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)

6001 Executive Blvd.
Rockville, MD

May 11, 2018 (Open Session) 8:00 a.m. – 1:00 p.m.

Meeting Minutes

Council Members Present
Eliseo J. Pérez-Stable, MD, Chairperson; Director, NIMHD
Margarita Alegria, PhD, Massachusetts General Hospital
Maria R. Araneta, PhD, University of California San Diego
Linda Burhansstipanov, MSPH, DrPH, Native American Cancer Initiatives
Marshall Chin, MD, MPH, FACP, University of Chicago
Giselle M. Corbie-Smith, MD, MS, University of North Carolina at Chapel Hill *
Ross Hammond, PhD, The Brookings Institute
Spero M. Manson, PhD, University of Colorado Denver
Fernando Sanchez Mendoza, MD, MPH, Stanford University
Amelie G. Ramirez, DrPH, MPH, BS, University of Texas Health Sciences Center
Gregory A. Talavera, MD, MPH, San Diego State University *

Council Members Absent
Sandro Galea, MD, MPH, DrPH, Boston University
Linda Greene, JD, University of Wisconsin
Brian Rivers, PhD, MPH, Morehouse School of Medicine

***Ex Officio* Members Present**
Said Ibrahim, MD, MPH, VA Health System
Carol Krulewitch, PhD, Office of the Assistant Secretary of Defense for Health Affairs

Executive Secretary
Joyce A. Hunter, PhD

Presenters
Diana Bianchi, MD, Director, NICHD
Said A. Ibrahim, MD, Co-Director, Center for Health Equity Research, Philadelphia, VA Medical Center/University of Pennsylvania
Deborah Duran, PhD, OSPARD, NIMHD

* present by teleconference

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 48th meeting of the National Advisory Council on Minority Health and Health Disparities (NACMHD) at 8:08 a.m.

INTRODUCTION OF Members
Council members and others present introduced themselves and their affiliations.

COUNCIL MINUTES APPROVAL – February 2018

Dr. Joyce Hunter brought the minutes before the Council for approval. Dr. Hunter called for a motion to approve the minutes. The Council unanimously approved the minutes of the February 2018 Council meeting. Dr. Hunter informed the Council that the September 2018 meeting would take place in Natcher, Building 45, on the NIH campus.

NIMHD DIRECTOR'S REPORT AND DISCUSSION

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

NIH News

- On March 21, 2018, Dr. Robert Redfield was appointed the Director of the Centers for Disease Control and Prevention (CDC). An experienced investigator in HIV research from the University of Maryland, Dr. Pérez-Stable noted that the selection of Dr. Redfield—along with Secretary Azar—signals the Department of Health and Human Services (HHS) has strong leadership.
- Dr. Richard Nakamura retired from NIH at the end of April 2018. Dr. Nakamura served as the Director of the Center for Scientific Review (CSR) since 2010. A neuroscientist, served in various positions at NIMH over the years. He earned the prestigious Presidential Rank Award and other leadership awards for his extraordinary efforts. He moved CSR to a new place and dealt with a lot of issues and adopted multiple policy changes. Dr. Noni Byrnes will serve as Acting Director during the national search for his replacement.
- Dr. Pérez-Stable noted the following Director positions are now open: the National Institute of Biomedical Imaging and Bioengineering (NIBIB), the National Center for Complementary and Integrative Health (NCCIH), and CSR. Dr. James Battey is also retiring as Director of the National Institute on Deafness and other Communication Disorders (NIDCD) at the end of May. His leadership has contributed to many discoveries particularly around the genetics of smell. A Nobel Laureate came out his grantees in that area of research. His own work has greatly impacted people with communication disorders across the age spectrum. Deputy Director Dr. Judith Cooper will serve as Acting Director of NIDCD.
- The All of Us Program launched its national enrollment on May 6. The cities involved in the rollout included New York City, Nashville, TN, Birmingham, AL, Chicago, IL, Pasco WA, Detroit, MI, and Kansas City, MO. A couple of Council members were involved. Greg Talavera leads the San Ysidro Research Group in San Diego County, and Said Ibrahim was involved in the New York effort. The New York event—held at the Abyssinian Baptist Church in Harlem—was attended by Dr. Francis Collins. Eric Dishman, director of the program, hosted the event in Detroit. Numerous NIH officials attended events nationwide. Roughly 12,000 people were enrolled during the national rollout, bringing the total membership to over 50,000 (with about 50% minority enrollees). Dr. Pérez-Stable promoted the event in Spanish and serves on the Advisory Group of Directors.

NIMHD News

- Dr. Chandra Jackson received the Bench-to-Bedside award. Bench-to-Bedside awards are typically laboratory oriented and moves to T1 to T2 translation, becoming very clinical. Dr. Jackson—an epidemiologist based out of North Carolina, at NIEHS, is an NIMHD associate investigator. Her proposal focused on population science and will use the funding to study how multiple products of metabolism are linked with Type 2 diabetes in racially diverse populations.
- Sriparna Sadhukhan (Intramural biologist) and Juliet Peña (science writer) have been hired as contractors with NIMHD.
- Dr. Regina Smith, former Director of the Clinical and Health Services Research interest area in Program has left NIMHD. Dr. James is a psychiatrist who graduated from the University of California, Los Angeles (UCLA) and did residency work in Cleveland. She focused on adolescent pediatric psychiatry. She worked in the NIMH Intramural Program before transitioning to positions at NIMH and later at NICHD. Dr. James came to NIMHD in 2015 and assumed leadership of the Clinical and Health Services research in 2016.Dr. Joyce Hunter is serving as the Acting Director of the program during the search for a new director.
- The budget was passed on March 23. It provided a $3 billion increase for NIH, the largest since the era of doubling. NIMHD got its proportional increase but was not singled out for extra funds.

Within the $3 billion increase for NIH, $500 million was allocated to opioids research. The $500 million has two unique components: two-year funding authority and comes with the Director's authority to transfer funds within NIH. The money is officially allocated to NIDA and NINDS but can be moved based on whatever the Agency decides will get opioid funding.

- NIMHD's budget is officially $305 million, with a net funding increase of $17.4 million (+6.1%) more than FY17. The only language in the Appropriations Bill from an NIMHD perspective was related to Research Centers in Minority Institutions (RCMI). Funding for RCMI increased by $3 million or 5% — "continues to support the core mission of RCMIs to develop new investigators from under-represented communities and to conduct world-class biomedical research that emphasizes minority health and health disparities." Although the President's proposed FY19 budget is significantly less than FY18, the legislative process is likely to yield a more favorable result for NIH.

NIMHD Activities

- April was National Minority Health Month. On April 11, NIMHD hosted its second annual Minority Health 5K, in which 400 NIH staff participated. NIMHD also co-hosted a conversation on Twitter on April 18 with other minority health offices within HHS. The Twitter chat had almost 15 million impressions. On April 25 NIMHD co-hosted the NIH Science Day at the National Library of Medicine (NLM), which reached out to 500 middle and high school students from the Washington D.C. metro area. Dr. Lynne Holden of Mentoring in Medicine group was the main driver of the event.
- Dr. Pérez-Stable noted that he has given several presentations since the last Council meeting, including at Hunter College on March 16 and a local meeting of the National Hispanic Medical Association. He spoke in Nebraska at the Medical Center Leadership Retreat. They invited people to give out-of-the-box talks including Dr. Joan Reede (Harvard) on diversity.
- Dr. Pérez-Stable spoke at the Society of General Internal Medicine Conference in Denver, CO from April 11-13, 2018. He gave a TED-Like talk on his career. He also attended the Latino Health and Research Policy Conference on April 13.
- Dr. Pérez-Stable spoke at an event for the National Minority Health Month on April 17 at HHS Headquarters. All the operating divisions minority health representative presented.
- On April 17, Dr. Pérez-Stable participated on a panel at the Resource Centers for Minority Aging with Dr. John Haaga of the National Institute on Aging (NIA).
- The Research and Education Week at Children's National was on April 19. Dr. Pérez-Stable gave a pediatric grand rounds equivalent. This was sponsored by Howard University and held at National Children's Hospital.
- Dr. Pérez-Stable spoke at the Translational Science 2018 Conference. There was big linkage to the CTSAs across the country.
- Dr. Pérez-Stable spoke about race/ethnicity to the Clinical Research Fellows at NIH. This event was essentially a grant-writing course, and Dr. Anna Nápoles also spoke on recruitment.
- On May 8, Dr. Pérez-Stable spoke at the Board of Regents, an Advisory Council, for the NLM.
- NIMHD has almost completed the listening sessions for the Strategic Plan. Listening sessions have been conducted live and via webinar, and future sessions are scheduled. A draft of the Strategic Plan should be finished this summer, and it will enter the clearance process by September.

Scientific Advances

- A recent study analyzed the Medical Expenditure Panel Survey data to examine colorectal cancer (CRC) screening rates in Asians. Notably, this study disaggregated their data, and found that all Asian groups have lower rates of CRC screening compared to Whites, and that older age and access to health insurance were linked to higher rates of screens. While many people think that one must get a colonoscopy to get screened, Dr. Pérez-Stable noted similar efficacy of annual fecal immunochemical tests (FIT). If the results are negative or don't show microscopic blood on

the test, a colonoscopy is probably not needed. A family history of cancer or a first degree relative with advanced neoplastic polyps would be a compelling reason to get a colonoscopy.

- NIMHD has long been an advocate of the importance of structural racism and perceived discrimination as factors for influencing overall health, an area that needs much more scientific inquiry. The Association of Lifetime Experience of Discrimination in a significant sample of Chinese adults from Chicago was examined. Racial discrimination and 30-day suicidal ideation in 3,157 Chicago-area Chinese adults over the age of 60 was evaluated. Researchers found that persons reporting discrimination had 1.9 times the odds of suicidal ideation compared to those that did not experience discrimination. The study controlled for usual demographics, social support, physical and cognitive and mental health function. Dr. Pérez-Stable mentioned a study conducted in their Aging Center in the San Francisco Bay Area looking at social isolation in Korean and Chinese elderly. The children have move away and as the adults age they become vulnerable and fragile. If they were not in an environment with a community, that may lead to discrimination. The study concluded that filial piety often led to suicidal ideation in isolated Korean and Chinese Americans.
- One study in the March issue of *Health* Affairs (*HA*) looked at how Oregon modified their Medicaid program to create coordinated care organizations (CCOs) in their community. Dr. Pérez-Stable noted he had a strong belief that the concept of primary care should be at the center of the healthcare system, as those services are a vehicle to address health disparities among minorities, which makes this an important topic for NIMHD. Still, this study showed that primary care alone may not be sufficient for overutilization of emergency departments and reducing disparities. Further, if access is expanded, there has to a place to go.
- A recent study by Partnership for Improving Lifestyle Intervention (PILI) looked at weight loss maintenance in Native Hawaiians and Pacific Islanders. Ultimately, researchers sought to understand whether the PILI@Work Maintenance Phase program was more successful if delivered face-to-face or via DVD. Interestingly, the more expensive face-to-face intervention was less successful, though they had a higher retention rate than those who did the program by DVD.
- A recent publication from an NIMHD funded basic mechanistic study, examined whether differences in TGFβ3 pathways contribute to prostate cancer. African-American (AA) men are two to three times more likely to have prostate cancer than any other population, and the study found that increased levels of TGFβ3s could be contributing to these rates.
- *APOL1* gene is present in a significant number of persons with West African ancestry and has a protective effective for trypanosome (sleeping sickness). It has also been studied in association with chronic kidney disease. *APOL 1* acts in synergy with known risk factors of renal disease, primarily hypertension and diabetes. One study looked at whether differences in the *APOL1* gene increased the likelihood of kidney disease in AA. Interestingly, researchers found that people of West African ancestry also have lower expression of the *UBD* (ubiquitin-like protein) gene, which targets other proteins for degradation. Thus, this study concluded that *UBD* could be a possible modifier of kidney disease for people with *APOL1* high-risk genotype. There is relevance of APOL1 carriage rates in kidney transplants, because of the higher rates of transplant failure. There are several important clinical and policy questions that address issues around *APOL1* and kidney disease. NIMHD is part of a network with NIDDK studying this.
- A publication from a group of San Francisco researchers, focuses on whole genome sequencing (WGS) pharmacogenetics study on the failure of asthma inhalers and racial/ethnic differences in responses to albuterol. Asthma is the most common chronic disease in children, and the leading cause of morbidity for children in terms of hospitalization and emergency departments visits. Generally, Puerto Rican and AA children are nonresponsive to albuterol, which poses increased risk for cardiac complications due to overuse of bronchodilators. This study looked at 1,441 children with asthma from the “tails” of the bronchodilator drug response (BDR) and identified specific genetic variants that could show how children respond to albuterol. This is a major consequence.

Division of Intramural Research (DIR) Updates

NIMHD plans to hire two tenure track investigators this FY. Dr. Pérez-Stable stated that NIMHD is pursuing the following kinds of experts: 1) An investigator with a focus on breast cancer disparities with expertise in health informatics, systems modeling, geospatial information systems, and CBPR. 2) An investigator with a focus on optimizing health technology for health disparity population with smoking cessation interventions, effective health messaging, and mHealth behavioral interventions expertise.

- Dr. Kelvin Choi recently published a paper—using the FDA PATH study, a large national representative study. The paper looked at the issue of tobacco promotion on tobacco use disparities. His study shows that adults of lower socio-economic status (SES) are affected by direct-mail tobacco discount coupons, and that they are more likely to receive those coupons than someone of high SES regardless of smoking status. Importantly, Dr. Choi found that these advertisements hindered cessation to smoking.
- In a related project, Dr. Sherine El-Toukhy utilized findings from the International Tobacco Control Four Country (ITC4)—which includes Canada, the United Kingdom (UK), Australia, and the U.S.—to examine 4,689 current and former smokers and their interaction with direct-mail tobacco coupons. They found that those who received coupons were more likely to associate smoking with calming nerves, and that policies that ban tobacco price promotion could ameliorate the harmful impacts of coupons on those of lower SES.
- Dr. Sharon Jackson published a study in *PLoS ONE* looking at the typology of diabetes. The study examined the National Health and Nutrition Examination Survey (NHANES) and The Coronary Artery Risk Development in Young Adults (CARDIA) Study and developed a Diabetes Typology Model (DTM). The studies included a large sample of African American and White youth. This is important since the boundaries between Type 1 and Type 2 diabetes are becoming mixed. Occasionally see Type 1 diabetics present in young adulthood (20s and even early 30s), and Type 2 diabetes now described in adolescence related to the obesity epidemic and metabolic dysfunction. Using typology in these secondary data analysis enables ascertainment of differences. This study will facilitate future population-based studies to examine differing types of diabetes as well as concomitant risk factors.
- Dr. Jung Byun published a paper with Dr. Kevin Gardner focused on the conceptual framework of raised cancer outcomes and tissue repair in the *American Journal of Pathology*. The ultimate goal of this framework is to provide insight on the underlying contributors to cancer disparities as well as to develop interventions to improve cancer outcomes.

Recent Grants and Programs

- A new Funding Opportunity Announcement (FOA) was put out to address challenges of the opioid epidemic in minority health and health disparities research. The receipt date for applications is June 14, 2018, and it should be up for second level review at the February 2019 Council. The FOA will target both the epidemiological and etiological factors in racial/ethnic disparities, as there is an incorrect perception that only lower SES Whites are affected by the opioid use disorder crisis. Although Latinos and African Americans have lower rates of overdose, both from prescription opioids and heroin, the rates are going up. American Indians and Alaska Natives are also disproportionately affected. Another factor in the opioids crisis is healthcare. Although practitioners and pharmaceutical companies are largely responsible for the initiation of the crisis, Dr. Pérez-Stable noted that opioid prescriptions started to decline in 2011, and the rise of synthetic opioids is also responsible for increasing fatalities. Several other Institutes and Centers (IC)—including The Office of Research on Women's Health (ORWH), the NIA, the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the National Institute on Drug Abuse (NIDA)—are participating in the FOA.
- The Fordham Research Ethics Scholars—including Drs. Celia Fisher, Alana Gunn, Faith Fletcher, and Nicole Overstreet—visited NIMHD on March 1, and gave presentations. The Mongan Scholars, from Harvard Commonwealth Fund, came with Dr. Joan Reede for a visit also.

Presentations

The Many Opportunities for Enhanced Partnerships between NIMHD and NICHD
Dr. Diana Bianchi, Director of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) gave an overview of the NICHD research portfolio and identified areas for collaboration with NIMHD. She stated that NICHD only funds 18% of NIH-based child health research, but about60% of its portfolio is dedicated to pediatric research.

NICHD strives to include underrepresented populations in their research. The main people NICHD treats are children, pregnant women, and lactating women, as well as people with physical and intellectual disabilities. To this point, Dr. Bianchi and her colleague Dr. Catherine Spong recently wrote a paper in the *Journal of the American Medical Association* (*JAMA*) entitled "Improving Public Health Requires Inclusion of Underrepresented Populations in Research." In this paper, they argued the current approach of personalized medicine excludes 58% of the total U.S. population. For example, 68% of pregnant woman are excluded from Phase 3 and 4 NIH studies, and many pregnant women are excluded from Clinical Center (CC) protocols. To ameliorate this problem, NICHD has established a working group to examine the risks and benefits of including pregnant women in CC research.

As part of the 21st Century Cures Act, a Task Force was formed at NICHD to address health effects on pregnant and lactating women. The Task Force will issue a report to the Secretary of HHS in September. As it currently stands there are few clinical trial studies on the health effects of medications on pregnant and lactating women (only 25 from 2006-2017). Exceptions to this rule include research on gestational diabetes, hypertension, preterm labor, labor pain medication, and substance use. Dr. Bianchi explained that NIH has curated the Research, Condition, and Disease Codes (RCDC) since 2009. These codes are used to categorize and report the amount of funding on 280 topics within NIH's portfolio. Before the Task Force required there was no category for pregnancy. The Task Force was able to implement categories for pregnancy, breastfeeding, and maternal health. At present NICHD funds the majority of research on pregnancy, breastfeeding, and maternal health. NIMHD is funding 12 pregnancy studies, 2 breastfeeding studies, and 11 maternal health studies.

There are many areas for collaboration between NICHD and NIMHD, as the former also addresses health disparities (especially for infants and mothers). A review of the NICHD Office of Health Equity, identified areas in which NICHD does or does not have health disparities data for the following topics: rare diseases, pregnancy, pediatrics, reproductive health, and rehabilitation. The review also identified diseases for which certain race/ethnic groups are at a higher risk, such as preeclampsia in Blacks, Down syndrome in Latinos, and SIDS in American Indian or Alaska Natives. Children and pregnant women represent an important opportunity for collaboration between NIMHD and NICHD. One useful tool for collaboration is PregSource, a free NIH program that allows pregnant women to self-report information on their sleep, nausea, exercise, weight, and medications in real time. This project will provide more information on what constitutes a "healthy pregnancy," which will allow researchers to develop better strategies for improving maternal care.

Another issue for NIH's pediatric researchers is neonatal opioid withdrawal syndrome (NOWS). In the 2018 budget Congress gave $500 million to combat the opioid crisis. To receive some of this funding, NICHD contends that research on infant exposure to opioids is fundamentally different from adults. Generally, babies don't die as a result of in utero exposure to opioids, and signs of withdrawal may not exhibit themselves immediately. While there are ways to help women exposed to opioids during pregnancy, few of them are identified as such, and even fewer seek treatment. Researchers have found there is no consistent approach to treating babies exposed to opioids. What's more, treatments for heroin and methadone are not entirely sufficient for treating babies exposed to synthetic opioids, which highlights a need for comparative research. Formerly called neonatal abstinence syndrome (NAS), children with NOWS tend to use a significant amount of social services (especially foster placement).

To combat this, NICHD has created the ACT NOW Partnership's Act One. Collaborating with the Neonatal Research Network Centers (NRN), NICHD also created the IDeA States Pediatric Clinical Trials Network (ISPCTN) to inform the design of a clinical trial for improving outcomes for infants with NOWS. Different protocols are being developed out of this effort, including the Eat, Sleep, and Console Study, which provides soothing care instead of pharmacological treatment. Additional funding is likely to continue this project for two or three more years, and NIMHD is a partner on the project. Act Two of the project will advance a tool to understand NOWS and cultivate new interventions. Future efforts will focus on long-term brain development and other developmental factors.

NIH funded $4.2 billion in pediatric research in FY2017, and child health research is significant across all of NIH's ICs. In 2017 NIMHD contributed $49 million (or 17.1%) of their funding toward child health research. To encourage overlap, Dr. Bianchi recommended the foundation of a Trans-NIH Pediatric Research Consortium. This consortium could reach across 27 ICs, identify additional areas for collaboration, and establish review panels comprised of senior researchers. These groups could also develop similar strategies to create more effective collaborations.

Racial Variation in Health Care: The Case of Joint Replacement Utilization
Dr. Said Ibrahim—the VA Ex Officio representative to the Council—gave a presentation on racial variations in joint replacement (JR). He noted that no professional group is directly responsible for disparities in knee/hip replacement. Therefore, Dr. Ibrahim used a generational framework to discuss the topic: 1st Generation: Detection, 2nd Generation: Understanding, 3rd Generation: Reduction of Disparity and 4th Generation: Implementation of Research.

Osteoarthritis (OA) will affect almost 70 million people by 2030, and women have higher prevalence than men. With no known cure, managing OA requires significant effort, and elective knee/hip replacement is occasionally necessary. Overall, more than 90% of those who get a replacement report improvement and the mortality rate for the operation is less than 1%. As JR is so effective, research shows that by 2030 almost 4 million people will have knee/hip replacement, and Medicare could be bankrupt if they do not find a viable way to shoulder the cost.

There are many variations in knee/hip replacement, particularly the fact that AA patients receive treatment 40% to 50% less often than Whites. In the first generation of documenting this disparity, one 1993 study showed that AA patients get JR two to three times less often than other races. Subsequently, a 2005 study by Dr. Ashish Jha showed that from 1992-2001 both White and AA men and women received progressively more knee/hip replacements, though White patients received more JR over time. Dr. Ibrahim showed another study of CDC data that demonstrated the same phenomenon, which indicates the disparity is getting wider.

To address this issue, researchers need a conceptual framework for understanding whether the system, the patient, or the provider is to blame for the disparity. In one study, Dr. Ibrahim did an analysis of the VA system, examining a cohort of over 260,000 people with OA along with 46,000 of those referred to orthopedic surgeons. The study found that AA patients are 30% less likely to receive JR treatment, which shows that the problem is not entirely about access (which makes sense given that 60% of JRs are funded by Medicare).

Patient issues—including attitudes, perception, and knowledge—may be a factor in disparities in receiving this elective surgery. To examine this, Dr. Ibrahim's team studied an equal ratio of 600 AA and White VA patients. Subjects needed to have moderate to severe OA with no prior JR. The study showed that AAs endorsed every treatment more than Whites except for knee/hip replacement. AAs were also more likely to be concerned about walking and pain post-operation than Whites, and in general they had less knowledge about JR. As few family members receive the treatment, AAs may have less overall knowledge about the procedure. During the study Dr. Ibrahim asked patients if they would get a JR if a doctor recommended it, and they found that AAs were about 50% less likely to be willing.

Physician bias may also be a factor for why AAs receive JR less often than other populations. To study this, Dr. Ibrahim looked at a cohort of patients who had been referred to orthopedic surgery, examining the severity of their disease, their willingness to undergo treatment, their health literacy, their expectations of outcomes, and their social support system. Meetings with clinicians were audiotaped, and the study found that AAs were 40% less likely to receive a recommendation for JR. Although adjusting for confounding factors altered results, adjusting for willingness made the disparity less statistically significant, which suggests that patient readiness to undergo treatment indirectly drove recommendation.

To begin to ameliorate this disparity, Dr. Ibrahim's group did another study using Decision Aids (DAs)—an educational video that provides comprehensive knowledge about JR— and motivational interviewing (MI) to see if they could alter patient willingness. Patients were selected, randomized, and put in a two by two factorial design. The study found DA and MI increased patient knowledge and willingness about the treatment and reshaped their preference for treatment. Because they were criticized for choosing such a simple outcome, the group did another R01 looking at knee replacement. In this study they identified patients who were selected for knee replacement and then randomized who would receive a DA. Viewing the DA was associated with 85% higher rate of receiving treatment, which suggests that educating patients will encourage them to make the right decision. Related to this study, Dr. Ibrahim wrote a piece in the *New England Journal of Medicine* (*NEJM*) contending that DA can help patients make informed decisions.

In the future, providers could either implement this research on a wider level or attempt to improve outcomes post-operation. To begin to do this, Dr. Ibrahim's group built a hybrid Type 1 implementation study to test clinical interventions and collect data on the easiest way to deliver information on JR. However, Dr. Ibrahim contended that DAs will be used more often in clinical settings, as the Center for Medicare and Medicaid Services (CMS) is using more shared decision-making. Therefore, the group also focused on post-op care to improve outcomes, and recently published a paper in *JAMA* on the impact of policy interventions on post-op care. Of course, the cost of JR is of great concern to CMS and can pose a chaotic situation to people who need treatment.

In an R01 from NIMHD, Dr. Ibrahim looked at whether CMS's payment program will increase or decrease disparities, as well as whether it will provide for quality post-op care. In the study the group looked at 193,000 JRs from 2001-2012 and found that upon discharge from the hospital patients receiving treatment either go home on their own, receive home health (HH), go to a skilled nursing facility (SNF), or go to inpatient rehab. Dr. Ibrahim's analysis showed that AA patients were more likely to go to institutions than whites. In addition, a propensity score analysis found that the risk of readmission is more significant if patients are sent to an institution for rehab, suggesting HH has better outcomes. Policy greatly impacts this area, as many AA patients go to SNFs, while whites tend to receive HH care. In his own data of 2,276 individuals, Dr. Ibrahim found that slightly more than 50% of AA patients receive HH, while almost 75% of whites receive HH. Dr. Ibrahim recently submitted a Patient-Centered Outcomes Research Institute (PCORI) grant to address this issue further.

HD*Pulse*: An Ecosystem of Minority Health and Health Disparities Resources

Dr. Deborah Duran from the NIMHD Office of Science Policy, Planning, Assessment, Reporting and Data's (OSPARD's) presented on project called HD*Pulse*. HD*Pulse* is an effort to merge data to better understand outcomes by race/ethnicity and geographic location. Started two years ago, HD*Pulse* will create a centralized dataset that shows differences across demographics and disease to acquire more information on disparities. Once differences are identified as disparities, interventions can be tailored to mitigate issues. In theory HD*Pulse* will build on previously completed interventions and thus bolster implementation.

HD*Pulse* has two portals: Intervention and Data, and the goal of the ecosystem becoming the go-to place for health disparities information. Dr. Duran then showed the HD*Pulse* homepage and commented that the system is incredibly vast. In the data portal, users can find copious information, including on mortality rate, socio-demographics, and screening/risk factors of various diseases. In addition, the data portal

contains a series of links to information from every known federal data source, as well as analytic tools (including epidemiological studies that have determined health disparities). Another component of the data portal is the HD*Pulse* Health Disparities Data Registry, which compiles information from every IC on what they consider a health disparity. The registry should be operational by the summer of 2018. An added benefit of this registry is that it forces other ICs to address health disparities.

The second key module of HD*Pulse* is the interventions portal, which will be finished in fall 2018 and is similar to Research-Tested Intervention Programs (RTIP). The thought process undergirding the interventions portal is to centralize interventions for health disparities, and the goal is to take already-developed interventions and do further implementations on that research. Like RTIPs, the intervention portal has "find" and "submit" features. When an intervention is found, a table is populated such that researchers can download information or export it from the website. Users can also use search criteria on socio-demographics, intervention characteristics, scientific integrity, conceptual framework, and populations.

To make this feature more community-centric, the submit feature has three types of interventions: emerging, promising, and proven. While emerging interventions are not necessarily given rigorous analysis, they have been tested. Promising interventions generally have had one grant and have shown some type of validity. Proven interventions capture when a practice has been adapted and shown to be effective in a specific population group. The intervention portal also has information on the type of intervention, the health disparity outcome, the population, the gender (including transgender or pangender), sustainability of the change, as well as if it was positive or statistically significant. Dr. Duran provided a demonstration of the HD*Pulse* system.

NIMHD Proposed Reorganization

Dr. Pérez-Stable introduced the proposal to reorganize NIMHD. The foremost reason for reorganization is to optimize resources to advance the science of minority health/health disparities, particularly with regard to the kinds of grants and areas that NIMHD funds. The main driver is the extramural research programs and the scientific topics. This restructuring will require clarifying and realigning supervisory structures and revising various functional statements. The reorganization will be a better way to adapt to the changing field of minority health and health disparities, to be able to adjust to what has happened over the last 20-30 years and strengthened the scientific basis of what we are doing and increase opportunities. It will also make it better for program staff to emphasize a particular area. He stated that it will also help with the mission of expanding the workforce diversity.

Dr. Pérez-Stable displayed the proposed NIMHD structure. In this structure, the Divisions represent the main organizational change. For example, the Division of Extramural Activities (DEA) would be divided into three divisions: the Division of Biological and Behavioral Sciences (DIBBS), the Division of Clinical and Health Science Research (DCHSR), and the Division of Community Health and Population Science (DCHPS). Conversation are on-going on how the divisions will align. The portfolio analysis will inform the conversation on what's where, how many grants, how many dollars. Eventually each division will have an allocated proposed budget with some authority for funding decisions within.

The Division of Intramural Research (DIR) has a Scientific Director now. DIR will have several labs depending on the investigators that are recruited. Currently, the Tobacco Control Lab (TCL), the Cancer Control Lab (CCL), and the Population Science Lab (PSL) are there.

Elsewhere in the reorganization, the Office of Extramural Research Activities (OERA) has proposed adding an Extramural Research Policy Branch (ERPB) within their purview to the Scientific Review Branch and the Grants Management.

In addition, the Office of Administrative Management (OAM) would be organized into two branches around administration and budget: the Administrative Services Branch (ASB) and the Finance Management Branch (FMB).

The Office of Communication and Public Liaison would have a Public Information and Outreach Branch (PIOB) and the Digital and Online Communications Branch (DOCB).

Finally, the Office of Science Policy, Strategic Planning, Reporting, and Data (OSPARD) would have a Policy, Planning and Reporting Branch and a Data Assessment and Analysis Branch. The policy part relates to NIH policy. A legislative person sits in the Office of the Director, along with other leadership in the Office of the Director. The proposal will be posted in the Federal Register for a week for public comment. An email address will be provided to receive comments. As part of the reorganizational structure planning, the public process is being done before the plan is finalized later in 2018. It has to go through Legislation to be finalized.

Public Comment
Dr. Pérez-Stable opened the floor for public comment.

Closing Remarks and Adjournment.
With no further business to attend to, Dr. Pérez-Stable adjourned the meeting at 1:10 p.m.