

**U.S. Department of Health and Human Services
National Institutes of Health
64th Meeting of the National Advisory Council on Minority Health and Health
Disparities (NACMHD)**

NIH Building 31
31 Center Drive
Bethesda, MD 20894

May 31, 2024
8:30 a.m. EDT - Adjournment

Meeting Minutes

Council Members Present

Eliseo J. Pérez-Stable, M.D., Director, NIMHD

Samuel E. Adunyah, Ph.D.,

Chairman, Department of Biochemistry, Cancer Biology, Neuroscience and
Pharmacology, Meharry Medical College

Emma Aguila, Ph.D., Sol Price School of Public Policy, University of Southern California

Jose Arturo Bauermeister, Ph.D., MPH, Department of Family and Community Health,
School of Nursing, University of Pennsylvania

Lisa M. Marie Cacari Stone, Ph.D., Department of Family and Community Medicine,
College of Population Health, University of New Mexico

Kendrick E. Curry, Ph.D., M.Div., Senior Pastor, Pennsylvania Avenue Baptist Church

Valerie Blue Bird Jernigan, DrPH, MPH, Director, Center for Indigenous Health
Research and Policy, Oklahoma State University

Frank J. Penedo, Ph.D., Associate Director, Cancer Survivorship and Translational
Behavioral Sciences, Sylvester Comprehensive Cancer Center, University of Miami

Chau Trinh-Shevrin, DrPH, Director, Division of Health and Behavior, Department of
Population Health, New York University School of Medicine

Council Members Absent

Mario Sims, Ph.D.,

Department of Social Medicine, Population and Public Health, University of California at
Riverside

Ex Officio Members Present

Jane Simoni, Ph.D., Associate Director for Behavioral and Social Sciences Research, NIH

Director, Office of Behavioral and Social Sciences Research (OBSSR), NIH

NIMHD Staff Present

Monica Webb Hooper, Ph.D., Deputy Director, NIMHD

Kimberly Allen, M.A., Executive Officer, Office of Administrative Management

Larissa Avilés-Santa, M.D., MPH, Director, Division of Clinical and Health Services Research, NIMHD

Rina Das, Ph.D., Director, Division of Integrative Biological and Behavioral Sciences, NIMHD

Nathan Stinson Jr., Ph.D., M.D., MPH, Director, Division of Community Health and Population Science, NIMHD

Executive Secretary

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

Presenters

Joshua Denny, M.D., MS, Chief Executive Officer, All of Us Research Program, NIH

Carlos O. Garrido, Ph.D., MS, MPH, Health Scientist Administrator, Division of Integrative Biological and Behavioral Sciences, NIMHD

Karina Walters, Ph.D., MSW, Director, Tribal Health Research Office, NIH

Dolly P. White, M.D., MSCR, Health Scientist Administrator, Division of Clinical and Health Services Research, NIMHD

Call to Order and Welcome

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

Roll Call and Council Minutes Review

<https://videocast.nih.gov/watch=54845&start=300>

Dr. Cotton called the roll and invited members and staff to introduce themselves. The council unanimously approved the minutes of its February 2024 meeting. Dr. Cotton announced future meeting dates of February 6, 2025, May 16, 2025, September 5, 2025, February 6, 2026, May 19, 2026, and August 11, 2026. The February dates will be virtual meetings, and the rest will be in-person. Members were reminded that NIH policy allows council members no more than one absence per calendar year and that members are prohibited from participating on NIH peer review panels while serving on council.

NIMHD Director's Report and Discussion

<https://videocast.nih.gov/watch=54845&start=580>

Dr. Pérez-Stable greeted the council and provided a report on NIH and NIMHD-related activities since the February 2024 council meeting.

- [Dr. Kathleen M. Neuzil](#) is the new Director of the Fogarty International Center as well as the Associate Director for International Research at NIH. She is the first woman selected for the position coming to NIH from the University of Maryland.
- [Dr. Sean Mooney](#) is the new Director of the Center for Information Technology at NIH coming from the University of Washington.
- NIH Director Dr. Monica M. Bertagnolli has launched a [primary care-focused clinical research network pilot through the Common Fund](#) – CARE for Health. The goal is to enable every clinical encounter to potentially contribute to data to improve care for all Americans.
- OMB Directive 15 was [substantively updated](#) in March for the first time since 1997, eliminating the two-part question asking about Hispanic/Latino ethnicity first in favor of a single, combined race and/or ethnicity question and adding a separate category for Middle Eastern or North African. There is also a second level question that asks about heritage categories, defined mostly by geographic origin, although for American Indian or Alaska Native (AI/AN) there will instead be Tribal groups.
- The Department of Health and Human Services (HHS) published a [2023 Equity Action Plan](#). Priorities include preventing neglect and improving care to help children thrive in their families and communities; promoting accessible and

welcoming healthcare; improving maternal health outcomes in rural, racial, and ethnic minority communities; prioritizing behavioral health of underserved populations; and increasing clinical research and trial diversity to support innovation.

- NIMHD developed the [NIH Health Equity Factsheet](#), which includes goals aligned with the NIH Minority Health and Health Disparities Strategic Plans, NIH policy and culture changes, health equity research priorities, and research-sustaining activities.
- NIMHD hosted [Surgeon General Vivek H. Murthy's Distinguished Lecture Series on May 23](#), 2024, in celebration of Asian American, Pacific Islander, and Native Hawaiian Heritage Month, moderated by Dr. Monica Webb Hooper. The guest speaker was Dr. Hahrie Han, Professor and Inaugural Director of the Stavros Niarchos Foundation Agora Institute at Johns Hopkins.
- The [NIH Mental Health National Youth Essay Contest](#), sponsored by NIMHD, NIMH, and NICHD, challenged high school students to raise awareness of mental health issues.
- Twenty-seven NIH Institute and Center directors and other leaders co-authored a paper in the [February 2024 Nature Medicine journal](#) on the All of Us Research Program.
- A bill to [fund NIH for the current fiscal year](#) was signed into law on March 23, 2024, just as the continuing resolution was set to expire. Overall, the NIH budget was flat, but NIMHD received modest increases in two specific areas. One is an initiative to improve Native American cancer outcomes in collaboration with NCI. A notice of funding opportunity (NOFO) should be published by mid-June. NIMHD was also directed to establish an office on Native Hawaiian and Pacific Islander (NHPI) research to help advance research on these groups, which is challenging due to the small populations.
- Since FY 2016, the NIMHD budget has almost doubled. And rather than going down in FY 2024, it increased by about \$10 million.
- R01 applications have been increasing since FY 2017 until a slight decrease in FY 2023. The success rate has varied, partly as a result of the small sample size and shifting funding from centers to R01s based on congressional direction. The success rate hit a low of 9.6% in 2020, but increased to around 18% in FY2022 and FY2023 and will hopefully stay around that level or higher. Award rates for early-stage investigators have increased but are still slightly below the rates for established investigators.
- In February 2024, Dr. Pérez-Stable briefed staff from the Senate Health, Education, Labor, and Pensions and Senate Aging Committees on implementation of people with disabilities as a population with health disparities. There were also briefings in March, to two Senate committees, as well as the

[Congressional Black Caucus](#) and [Asian Pacific American Caucus](#), on changes to the [Research, Condition, and Disease Categorization \(RCDC\)](#) minority health and health disparities categories brought about by machine learning. It had been one of the few RCDC categories that had been produced manually, involving a lot of staff effort, and although there was reasonable intercoder reliability, there were still errors. Demonstrations have shown the new technology is at least as good as the manual coding and much more efficient.

- The [FY 2025 NIMHD Congressional Budget Justification](#) was published in March, summarizing major accomplishments and outlining funding needs, strategic priorities, and the anticipated impact of those priorities.
- Dr. Pérez-Stable discussed numerous engagements by NIMHD leadership, including his participation in a [White House Minority Health Forum on April 18, 2024](#), hosted by the Office of Science and Technology Policy and Secretary Cervera, and a webinar, in collaboration with NIMH, with the Children's Inn at NIH that focused on mental health disparities among youth.
- Former Secretary of HHS Dr. Louis Sullivan visited NIMHD for a [fireside chat](#) in April to commemorate National Minority Health Month and celebrate his accomplishments. The event was intended to leave a record via oral history and was attended by several Institute and Center Directors and Deputy Directors as well as NIMHD Leadership.
- The annual meeting of the [Research Centers in Minority Institutions \(RCMI\) was held April 29-May 1](#), attended by principal investigators, program directors, scientists, university presidents or their representatives from the 22 RCMI, as well as leadership from NIMHD, NIGMS, NHLBI, NCI, and NIDA, to discuss opportunities for collaboration and ways to solve shared challenges.
- The [Center of Excellence on Environmental Health Disparities annual grantee meeting](#) was held in February on the NIEHS campus to discuss ways to reduce health disparities related to environmental harms.
- A [Workshop on Research on Native Hawaiian and Pacific Islander Health](#) was held, following approval of a research concept by the council in September. That approval included a recommendation for such a workshop prior to publishing a NOFO, which is in development. There were four sessions: determinants of NHPI health, mechanisms/processes of health outcomes, methodologic approaches/tools, and cultural interventions. Key points identified at the workshop were the importance of enhancing social determinants of health data collection, culturally valid assessment tools, and community-driven research and community participation.
- [The 2024 Health Disparities Research Institute](#) will be held in-person from August 5th to 9th on the NIH campus. It is a week-long training experience to support career development of early-stage investigators, with opportunities to

learn about NIH, interact with program staff, attend lectures, learn about grant-writing, and participate in mock grant reviews.

- [Data from the American Association of Medical Colleges for 2021-2022](#) shows less than 1% of medical school graduates were AI/AN, less than 1% were NHPI, and Black/African American and Latino/Hispanic together accounted for about 14%. Empirical evidence shows that training more clinicians from underrepresented groups decreases health disparities because they are more likely to provide good care, not only to members of their group, but also to those who are poor, uninsured, and on Medicaid.

Dr. Pérez-Stable provided selected science advances from the published literature informed by NIMHD-funded grants since the February 2024 council meeting.

- The Heart Failure Optimization at Home to Improve Outcomes (Hózhó) randomized clinical trial, [published in JAMA](#), compared a telehealth, guideline-directed therapy optimization to standard care for reduced ejection fraction heart failure in the Navajo Nation. The intervention was effective in increasing use of recommended classes of drugs filled, 66% versus 13%.
- A [study](#) by Dr. Leonard Egede and colleagues, published in *Diabetes Care*, found a direct association between historic redlining and diabetes prevalence, as well as an indirect association with incarceration, poverty, discrimination, substance use, housing, education, unemployment, and food access.
- A [cluster randomized clinical trial](#) compared enhanced usual care (EUC) with EUC plus peer coaching and practice facilitation (PCPF) among Black adults with persistently uncontrolled hypertension at rural care clinics in Alabama and North Carolina. While the overall results showed no effect, a preplanned subpopulation analysis of those under the age of 60 showed PCPF led to 5mm greater reduction in systolic blood pressure, which was both clinically and statistically significant.
- An NIMHD-funded [study](#) looked at the relationship between reported self-esteem and immunometabolism among NHPI adults. Compared to people with normal self-esteem, those with low self-esteem had higher levels of biomarkers linked to inflammatory disease, differences in relative abundance of specific gut bacteria, and differences in DNA methylation.
- Another [study](#) looked at trait mindfulness as a protective factor for collective trauma among Gulf Coast residents exposed to catastrophic hurricanes. More severe post-traumatic stress symptoms were related to lower trait mindfulness, greater COVID-19 exposure, history of anxiety/depression, Latino ethnicity, lower income, and older age. TM may improve resilience and recovery, especially among populations with multiple trauma exposure.

- Another [study](#) examined the link between maternal adverse childhood experiences (ACEs) and DNA methylation. Discrimination was associated with hypermethylation of growth factor IGF2 and NNAT in Latino newborns and hypomethylation of PEG3 in Black newborns. Maternal ACEs and other social stressors may influence DNA methylation of several imprinted genes in newborns; further studies of gene expression are needed.
- A [study](#) published in *Nutrients* by a NIMHD K-grant awardee found that adherence to a traditional Mexican diet, including beans, is associated with lower hepatic steatosis among U.S.-born Mexican Americans.
- Another K-grant awardee [studied](#) the effectiveness of a culturally-tailored community health worker intervention to manage hypertension in South Asians with diabetes. The intervention was found to be both feasible and effective in this population.
- Another [study](#) examined the Black-White disparity in severe maternal morbidity in Georgia. Data for 2016-2020 showed the rate of severe maternal morbidity per 100 discharges was 3.15 for Black individuals and 1.73 for White individuals. Much of the gap was explained by three factors: 1) hospital fixed effects, showing that racial differences in care processes and other factors within the same hospital translated into disparities; 2) access to care (15%), and sociodemographic factors (14%). Residential factors were found to be protective for Black individuals.
- A [publication](#) coming out of the Hispanic Community Health Study found that women with a history of hypertensive disorders of pregnancy (HDP) had a higher prevalence of abnormal left ventricle structure and function; a history of HDP was a stronger risk factor for heart structure abnormalities than presently having hypertension. Prevention of HDP should be actively addressed during pre-conception and prenatal care.
- A retrospective review of medical records found that Latinos have rates of psychiatric diagnoses similar or higher than White individuals but only 14% received mental health services and are less likely than White persons to receive mental health treatment.
- A [study](#) looking at the impact of Medicaid expansion on racial and ethnic disparities in cardiovascular disease (CVD) found that the expansion was associated with a reduction in CVD mortality overall as well as in White, Black, and Latino subgroups, and no difference in the effect across race/ethnicity.
- In the area of HIV testing and PrEP, there are tools and barriers to their implementation. Those infected with HIV at age 25 should have normal life expectancy with viral suppression; HIV testing and use of PrEP should be implemented more broadly.

- A [project](#) from the NIMHD intramural division, led by Kosuke Tamura, looked at sociodemographic disparities and geographic availability of COVID-19 treatments. There was less access to treatments in counties with high poverty and uninsured rates, individuals with high social vulnerability scores and COVID-19 community vulnerability scores, and counties with a high proportion of Black individuals.
- Sherine El-Toukhy from NIMHD Intramural published a [study](#) of cultural adaptations to improve retention and engagement in smoking cessation treatment. The study involved Latino and White users of Smokefree.gov text messaging. A Spanish language version of the text messaging improved retention and engagement among Latino users but did not affect abstinence. However, smoking cessation is not a short-term issue, so retention and engagement is still an important outcome.
- NIMHD's Faustine Williams [examined](#) trends in U.S. adolescent suicide by method from 1999-2020. Suicide rates increased across all methods. Firearm is the most effective and most used method; rates of suicide by firearm increased among all races and ethnicities. The increasing suicide rates among all youth is concerning and effective prevention strategies are urgently needed.

Dr. Pérez-Stable ended with a celebration of awards for individuals in the NIMHD intramural program and NIMHD research trainees who presented at the [2024 NIH Post-Baccalaureate Poster Day](#).

A discussion by the council members followed Dr. Pérez-Stable's presentation, including on the structure of the office on NHPI; the possibility of supporting a network of mentors around environmental health disparities; the effect of, and strategies to mitigate, the consequences of the recent Supreme Court decision on use of race as a consideration in college admissions and how this may impact efforts at diversification of the workforce; why Latinos may be less likely to receive mental health treatment; and comorbidities associated with redlining and structural racism.

Approval of Concepts

Research on Primary Care for Populations that Experience Health Disparities; Presenter: Dr. Dolly Penn White

<https://videocast.nih.gov/watch=54845&start=7880>

Analysis of national health data from 2019-2021 found that, compared to White counterparts, racial and/or ethnic minority groups were more likely to report fair or poor health status, more likely to die of diabetes and heart disease, more likely to report going without medical care, and more likely to report not having a primary care provider. Primary care may be a gateway for addressing these and other health disparities and

advancing health equity because of its comprehensive nature, covering prevention, wellness, management of acute and chronic conditions, and treatment for a variety of health concerns, including physical, behavioral, and social. The proposed initiative would support research on primary care for populations that experience health disparities to understand the association between receiving primary care, health disparities, and health equity; to evaluate factors and mechanisms that influence effectiveness of primary care; and to develop innovative and sustainable interventions to improve health outcomes. Access to primary care has increased over time, largely due to healthcare reform, but health disparities persist. Populations that experience health disparities are less likely to receive preventive services and evidence-based treatment for a variety of conditions. They are also more likely to receive low-value care, such as non-evidence-based cancer screening or opioid prescription for treatment of migraines and may have uncontrolled blood pressure and glucose levels above recommended levels. A recent study found a positive association between access to primary care physicians and life expectancy, but there has been a steady, ongoing decline in the primary care clinician workforce.

High quality primary care, which is defined by the National Academies of Science, Engineering, and Medicine as whole person, integrated, accessible, with continuity, and equitable, provided by interprofessional clinician teams accountable for addressing the majority of an individual's health and wellness needs across settings through sustained relationships, may reduce disparities and advance health equity, but more research is needed. The primary healthcare research portfolio accounts for about 2% of the NIH budget and 15% of the NIMHD budget in FY2023. This concept would support research using a variety of methods to investigate the effectiveness of primary care in addressing the healthcare needs of those populations with health disparities or studies proposing to develop and test, implement, and/or evaluate sustainable interventions within primary care to reduce disparities and advance equity.

Research priorities:

- Provision of high-quality primary care to improve health outcomes
- Coordination of care through interprofessional clinical teams to improve primary care quality and health outcomes
- Role, structure, and effectiveness of primary care in unique populations and/or settings
- Role of the primary care workforce in facilitating or challenging the effectiveness of primary care

Dr. Curry discussed the importance of the cultural competency of care providers, as well as the health literacy of the populations they serve, in understanding how to provide high quality low-cost primary care. Dr. White said additional research is needed in those

areas and noted the importance of patient-clinician concordance and its impact on equity. Dr. Curry also talked about the impact of trust, and Dr. White said there's a current NOFO focused on the patient-clinician relationship. Dr. Curry also discussed the importance of working with community-based organizations and caregivers, the need for an intersectional approach, the importance of interprofessional teams that include individuals that are part of a person's personal network, and consideration of those who may work non-traditional hours. Dr. Penedo discussed the need for proactive care, coordination with specialty care, adequate follow-up, and the shortage of access to specialists, which places additional burdens on primary care settings to deal with complex management and follow-up. Dr. Penedo asked about initiatives to promote evidence-based strategies to address people with multiple chronic conditions. Dr. White said there are NOFOs focused on that issue, but there is a need to tailor those strategies for populations that experience health disparities. Dr. Penedo proposed providing guidance and implementation models to ensure sustainability of implemented programs, as well as early engagement with decision-makers who manage budgets, workflows, and training. The concept was approved on a motion from Dr. Curry, seconded by Dr. Penedo.

Understanding the Influence of Interpersonal Biases on Health Outcomes and Disparities; Presenter: Dr. Carlos Garrido

<https://videocast.nih.gov/watch=54845&start=9380>

The proposed initiative would support research to examine mechanisms and pathways linking bias exposure to adverse health conditions and disparities. Interpersonal bias refers to implicit and explicit attitudes and stereotypes that lead to discrimination. Research has consistently shown that bias exposure predicts preclinical endpoints such as inflammation, oxidative stress, and cortisol dysregulation and health outcomes including asthma, hypertension, maternal health outcomes, and mental health and well-being. Knowledge gaps remain, including the mechanisms linking bias exposure to health, and little to no research has examined intersectional approaches. There are current NIMHD initiatives on structural racism and discrimination, the patient-clinician relationship, and youth violence prevention with a focus on interventions to lessen the impact of discrimination. NIMHD will be leading a workshop in June titled Addressing the Influence of Interpersonal Biases on Health Outcomes and Disparities. A portfolio analysis identified 171 NIH projects from 2019-2023 associated with interpersonal biases. Thirty were funded by NIMHD, but none looked at mechanistic factors.

The initiative would support multidisciplinary, multilevel research to understand mechanisms and pathways linking biases to health outcomes. Various study types would be included, with an emphasis on intersectional approaches to examine the implications of multiple forms of biases as well as various biobehavioral factors,

including cognitive-perceptual, physiological responses, and chronic physical and mental health conditions. Research priorities:

- Assess temporal processes between actual and perceived exposure to biases and development of adverse health outcomes
- Examine the effects of incremental and cumulative exposure to biases on oxidative stress and other health outcomes
- Investigate combined and interactive influence of bias exposure with multiple SDOH across domains and levels of influence
- Assess key transitional periods in exposure to bias to identify risk factors and optimal time points to mitigate the influence of bias on health
- Examine influence of bias exposure on health promotive behaviors and health care utilization
- Identify and isolate key cognitive mechanisms linking biases to maladaptive physiological responses and poor health
- Assess similarities and differences between encounters with stereotyping and prejudice in contrast to encounters with discrimination on stress and other physiological responses
- Develop methods to improve existing measurement tools and develop new tailored tools that measure the impact of biases for different populations, including different multi-categorizable populations.

Dr. Bauermeister discussed the built environment and its role in situating identities that may result in bias. Dr. Garrido said to really target the problem of bias, whether structural or interpersonal, one must look at interpersonal associations and their influence on higher level domains, including the built environment. Dr. Bauermeister also pointed to the need to think about network level dynamics and the importance of systems, including policies, laws, structures, or community norms, that may be enabling or dissuading biases from occurring. Dr. Cacari Stone suggested there is an opportunity to look at the social domains and structures within which interpersonal biases occur. She suggested another priority to consider is exposures related to intergenerational historical trauma; current exposures can serve as triggers for particular health outcomes. There may be an opportunity to look at intergenerational, familial health outcomes. Dr. Cacari Stone also said there may be an opportunity for NIMHD to take the lead on calling for quantitative methods for intersectionality research on health outcomes. Dr. Adunyah discussed the potential role of other exposures or stressors apart from biases and the need to account for those. Dr. Penedo proposed consideration of technology to captures exposures in real-time. Dr. Jernigan asked about the potential to start interventions during the work and about potential ethical concerns. Dr. Garrido said there is a need to have a clearer picture of the mechanisms and pathways before considering interventions, but also noted that interventions are

being developed in social psychology to address biases without neutralizing them. He also stressed the importance of ensuring ethical processes and protocols given the sensitive nature of implicit bias. The concept was approved upon a motion by Dr. Bauermeister, seconded by Dr. Cacari Stone.

Presentations

Socioeconomic status, health, and well-being of vulnerable populations: a life-course perspective; Presenter: Emma Aguila, PhD

<https://videocast.nih.gov/watch=54845&start=10930>

Dr. Aguila presented on supplemental income or social insurance programs. She began by highlighting the importance of researchers working with policymakers to design more effective programs for vulnerable populations. Socioeconomic status (SES) is a fundamental cause of health disparities. Lower SES individuals experience health problems shortly after adolescence; those with higher SES may not present health problems until retirement. These life course patterns suggest increasing health disparities as people age. Social insurance programs to alleviate poverty can either be cash, such as supplemental income or cash transfer, or non-cash, such as healthcare, food stamps, or utility subsidies. Dr. Aguila focused on cash benefits, either temporary or permanent, particularly for low-income older adults and single mothers. Interventions that improve SES could offset the effect of life exposures and reduce health disparities.

An experimental supplemental income program for low-income older adults was conducted in Yucatan, Mexico. Different implementation designs were tested; supplemental income was disbursed monthly or bimonthly, using cash or a debit card for unbanked or illiterate populations. There was a baseline survey with follow-up every six months; in addition to in-person interviews, data was collected on biomarkers and anthropometric measurements. Data was also collected at the community level on prices, community infrastructure, economic activity, and macro shocks. Six-month results for the monthly disbursement included increased healthcare utilization, some improvement in health outcomes, improvement of food availability, a reduction in work for pay, and a reduction in family transfers of wealth. Analysis by gender revealed strong effects on health; women spent more on healthcare utilization while men spent more on food availability. Monthly and bimonthly programs were compared at 18 months. The monthly payments appeared to be more effective in smoothing food consumption. Potential explanations for this are difficulties in saving by low-income individuals, unwillingness to maintain large amounts of money due to family pressures, and the possibility that the less frequent but larger payments facilitate investments in home improvements or durable goods. The monthly program had a stronger impact on food availability and healthcare utilization. Bimonthly recipients were more likely to have an increase in durable goods, particularly cell phones. Additionally, there were strong

health effects among the monthly recipients; so far, no health effects have been observed in the bimonthly recipients.

Beginning in July 2023, an ongoing program provides \$500 monthly to single mothers with children 0-17 years old in the city of El Monte, California, with income below the federal poverty line. Focus groups were conducted in December after implementation of the program. Participants reported spending the money on food, clothing, school supplies, rent, and gas. Key findings included reduced economic strain, improved mental health, improved sleep, improvements in their children's mental health, improved home environment, and the ability to get out of survival mode and plan ahead. In terms of overall findings, causality runs both ways between SES and health; experimental methods provide an opportunity to analyze the effects of exogenous permanent or temporary income shock on health and well-being. Experiments may help identify the mechanisms between income and health. A key takeaway is that implementation matters. The program conducted in Mexico informed implementation of the U.S. program. In both permanent and temporary income programs, more frequent payments improve the health and well-being of participants.

Dr. Bauermeister inquired about bundling other programs with the supplemental income. Dr. Aguila said it is an area in need of further research. Dr. Pérez-Stable asked about critiques that have been made that these types of programs keep people from doing gainful employment and that the funds are not used as intended. He also referenced behavioral economics research where individuals are paid to change behavior. Dr. Aguila noted that previous research has shown that recipients do not spend the money on things like alcohol and smoking; she also noted that cash transfer programs give individuals the agency to decide how best to spend the money. Dr. Cacari Stone asked whether information on immigration status was collected for the California program and noted that undocumented immigrants are not eligible for federal assistance. Dr. Aguila said they did not collect information on immigration status so as not to cause any fear around that issue.

**Indigenous Knowledges Powering Science: The Tribal Health Research Office;
Presenter: Karina Walters, PhD**

<https://videocast.nih.gov/watch=54845&start=13195>

The Tribal Health Research Office (THRO) sits in the Office of the NIH Director. It coordinates and collaborates with other NIH Institutes and Centers and works closely with Tribal partners. THRO's goal is to improve Indigenous health and health equity through culturally credible and meaningful Indigenist-driven science. The office is guided by values represented in the acronym CEDAR, which stands for creativity, ethics, determination, accountability, and respect and relational responsibilities. THRO

serves 574 federally recognized Tribal nations as well as Native Hawaiians and other Indigenous populations of U.S. territories. Tribal nations have a unique political status and retain powers of self-government; aligned with that is the federal Indian trust responsibility, a legal, moral, and enforceable fiduciary obligation on the part of the United States to protect Tribal treaty rights, lands, assets, and resources. Tribal populations suffer under a chronically underfunded, inaccessible, and inadequate healthcare system. Structural determinants of health for Native Americans are the poorest in the nation, including substandard overcrowded housing, food deserts, high rates of food insecurity, lack of clean and accessible water, lack of electricity in some communities, and disproportionate exposure to damaging environmental hazards, pollutants, and toxins, all of which contribute to high multiple chronic disease burden. Looking at mortality disparity rates, the AI/AN population had the highest drug overdose death rates in 2020 and 2021, as well as the highest suicide rates by any racial or ethnic standards. Native populations also have the lowest rates of participation in clinical trials. One impact of these disparities is the lowest life expectancy (65). Native populations face multiple public health crises but are largely invisible from public awareness and not included in most major national health data.

THRO aims to harness the power of Native communities to improve health through science in four main areas: advancing Indigenist research; cultivating capacity, internally and externally; engaging and consulting with Tribes; blazing new paths for strategic initiatives, policies, and collaborations; and embodying the values of CEDAR. THRO's goals for 2024-2025 include revising and developing a new strategic plan, developing Indigenous knowledge guidelines, developing an Indigenous data sovereignty policy, developing cross-cutting initiatives, and rapid response to public health crises. Data sovereignty and governance was recognized in a recent executive order as being a part of Tribal self-governance. The Boarding School Healing Initiative was launched by Secretary of the Interior Deb Haaland in 2021 to address the intergenerational trauma caused by the family separation and cultural eradication that resulted from boarding school policies, but there is a need to develop research on intergenerational trauma. THRO is looking to have a summit on that topic in the fall to bring together subject matter experts on intergenerational trauma, scientists, and boarding school survivors.

Dr. Aviles-Santa asked about the policy on participation by Tribal members in genomic studies and the difficulty in recruiting study participants within reservations. Dr. Walters said the Indigenous data sovereignty policy would directly address issues like genomic sampling. Regarding study recruitment, it may be necessary to use small sample sizes or to be creative, such as randomized stepped wedge sampling, randomized by community. Dr. Bauermeister asked about portfolio analysis and how many PARs and

NOFOs are currently available. Dr. Walters said THRO has requested a detail staff member from NIH to work on portfolio analysis. There are some ongoing NOFOs, including Intervention Research for Native American Health (IRINAH) and Native American Research Centers for Health (NARCH), and there are some more forthcoming. Dr. Pérez-Stable noted there is an RCMI in Northern Arizona with a major focus on AI/AN, and NIMHD continues to work with the Tribal Epidemiology Centers. He asked about Indigenous people of Latin America, and Dr. Walters said THRO is inclusive, supportive, and open to working with Indigenous populations, particularly since some are on both sides of the border.

The All of Us Research Program: Creating New Opportunities and Enhancing Diversity for Biomedical Research across the NIH; Presenter: Joshua Denny, MD
<https://videocast.nih.gov/watch=54845&start=16137>

The first awards for the All of Us Research Program were made in 2016, and the program launched in 2018. The mission is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us. The idea is to enroll individuals from across the country, reflecting our rich diversity, in a longitudinal study meant to last for decades. Over 800,000 people have consented to participate, across all 50 states and most U.S. territories, the vast majority of whom have agreed to share electronic health records (EHRs), though there is still a big gap between the number who have agreed to share and those from whom those records have been gathered. Although not everyone wants to provide one, the goal is to collect one million biospecimens. In 2023, Puerto Rico was launched as a larger recruiting site, and over 5,000 people in Puerto Rico have joined. Race and ethnic diversity are one very important, though not the only, measure of underrepresentation in biomedical research that All of Us is focused on. About half of participants identify as a race and/or ethnicity other than White. There have been updates over time, for instance the addition of a questionnaire to assess disabilities and looking at ability to access healthcare. Many categories are overrepresented compared to the overall U.S. population and about 10% identifying as sexual and gender minorities (SGM). Data is collected from surveys, with about one new survey released every year; EHRs; biospecimens; physical measures, for those who donate biospecimens in person; data from Fitbits and other devices, including about 60,000 given to participants in pilot programs; DNA; and, in some cases, other kinds of -omics data.

One focus of the program has been to return value to participants, and they have been asked what would be valuable to them. The number one thing they have said is to help provide for a healthier future, but genetic information has also been at the top of the list. Two classes of genetic information are provided. One is non-health-related, such as ancestry and specific traits. Launched in 2020, about 170,000 people have seen those

kinds of information. There are also health-related genetic results, which are offered to between 1,000 and 5,000 people per week and have been received by over 100,000 people. If they say yes, the information is generated and the researchers look at the variants and see if they have a pathogenic or likely pathogenic in one of 59 genes identified by the American College of Medical Genetics and Genomics, known as the ACMG 59. Any secondary findings are returned through genetic counselors. About 3% of those who have received health-related genetic results have a positive result among the ACMG 59. On the pharmacogenetics side, about 90% of people have an actionable result, and research suggests that about 20% of those people will benefit from an alternate medication recommendation based on their results. Genetic variants will be returned into ClinVar, which aggregates clinical interpretations on genetic variants. All of Us made its first submission about a month ago of about 32,000 interpreted genetic variants. The current genomic dataset is 245,000 whole genome sequences, with over a billion points of variation across the genome. Two-thirds of those were not in the common aggregation service gnomAD, and 275 million of those variants were not present in dbSNP.

Turning to researcher access to data, there is a public tier that anyone can use to query the dataset for high-level, aggregate data that does not allow for re-identification but gives people an idea of what is in the data, stimulating hypothesis generation. Approved researchers have access to the Researcher Workbench and can do research on a more de-identified register tier or a deeper, more detailed control tier that includes genetic information. All the above is not identifiable human subjects research that is already covered by participants' consent, so IRB approval is not needed. A form must be filled out which will help identify whether someone is potentially doing stigmatizing research, for instance, which would then go to a review board. Some aspects of these research projects will be posted publicly, but all of it is available to the All of Us team. Basic cohort development is done using web-based tools, and there are various statistical environments with which to conduct analysis. Individuals from institutions with a master agreement already in place may only take 1.5-2 hours to create an account and go through training, after which they can begin doing research. Engagement with both participants and researchers has been critical; 77 engagement studies or focus groups were conducted before anything else. So far over 11,000 researchers have signed up. There has been a focus on going beyond typical research institutions to less resourced institutions, non-profits, HBCUs, and Hispanic-serving institutions. International researchers were allowed to sign up starting in fall of 2023. Six continents are now represented, including many low or middle-income countries. There have been almost 500 publications using All of Us data to date.

The scientific roadmap for All of Us begins with a foundation of data, but more people are needed to come in and do research on it, use the biospecimens, or build out and enroll participants into ancillary studies. Ancillary studies already initiated include the COVID Serology Study and Exploring the Mind. One of the most intensive ancillary studies thus far is Nutrition for Precision Health, which will enroll 10,000 All of Us participants for randomized diet studies. It was featured on Good Morning America, resulting in the highest single day enrollment for All of Us.

All of Us is funded through base annual appropriation, but in 2016 the 21st Century Cures Act provided additional funding, which then led to the base funding being reduced in 2023. The Cures funding went down in 2024, but there was no change in the base funding, resulting in a 34% budget decrease. Given the need to do basic things like maintain existing samples, protect data, and keep promises made to existing participants, enrollment and engagement have been the hardest hit areas. The budget shortfall has also resulted in a pause on the launch of a pediatric cohort. Revised priorities for 2024 include implementation of new technologies, including to reduce the gap in EHR data and change participant-facing technologies, both of which have the potential to help reduce costs; closing the gap to return genomic results to participants; expand ancillary studies; and diversify researcher access, including to those from commercial organizations. Preparations are underway for the next data release in late 2024. This will increase the number of whole genomes to over 400,000 and add several new data elements, including racial and ethnic subcategorizations, which can now be released without risk of re-identification due to the increasing size of the data sets.

Dr. Adunyah, considering budget cuts, asked about the overall outlook for 4-5 years into the future. Dr. Denny said he is hoping for action to increase base support and noted the President's budget request would restore funding to 2023 levels. Increased sustained funding is needed to support enrollment and launch of the pediatric cohort. Additionally, the program is looking at ways to reduce costs and become more efficient. Dr. Aguila asked whether they had compared characteristics of minority groups to Census data and whether there is potential sample selection bias within specific groups, such as with education levels, and how they might overcome that. Dr. Denny noted that All of Us is not, and is not intending to be, a representative cohort; rather the goal is to reflect and over-represent U.S. diversity. Anyone can sign up, and there are also specific engagement enrollment efforts that have been undertaken. He detailed some of the ways they have sought to close gaps and said they love to hear other ideas. Dr. Trinh-Shevrin asked about socioeconomic diversity. Dr. Denny said that has been captured but said in general they are like Census numbers in most categories. The study population may be a little more educated than the overall U.S. population, but not by a lot. Dr. Trinh-Shevrin followed up to ask about SDOH. Dr. Denny said the SDOH

module was the only one for which participants in the pilot said they wanted more questions. The module builds on standard questions such as those from PhenX toolkit. Dr. Bauermeister said one of his doctoral students just finished a dissertation using All of Us data on SGM elders and housing access from the SDOH questionnaire. He also mentioned the possibility to have statistical sampling weights as a variable to adjust how much a single participant or row of data contributes to population health analyses, which could advance existing limitations for some populations. Dr. Denny said they have a partnership with Muin Khoury at CDC, who is developing population weights that could be used to adjust some of those metrics. Dr. Adunyah asked how much overlap there is between All of Us and eMERGE III and eMERGE IV. Dr. Denny said there is probably some overlap at some of the sites, but less than might be expected. He said the best way to do an eMERGE analysis would be to remove the sites that overlap with All of Us. Given the complications in harmonizing return of results in eMERGE, Dr. Adunyah asked how All of Us compares. Dr. Denny said in some ways that is easier with All of Us, after scaling up. Dr. Pérez-Stable asked about the race and ethnic data. Dr. Denny said right now there is only high-level classification, but the next release, in the fall or winter of 2024, will include subcategorizations and those who self-identify as AI/AN. Dr. Pérez-Stable asked if All of Us was set up to align with the new OMB directive. Dr. Denny said All of Us was largely designed around the original planned single question for the 2020 Census. Dr. Pérez-Stable said in some ways it is well-aligned, given that there is a single question and there is a Middle Eastern/North African category, but for researchers there are probably subpopulations that would be helpful to be able to identify, particularly in very heterogeneous categories, such as Asian, or the very mixed categories, such as Latino/Hispanic. Dr. Denny said the next level will include some of those subpopulations and said they are open to revising if needed.

Closing Remarks and Adjournment

<https://videocast.nih.gov/watch=54845&start=19365>

Dr. Pérez-Stable acknowledged that this is Dr. Aguila's last meeting as a council member and invited her to provide some remarks. After ascertaining there were no public comments, Dr. Pérez-Stable adjourned the meeting at 3:01 p.m.

END NOTE: REVIEW OF GRANT APPLICATIONS_ CLOSED SESSION A portion of the meeting was closed to the public in accordance with the provisions set forth in Sections 552b(c)4 and 552b(c)6, Title 5 U.S.C. and 10(d) of the Federal Advisory Committee Act as amended (5 U.S.C. appendix 2). Dr. Pérez-Stable called the Closed Session to order at 1:00 pm, May 30, 2024, Dr. Cotton led the second level review of

grant applications submitted to NIMHD programs. Council members and NIMHD staff members were instructed on conflict of interest and confidentiality regulations. Council members and staff absented themselves from the meeting room and discussions for which there was a potential conflict of interest, real or apparent. The Council considered 327 competing applications requesting an estimated \$200,674,767 in requested total costs for year 1 for non-fellowship grants. Funding recommendations for all applications submitted in response to funding opportunity announcements were reviewed. Applications submitted in response to program announcements and special program review announcements were considered by the Council through En Bloc voting.

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

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