for Whites, 13.2% and 7.8% for Blacks, and 13.7% and 14.8% for Latinos. Dr. Pérez-Stable added that NIMHD has been trying diligently to get more data on this topic. Dr. Pérez-Stable said that this was an interesting topic given that the overall rate of youth smoking has decreased significantly, while the proportion of youth who have been susceptible to smoking remains unchanged. Dr. Pérez-Stable explained that this is bad because combustion smoking is much more dangerous than vaping and noted that Whites were much more likely to use electronic delivery methods than other race-ethnic groups. As the number one source of preventable death in the United States today, this issue needs to be more strongly investigated.
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- A study from the *Journal of the National Cancer Institute* analyzed the development of lung cancer by the amount one smokes as well as racial/ethnic status. By 2012, 4993 cases of lung cancer had been ascertained. This multiethnic Cohort study update showed rates of 21.0 for Native Hawaiians, 19.1% for African Americans, 11.9% for Whites, 10.1% for Japanese Americans, and 8.0% for Latinos. After adjustments for predicted total nicotine equivalents, African Americans and Japanese Americans did not differ from Whites. The study found that African American and Japanese American lung cancer rates may be affected by their ability to metabolize nicotine.

ECHO Update and Early Results: Dr. Matthew W. Gillman, Program Director, Environmental Influences on Child Health Outcomes (ECHO), Office of the Director, NIH

ECHO's mission is to enhance the health of children for generations to come. With the guiding principles of teamwork, impact, responsibility, and value, ECHO's motto is "A good start to life can last a lifetime." This outlook is related to the developmental origins of health and disease outlook, which states that perturbations that occur early in life can have long-lasting effects. To ensure a good start to life, researchers need to understand potential risks and resiliencies as well as when and to whom they apply. The ECHO Program has a nation-wide presence—with representation in 44 states as well as Puerto Rico—and is comprised of five supporting cores or centers. The ECHO cohorts are made up of 31 grant awards, 68 Principal Investigators (PIs), 71 cohort, and roughly 150 performance sites. With these components, ECHO's overall scientific goal is to answer solution-oriented questions about effects of a broad range of early environmental exposures on child health and development. The category of broad range of exposures includes physical and chemical exposures as well as societal, medical, psychological, behavioral, and biological exposures. ECHO studies exposures from conception to age five, and the health outcomes focus on high-impact conditions throughout childhood and adolescence. These conditions include pre-, peri-, and postnatal, upper and lower airway, obesity, and neuro-development. In addition, ECHO has added the category of positive child health, which focuses on assets that enable a child's well-being. These developed assets include happiness, life satisfaction, meaning and purpose, relationships, achievement, and sleep.

While supporting each entity within the cohorts, ECHO is striving to make an ECHO-wide cohort, which weaves together the 71 cohorts of mothers and children to enhance follow-up. The aim of this expansive cohort is to establish a single data platform to conduct etiologic and prediction research, and to harmonize existing measures while standardizing new ones. Studying 50,000 children and their families, the ECHO-wide cohort aims to research questions that no single cohort or small collections of cohorts could answer on their own. With a broad array of geographic, racial, and SES data, the ECHO-wide cohort will be a resource for the entire scientific community and will pursue solution-oriented research to impact policies, programs, and practices. The ECHO's Steering Committee ratified their data collection protocol as well as their policies on data sharing, bio specimens, publications, and conflicts of interest. Cohorts have collaborated to provide collective analyses and have been productive in their own right, publishing over 200 papers in the first 2.5 years of the program. One notable ECHO cohort is the Navajo Birth Cohort Study (NBCS), which looks at how prenatal exposure to uranium and other metals affects

child growth and development. Within that study, families are followed from the prenatal period through early to mid-childhood throughout the Navajo Nation.

Like all ECHO cohorts, the NCBS had to meet certain conditions of the 2-year UG3 period to be eligible for the 5-year UH3 phase. Some of these conditions were cohort-specific, while others were collaborative, including leadership, test data transfer, and data sharing. Interestingly, the NCBS could not move to the UH3 phase until the Navajo data sharing agreement was implemented. While the Navajo Nation had previously participated in NIH studies, they had never before agreed to required data sharing on a nationwide scale. Due to this, ECHO came to a program-specific agreement with the Navajo, allowing the NCBS to share individual-level data onto the ECHO-wide cohort data platform with no change in NIH or Navajo Nation policies. To do this, ECHO started with data only, and did not require bio specimens or genetic analyses. Thus, ECHO and the Navajo have a dual layered data sharing agreement, with one in a restricted dataset and another in an anonymized public use dataset

ECHO's principles of engagement with the Navajo are, firstly, to be committed to consultations with Tribal Nations, as well as to collaborate with American Indian/Alaska Native (AI/AN) partners. This latter principle involves attending to cultural/historical issues and tribal sovereignty. In addition, this principle strives to do research that serves the AI/AN community as well as the ECHO-wide cohort. To do this, ECHO staff has worked to find common ground with potential participants, which could serve as an example for other studies moving forward. ECHO's engagement strategies include working closely with the NIH Tribal Health Research Office (THRO), and engaging other key stakeholders at NIH like the General Counsel. Within ECHO itself a stakeholder working group helped establish principles of engagement, and ECHO frequently collaborates with NBCS' PI.

From August 2017 to May 2019, ECHO researchers made six visits to the Navajo Nation, and Dr. Gillman said ECHO served as a broker between the Navajo Nation, NBCS, and ECHO awardees. Through multiple in-person visits, ECHO researchers were able to build trust and discuss content. Over the course of these visits ECHO had to weather many ups and downs, especially with ECHO and THRO improving on their processes and the Navajo government holding their own elections. These elections were particularly important, Dr. Gillman said, as the shifting governmental personalities meant that multiple stakeholders would be meeting several times and occupying different positions within the community. Eventually what came out of these efforts was an ECHO-wide cohort analysis in restricted enclave, with protections throughout the system for data sharing as well as the use pipelines. This pipeline specifies who participates in the analysis proposals, who is on a publications committee, and who reviews publications before they go out. Dr. Gillman shared that the agreement was signed in March 2019, and there was a ceremonial signing on 5/7/19 with ranking members of HHS, NIH, and the Navajo Nation. With all of that effort, Dr. Gillman reminded attendees that this was merely the beginning of the study, as they now have to do the work they've been trying so hard to undertake.

Dr. Gillman displayed a map showing the 17 IDeA States Pediatric Clinical Trials Network (ISPCTN) across the country. The goals of the ISPCTN is to provide access to state-of-the-art clinical trials to rural and underserved populations, build national pediatric research capacity, and apply findings from relevant pediatric cohort studies to children in ISPCTN locations. Currently there are five trials underway or in development. Two of the trials work on pharmacokinetics, while another two trials focus on opioids. The final ISPCTN project is focused on the IAmHealthy Pilot Protocol.

Turning to the Accelerating Clinical Trials for Neonatal Opioid Withdrawal Syndrome (ACT NOW), Dr. Gillman said that while this kind of research had been going on for a long time it was often in locations that do not have a very high prevalence of NOWS. Thus, in 2016 ECHO's ISPCTN began studying NOWS in areas that had higher prevalence. To date, 30 sites have participated and tried to understand varied current approaches to treatment. These protocols have also attempted to develop protocols for randomized clinical trials. Through these efforts, ECHO has collected data on 1800 participants with NOWS. This study has been led by three early-stage neonatologist investigators.

NCCIH Strategic Priorities: Dr. Helen Langevin, Director, National Center for Complimentary and Integrative Health (NCCIH), NIH

Dr. Langevin explained that her talk would examine the following questions:

1. What is Integrative Health?
2. Why is Integrative Health important for minority populations and health care disparities?

She said that while integrative health is usually thought to be comprised of bringing conventional and complementary approaches together in a coordinated way, she argued that the concept should include emphasizing practices that prevent disease, restore health, and treat the whole person.

Many patients today complain that they are treated as though they are a disparate set of body parts rather than a whole, integrated person. Moreover, some diseases—like obesity, diabetes, cardiovascular disease, chronic pain, and chronic stress—disproportionately affect minority populations with health care disparities, a problem that integrative health can uniquely work against. The medical field is currently defined by the disease model, in which different diagnoses are applied to the body's various organ systems. In the biopsychosocial, whole health model of treatment, there are methods for treating the total physical and emotional well-being of the patient. However, these systems often seem to not be working in concert, and Dr. Langevin asserted that there may be a piece of the puzzle missing between the two methodologies. With that, she displayed a slide with three plants. Of the middle plant, Dr. Langevin said it displayed a vague sense of unhealth. While our current medical treatment system is adept at treating disease once it has been contracted, disease prevention and health restoration offers many different primary, secondary, and tertiary mechanisms to fortify one's health (including environment, nutrition, and lifestyle).

Complementary and Integrative Health Care inhabits the health-disease spectrum, operating through symptom management. On one end of the spectrum, diet and low-dose supplements are ways to improve one's health. On the other end of the spectrum, researchers develop single molecule pharmacological substances to treat disease. Dr. Langevin argued that there is middle ground between these two poles, as probiotics and whole health systems also have a beneficial effect on many patients. Many of these whole-health systems utilize traditional plants to treat patients, and researchers are starting to understand that there can be different synergies within some of these plant compounds. For example, some of these traditional healing models (such as traditional Chinese healing practices) have the explicit intended purpose of building up one's total constitution. Whole health restoration is extremely important in the context of behavioral interventions. Humans can modulate their diet and activity levels to improve health in ways plants cannot. Dr. Langevin said another aspect of this research topic that needs more attention are the endogenous healing mechanisms like repair, remodeling, resolution, regeneration, and regrowth. She said experts know that diseases like diabetes tend to be co-morbid, and people with diabetes are more likely to develop degenerative joint disease and disc disease.

Traditionally, scientists have considered chronic pain as a disease of the brain rather than that of the body. However, new research is suggesting that the body itself has a greater role to play in that matrix. Dr. Langevin said much of her research is on connective tissue, which literally connects the body together and creates a kind of scaffold for a person. This tissue is always remodeling based on gravity, externally applied forces, and muscle contractions. While the brain does not have a direct connection to tissue it does connect to muscles, which are constantly reshaped over the course of our life by activities we undertake. Therefore, if someone practices poor musculoskeletal behaviors, those tissues could remodel in a way that will eventually cause something like degenerative joint/disc disease. While it can degenerate, connective tissue can also be improved. If movement is applied in a gentle, mindful way (such as with yoga or physical therapy) those tissues can often be brought back to health. Dr. Langevin said that this phenomenon is especially relevant to NIMHD, because experts know that sedentary lifestyle and poor diet are co-morbid with psychological stressors and poor sleep habits. In addition, numerous studies have shown that dementia and depression are more likely to occur for individuals with chronic, systemic inflammation problems. Thankfully, the same interventions used for treating poor musculoskeletal problems are also good for sleep, psychological stress, and "mindful eating."

Dr. Langevin said there are myriad ways that people can reduce their overall inflammatory burden, which could be taught to children at early ages. She shared a study from the *Annals of Internal Medicine* from a few years ago showing that yoga was similar to physical therapy (PT) in helping low-back pain in a diverse urban population. While both methods can be effective, patient preference and what insurance will compensate shows that looking at a person's whole health can be important. In addition, allowing for group visits for treatment like acupuncture could offer new avenues to whole health for many people.

Dr. Langevin noted that the National Center for Complementary and Integrative Health (NCCIH) is one of NIH's smallest centers, and they often rely on collaboration with partners like the Department of Veterans Affairs (VA) and the Department of Defense (DoD). In addition, NIH undertakings like the Helping to End Addiction Long-term (HEAL) Initiative offers helpful points of collaboration for NCCIH, and they are deeply involved in one HEAL Initiative aimed at studying Pragmatic Randomized Controlled Trial of Acupuncture for Management of Chronic Low Back Pain in Older Adults. She stated that integrative health is for everyone, as treating the whole person is extremely important.

Precision Medicine and the Eastern Caribbean Health Outcomes Research Network (ECHORN): Dr. Marcella Nunez Smith, Associate Professor, General Internal Medicine; Director, Equity Research and Innovation Center, Yale University.

Dr. Nunez-Smith said ECHORN was born out of a desire to study health in the U.S. territories as well as the 5 million residents who live in those regions globally. Although there are five distinct regions for territory health, they tend to be treated similarly from a policy perspective. This has several important consequences, including the ways CMS funding is applied in these communities. ECHORN aimed to look at quality of care in these regions as opposed to the U.S. mainland, looking especially at heart attack, heart failure, and pneumonia. The somewhat surprising result of the study was that hospital mean mortality rates were significantly higher in the territories than in the States for those three conditions. One lesson ECHORN staff quickly learned from their research was that the state of the National Quality Forum (NQF) quality care metrics only explained a portion of their results, as regions like the Eastern Caribbean were threatened with a non-communicable disease (NCD) epidemic at the same time. Dr. Nunez-Smith said many of the island nations felt like they were unable to effectively combat the NCDs, and the United Nations (UN) even held a General Assembly High-Level Meeting on NCDs, the first one not specific to HIV/AIDS. Dr. Nunez-Smith noted that this meeting was spearheaded by CARICOM, specially Sir Trevor Hassell, and Sir George Allyene. One of the main takeaways from this meeting was that many of the Caribbean nations did not have the data infrastructure to provide people with adequate healthcare planning or strengthening.

With that, Dr. Nunez-Smith and her partners created ECHORN, using funding from NIMHD and other partners from Puerto Rico, Barbados, the U.S. Virgin Islands, and Trinidad-Tobago to collaborate on what was happening in each community's cultural context. The core outcome of ECHORN is the ECHORN Cohort Study (ECS), a community dwelling cohort across the islands with advisory boards. To be eligible for the ECS, potential participants had to be English or Spanish speaking, more than 40 years of age, and a permanent resident with no plans to relocate within the next five years. Sampling differed across sites, as in Barbados adults were recruited from households within randomly selected enumeration districts across the island. In addition, Puerto Rico and Trinidad's sampling was restricted to two select enumeration districts, and in the U.S. Virgin Islands they were able to use random sampling. Three thousand adults were involved with the first wave of the ECS, in which they conducted a three-part baseline assessment that included a self-administered questionnaire, clinical exam, laboratory assessment, and optional bio banking (in which 20% of people participated). Female representation in the study was 66%, with a mean age of 57.3. Dr. Nunez-Smith displayed a slide showing the prevalence of chronic diseases in the ECS compared to mainland cohorts, which indicated that ECS participants had a higher prevalence of diseases like hypertension, diabetes, and obesity.

In 2015, Dr. Nunez-Smith's team partnered with Yale's Global Health Leadership Institute (GHLI) to chart a strategic directive forward for ECHORN. Through this process they identified a number of key objectives, including the need to focus on pediatric and intergenerational research, implementation and intervention research, and data sharing and expanding the stakeholder network. ECHORN subsequently changed their strategic direction, and expanded their network to include relevant parties from New York and New Jersey, which included the Yale Transdisciplinary Collaborative Center for Health Disparities Research focused on Precision Medicine (Yale-TCC).

The second wave of the ECHORN study had five essential goals:

1. Expand investigator network
2. Expand stakeholder network
3. Implement evidence-based interventions
4. Address data sharing needs
5. Explore population-based research ethics

Actively in wave two of the project, many of ECHORN's goals have remained the same, though Dr. Nunez-Smith mentioned that they added dried blood spot cards to their laboratory testing. While in the first wave of the project bio banking included collecting sample of whole blood, serum, and clot samples from over 600 participants, in wave 2 these participants were invited to include urine in their sample. ECS wave 2 includes a number of subprojects, including ones on hypertension, diabetes, and bio banking.

In the hypertension subproject, researchers are assessing 24-hour ambulatory blood pressure in the context of daily life. Looking closely at 26 participants with 1,137 valid readings during the 24 hour period of measurement, researchers found that only four of those individuals had normal blood pressure, and 21 exhibited nocturnal non-dipping. While these numbers are small they suggest a higher burden for these populations, and Dr. Nunez-Smith said ECS will continue to recruit and look to identify phenotypes of hypertension risk.

In the diabetes subproject, ECS's goal was to identify type 2 diabetes biomarkers to better predict and monitor diabetes development. Dr. Nunez-Smith said that this study has shown some evidence that looking at the distribution and ratio of amino acids in the blood may give more insight into the onset of diabetes. After validating the assays, researchers have gotten very interesting results, and ECS is now looking to add factors like age, sex, and body-mass index (BMI) to this study. She said during this Yale-TCC project they hope to identify biomarkers and do annual testing of urine and serum samples.

Dr. Nunez-Smith acknowledged ECHORN's pilot project awardees, including Drs. Damian Cohall and Nkemcho Ojeh—who are studying hypertension in populations of African descent—as well as Dr. Yuri Clement, who is devising a protocol for the study of polymorphisms and repose to metformin in patients with type 2 diabetes in Trinidad. The Yale-TCC Consortium Core now includes more than 60 stakeholders in the region, who assist with collaborative learning, data sharing, implementation, and consortium well-being. Dr. Nunez-Smith said that the Consortium also looks to support the upcoming generation of researchers, and she acknowledged the Fellows affiliated with the program. She said the Yale-TCC project has a Demonstration Project Program focused on diabetes prevention with Lifestyle Intervention and Metformin Escalation (LIME). LIME is an evidence-based intervention that seeks to reduce the incidence of diabetes among higher risk patients with prediabetes using lifestyle modification. Dr. Nunez-Smith said the LIME study was done in collaboration with NIMHD and Dr. Carol Horowitz, with clinical partners across the sites. Already complete with the first run of workshops, LIME is trying to be conscious of how they share participant data, and ECHORN is working to develop data use workshops.

Dr. Nunez-Smith said ECHORN has many goals going forward, especially looking at sleep deficiency and pediatric outcomes. Given that two sites were recently devastated by hurricanes, ECHORN will also be deploying a hurricane readiness kit.

Concept Clearance: Centers of Excellence (COE) Program Update: Dr. Nishadi Rajapaske, Program Director, Specialized Centers of Excellence with Environmental Health Disparities (EHD).

In February 2017 the NIMHD COE program was redesigned, presented and approved by the NIMHD Advisory Council to establish *NIMHD Specialized Centers of Excellence for Research on Minority Health and Health Disparities*, where each Center is expected to have a unifying thematic scientific focus. The proposed COE with a thematic focus on environmental health disparities will significantly enhance and fill a gap within NIMHD's broad COE program portfolio and provide opportunities to collaborate with the National Institute of Environmental Health Sciences (NIEHS). The proposed centers will conduct multidisciplinary research, research training, and community engagement activities aimed at alleviating environmentally driven health disparities and improving access to healthy environments for vulnerable populations.

In 2017, 12 new COEs were funded under RFA-MD-17-005. Although the RFA encouraged applicants to choose a thematic focus that addresses multiple domains of influence including the physical and sociocultural environment, none of the funded COEs had an environmental health disparities theme. Therefore, the components of the COEs include an administrative core that provides overall project oversight and evaluation, and there are 1-3 required research projects relevant to the application. The community engagement and dissemination core develops, demonstrates and evaluates strategies to translate scientific findings of the center into information for affected community members, the public, and policy makers to use to promote healthy environments for vulnerable and health disparate populations. The Investigator Development Core supports a pilot project program that provides opportunities for post-doctoral fellows, junior faculty, and other early stage investigators to generate preliminary data in the thematic focus of the center for subsequent submission of grant application.

The purpose of this program is to support Specialized COEs with an Environmental Health Disparities (EHD) research theme under the current NIMHD COE program, in partnership with the NIEHS. The proposed centers will conduct multidisciplinary research, research training, and community engagement activities aimed at alleviating environmentally driven health disparities and improving access to healthy environments for vulnerable populations.

The existing programs established independently and collaboratively by the NIEHS and NIMHD fostered collaboration across disciplines and enabled multidisciplinary teams of community and academic experts from diverse backgrounds to conduct research on health disparities and environmental health disparities. From these programs, the RFA encourages research that focuses on the links between environmental, biological, and non-biological determinants of health. Research proposals should:

- Stimulate research of the multiple factors underlying EHDs
- Promote innovative approaches to mitigate environmentally drive EHDs and improve access to healthy environments for vulnerable populations
- Include community engagement

An overarching program goal would be to address EHDs through mitigation or reduction of modifiable environmental factors.

This proposed program could advance the study of EHDs by considering cumulative harmful exposures over the life course, examine the results of the synergistic effect of exposure to multiple environmental hazards in the context of social stressors like poverty, psychosocial stress and discrimination and the built environment, and promote resilience in health disparate communities to improve the ability of minority and economically disadvantaged populations to withstand or mitigate harms.

NIMHD is seeking Council concurrence to continue its collaboration with NIEHS to support Centers of Excellence with the theme of Environmental Health Disparities Research using the existing, Council-approved NIMHD COE specialized center framework.

Public Comments

Dr. Pérez-Stable invited Dr. Derrick Tabor to give his comments. Dr. Tabor said in his role as a project scientist for the Morehouse College Transdisciplinary Cooperative Center for Health Policy, he would like to acknowledge visitors from the Satcher Health Leadership Institute. Dr. Tabor invited Dr. Megan Douglas (Assistant Professor, Morehouse) to introduce the Fellows. She introduced Drs. Chelsea Ukoha, Roselyn Hicks, Mirnouve Domond, and Debbie Vitalis.

Closing Remarks

Dr. Hunter said the next Council meeting would take place in September. Dr. Pérez-Stable said NACMHD would have new Council Members in September, and thanked Drs. Brian Rivers, Happy Araneta, Ross Hammond, and Sandro Galea for their participation in the present meeting. With no further business to attend to, Dr. Pérez-Stable adjourned the meeting at 1:08 p.m.