

**U.S. Department of Health and Human Services  
National Institutes of Health  
63rd Meeting of the National Advisory Council on Minority Health and Health Disparities (NACHMD)**

NIH Building 31  
31 Center Drive  
Bethesda, MD 20894

May 23, 2023  
8:30 a.m. EST - Adjournment

**Meeting Minutes**

**Council Members Present**

Eliseo J. Pérez-Stable, M.D., Chairperson; Director, NIMHD  
Emma Aguila, Ph.D., University of Southern California  
Lisa L. Barnes, Ph.D., Rush University Medical Center  
Neil S. Calman, M.D., Icahn School of Medicine at Mount Sinai  
Amy J. Elliott, Ph.D., University of South Dakota School of Medicine  
Kimberly S. Johnson, M.D., Duke University School of Medicine  
Kenneth A. Resnicow, Ph.D., University of Michigan  
William M. Southerland, Ph.D., Howard University  
Chau Trinh-Shevrin, Dr.PH, New York University School of Medicine

**Council Members Absent**

Esteban G. Burchard, M.D., MPH, University of California at San Francisco  
Mario Sims, Ph.D., University of California, Riverside

**Ex Officio Members Present**

Christine M. Hunter, Ph.D., Office of Behavioral & Social Sciences Research, NIH  
Judith A. Long, M.D., VA Center for Health Equity Research and Promotion  
Donald Shell, M.D., Office of the Assistant Secretary of Defense, Defense Health Headquarters

**Representatives Present**

Monica Webb Hooper, Ph.D., Deputy Director, NIMHD  
Rina Das, Ph.D., Director, Division of Integrative Biological and Behavioral Research, NIMHD  
Nathan Stinson, Jr. Ph.D., M.D., MPH, Director, Division of Community Health and Population Science, NIMHD  
Larissa Avilés-Santa, M.D., M.P.H. Director, Division of Clinical and Health Services Research

**Executive Secretary**

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

**Presenters**

Lisa L. Barnes, Ph.D., The Alla V. and Solomon Jesmer Professor of Gerontology and Geriatric Medicine, Rush Medical College

Patricia Flatley Brennan, RN, Ph.D., Director, National Library of Medicine, NIH

Arielle Gillman, Ph.D., Program Director, Division of Integrative Biological Behavioral Sciences, NIMHD

Deborah E. Linares, Ph.D., M.A., Program Director, Division of Integrative Biological Behavioral Sciences, NIMHD

Carolina Solis Sanabria, M.D., MPH, Program Director, Division of Clinical and Health Services, NIMHD

## **Call to Order and Welcome**

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

## **Roll Call, Minutes Review**

Dr. Cotton called the roll and invited members and staff to introduce themselves. The council unanimously approved the minutes of its February 2023 meeting and announced the next open session of NACMHD on September 1, 2023. The 2024 meeting dates are February 2, May 31, and September 6; the 2025 meeting dates are February 4, May 16, and September 5. Members were reminded that NIH policy allowed them no more than one absence per calendar year, and that they were prohibited from serving on NIH peer review panels while on the council.

## **NIMHD Director's Report and Discussion**

<https://videocast.nih.gov/watch=49533&start=590>

Dr. Pérez-Stable welcomed the council to the first in-person meeting since September of 2019 and provided a report on NIMHD-related activities since the February 2023 council meeting.

- Monica M. Bertagnolli, M.D., currently serving as Director of the National Cancer Institute (NCI), has been nominated by President Biden to be the next NIH Director. After meeting with the Senate Committee on Health, Education, Labor and Pensions, a hearing will be scheduled with the full Senate to confirm her nomination. Until then, Lawrence A. Tabak, D.D.S., Ph.D., continues as Acting Director of NIH.
- Anna Nápoles, Ph.D., M.P.H., has retired from her position as NIMHD Scientific Director. Kelvin Choi, Ph.D., M.P.H., is serving as Acting Scientific Director while a national search is conducted.
- NIMHD Deputy Director, Monica Webb Hooper, Ph.D., was recognized as one of the Most Influential People of African Descent (MIPAD) in the class of 2023 Global Top 100 List for Health Care, which is supported by the United Nations International Decade for People of African Descent from 2015 to 2024.
- Karina L. Walters, Ph.D., M.S.W., has joined NIH as the Director of the Tribal Health Research Office.
- NIMHD is trying to create an evaluation of its supported Loan Repayment Program (LRP). Since the program's inception over twenty years ago, NIMHD has been authorized to provide loan repayment to individuals with proposals for health disparity research. A smaller proportion of the LRP grants has been awarded to individuals from disadvantaged backgrounds. Since 2019, any institute in NIH can fund LRP grants in health disparities, not only NIMHD.
- Grant applicant award rates for NIMHD have been increasing since FY20, due partly to the higher quality of applications and the rising diversity of review committees, but also because of increased discretionary funding received from Congress in FY21 and FY22. Both early stage and established investigators' success rates increased to greater than 20% in this time frame.

- Legislative Updates:
  - Dr. Tabak attended a House Appropriations Labor, Health and Human Services (HHS), Education Subcommittee hearing with the Directors of the Centers for Disease Control and Prevention and Director of the Administration for Strategic Preparedness and Response.
  - At the Senate Appropriations Labor, HHS, Education Subcommittee hearing on the FY24 NIH budget request and justification, Dr. Tabak testified alongside directors from NCI, the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), and the National Institute on Drug Abuse (NIDA).
  - Dr. Pérez-Stable briefed the House Ways and Means Committee staff and the House and Senate Appropriations and Labor HHS Education Subcommittee staff on the NIH Climate Change and Health Initiative and on potential impacts to the healthcare system.
  - Dr. Pérez-Stable and Dr. Webb Hooper briefed the Senate Health, Education, Labor, and Pension Committee staff on the status of recommendations from the Advisory Committee to the Director (ACD) Working Group on Diversity (WGD) Subgroup on individuals with disabilities.
- NIMHD has made new hires in the divisions of Intramural Research, Clinical and Health Services Research, Community Health, and Population Science, Integrative Biological and Behavioral Research, and in the Offices of Administrative Management, Extramural Research Activities, and Science Policy, Planning, Evaluation and Reporting.
- Dr. Webb Hooper moderated a discussion between U.S. Surgeon General Vivek H. Murthy and Dr. David Chokshi for Dr. Murthy's Lecture Series on Public Health Leadership.
- The Health Disparities among Sexual and Gender Minorities (SGM) Workshop was held on March 1-2, 2023. Its goals were to identify research gaps in data sources and measures that can be used to assess and address SGM health disparities, mechanisms and pathways that drive and cause SGM health disparities, and interventions with the potential to mitigate and reduce SGM health disparities focused on racial and ethnic minority populations.
- Over 800 participants attended the Inclusive Participation in Clinical Research workshop on March 30-31, 2023, which explored evidence-based best practices to increase inclusive participation in clinical research strategies. The workshop was driven by a 30-year effort at NIH to have investigators report on the race and ethnicity, age, and sex or gender of the human participants in their studies as part of the application process. The focus was on best practices to continue to enhance inclusive participation that is meaningful for the race and ethnic minority populations with disproportionate burden of specific diseases.
- The NIH UNITE Initiative held 14 external listening sessions between December 2021 and February 2022 comprising 1,295 individuals. A report was created summarizing findings in five major areas: the state of equity in the biomedical sciences, challenges in career pathways and workforce, practices, and policies as barriers to equity, challenges in health disparities research, and challenges in addressing healthcare equity and health outcomes. It proposed solutions for NIH and the extramural biomedical research community.

- UNITE has continued its activities including leading efforts to recommend the development of funding opportunities that promote equity, such as:
  - Research With Activities Related to Diversity (ReWARD)
  - Instrumentation Grant Program for Resource-Limited Institutions
  - Strengthening Research Opportunities for NIH Grants (STRONG)
- The Community Engagement Alliance (CEAL) Against COVID-19 Disparities conducted a campaign in Puerto Rico to encourage uptake of the COVID-19 booster vaccine.
- The Community Partnerships to Advance Science for Society (ComPASS) Initiative is reviewing applications for a coordinating center. The Community-Led Health Equity Structural Interventions (CHESIs) applications have been submitted and are being reviewed internally. There was a robust response. ComPASS will fund up to 25 community organizations for implementing CHESIs to intervene on structural factors that produce and perpetuate health disparities. ComPASS will publish a funding opportunity announcement for the academic hubs in the coming months.
- Jean de Dieu Gatete, District Clinical Director of Kirehe Hospital, Rwanda, is the seventh graduate of the NIMHD-National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Rwandan Fellowship Program. The program will continue with a new fellow starting in January 2024.
- The Science Collaborative for Health disparities and Artificial Intelligence Bias Reduction (SchARe) Initiative is an effort to increase the representation of women and racial and ethnic minority populations in data science, to foster a paradigm shift in conceptualizing health disparities, healthcare delivery, and health outcomes research, and to mitigate biases that arise from design, data, algorithms, training, and implementation. SchARe has conducted monthly think-a-thons, and instructional virtual meetings on cloud computing focused on research. The goal is to have a platform for researchers to have the tools to look at large data sets and metadata.
- The Clinical Research Education and Career Development (CRECD) Program is funded by NIMHD to expand capacity of clinical researchers at institutions with less resources, including the Morehouse School of Medicine, the University of Puerto Rico, the Charles R. Drew University of Medicine and Science, and the State University of New York Downstate Health Sciences University. There are 36 current scholars, 94% of which are from underrepresented minority groups.
- The National Eye Institute (NEI)-NIMHD Workshop on Vision Health Equity was held on April 11, 2023, and fostered interaction between health disparities scientists and NEI vision researchers. There are several opportunities and areas that are common and in the interest of public health, including access to diagnosis and therapies related to glaucoma and cataracts.
- The 2023 Research Centers in Minority Institutions (RCMI) Consortium National Conference brought together over 400 participants including U54 grant Principal Investigators/Program Directors (PI/PDs) and other senior scientists, university presidents and provosts, as well as NIH staff and leadership, to exchange information and discuss opportunities for collaboration and strategies for solving shared challenges. NIMHD's management of RCMI together with the

programs funded by the National Institute of General Medical Sciences accounts for around 75% of funding to lower resourced and minority-serving institutions.

### Health Disparities Science Advances

- The rate of COVID-19-Associated Deaths per 100,000 individuals in the US from 2020-2022 shows that children have a very low rate of serious illness and death, like influenza, and the rate climbs with age starting in the mid-30s with the burden of mortality primarily resting on older adults over 65 and especially over 75 years old. There has been a relative leveling of mortality rates among different races and ethnicities since 2020 which is a major accomplishment of community activation with academic and government partnerships.
- NIMHD and collaborators from Johns Hopkins and Tulane Universities published a [paper](#) in the *Journal of the American Medical Association* on the economic burden of racial, ethnic, and educational health inequities in the U.S. In 2018, racial and ethnic minority group analyses suggest a cost of \$451 billion to the U.S. economy, while the burden of disparities among people who did not complete a degree from a four-year institution costs about \$978 billion through factors such as excess medical care expenditures, lost labor market productivity, and premature death.
- The *Journal of Community Psychology* published a [study](#) that concluded that a sense of community improves health-related quality of life among Black Americans. The sense of community buffers against the adverse effects of low physical activity on health-related quality of life rates, which tend to be lowest among Black Americans compared with other groups.
- Data evaluating 580 Black participants in Jackson, MS and Atlanta, GA from the Rationale, Design and Methods of the Ecological Study of Sexual Behaviors and HIV/STI Among African American Men Who Have Sex With Men in the Southeastern US ([MARI study](#)) of adults assigned male at birth who reported having sexual relations with men in the previous 6 months and provided data on parental sexuality disclosure. Results determined that experiences of discrimination were associated with higher levels of depression, and that depression levels increased as parental disclosure of one's identity within the LGBTQ+ community decreased. Families may play an important role in supporting the mental health of Black SGM populations.
- The [Panel Study of Income Dynamics](#) examined intergenerational neighbourhood mobility using 2828 parent-child pairs from a longitudinal household survey. Study findings indicate that different patterns of intergenerational neighbourhood mobility between White and Black families may be an important factor for persisting racial disparities in the neighbourhood context.
- A large [study](#) of data from more than 44 million Medicaid enrollees identifying 858 Black and 1,749 White patients with abnormal uterine bleeding found racial disparities in diagnostic evaluation of uterine cancer. Black patients were more likely than White patients to experience delayed diagnosis and not receive recommended diagnostic procedures. Additionally, Black patients were more likely to experience delay in time to the first diagnostic test.
- The *Journal Nicotine & Tobacco Research* published a [study](#) which concluded that a potential precision medicine approach to smoking cessation among Native American populations tailoring

pharmacotherapy to a biomarker known as the nicotine metabolite ratio (NMR) may show promise. NMR-informed pharmacotherapy selection may have potential for enhancing smoking quitting success among Native American populations.

- Data from the [Health and Retirement Study](#) on 5,062 adults over the age of 50 were analyzed to determine the relationships between perceived discrimination, chronic stress as measured by a composite of biomarkers and physical examination known as allostatic load, and mortality. Allostatic load mediated the relationship between perceived discrimination and all-cause mortality. This perceived discrimination induces stress, and elevates cardiovascular, metabolic, and inflammatory biomarkers related to mortality. The findings highlighted the importance of developing interventions to mitigate the negative impact of discriminatory events on health and mortality.
- Study Cross-sectional [online study](#) of  $N=178$  Latino adults (31.5% female,  $M$  age=34.1)= Measured fear of COVID-19, anxiety-related sleep disturbance, anxiety and depression symptoms, and resilience evaluated resilience in relation to these negative health outcomes. COVID exposure, COVID-related work and financial troubles, and home-life distress, resilience explained significant variability in and was negatively associated with COVID-19 fear ( $\Delta R^2 = .06$ ,  $p < .001$ ), anxiety symptoms ( $\Delta R^2 = .03$ ,  $p = .005$ ), sleep disturbances ( $\Delta R^2 = .06$ ,  $p < .001$ ), and depression symptoms ( $\Delta R^2 = .04$ ,  $p = .001$ ). Resilience is a protective factor against behavioral health problems during COVID-19 among Latino adults and resilience training interventions may benefit Latino adults.
- A [study](#) on the relationship between housing characteristics and care outcomes among women living with HIV conducted a latent class analysis to identify patterns of housing situations and collected clinical data on 1,501 women living with HIV who received services under the Ryan White Part A program in Miami-Dade County in 2017. Women living with HIV who were homeless or unstably housed, lived alone, with no minors and no other adults, and reported not disclosing their HIV status were at risk of poor HIV care outcomes, including lower odds of being retained in care, being virally suppressed, and having sustained viral suppression. These data reinforced assessing housing status as an important component of healthcare for women living with HIV.
- [Study](#) evaluated the association of pre-diagnostic smoking and alcohol with mortality among 1,926 Black women from the Women's Circle of Health Follow-Up Study, a population-based cohort of Black breast cancer survivors in New Jersey, U.S. Compared with never smokers, current smokers had increased risk (52%) for all-cause mortality ( $HR=1.52$ , 95% CI: 1.15-2.02) and breast cancer-specific mortality (1.27, 0.87-1.85). This association was most pronounced for women with greater pack-years of smoking and regular alcohol consumption. Regular alcohol consumption the year before diagnosis was not associated with all-cause or breast cancer-specific mortality. Smoking at the time of diagnosis was associated with a higher risk of mortality among Black breast cancer survivors, particularly among those with greater pack-years of smoking. Elevated risk of all-cause mortality for current smokers consistent with literature
- The first [study](#) to examine association between sleep measures and Complex Multimorbidity (CMM) among two populations of 200 Chinese and 200 Korean Americans found a prevalence of

having CMM was higher in those reporting sleep disturbances and concluded interventions are needed to increase awareness of the importance of sleep on health.

### **Health Disparities Science Advances in the NIMHD Intramural Research Program**

- Firearm-related deaths became the leading cause of death for Black children and adolescents in 2020. Mortality and race/ethnicity [data](#) from the Centers for Disease Control and Prevention (CDC) Wide-ranging ONline Data for Epidemiological Research (WONDER) revealed an immense disparity between firearm-related deaths for male Black children and adolescents and those of all females and males of other races.
- The Multi-Ethnic Study of Atherosclerosis (MESA) has contributed longitudinal cardiovascular mortality information identifying both lifetime and everyday discrimination as a mediator of adverse health outcomes. The [study](#) analyzed data from 1,633 Black, 1,403 Hispanic/Latino, and 2,473 White participants (45-84 years old) enrolled in MESA from 2000-2002 and discrimination was associated with mortality; highest hazards among Black adults.
- Cross-sectional [survey](#) of a nationally representative sample of adults who used tobacco products (N=1,700); mean age=43 years, evaluated vicarious and directly-experienced COVID-19-related discrimination. These were associated with higher levels of concern for experiencing such discrimination and vigilance, particularly among Asian and other racial and ethnic minority individuals. The effects were discovered even in localities with a large racial and ethnic minority population, such as San Francisco and New York.
- The Population Assessment of Tobacco Health (PATH) study has shown a dose-response relationship with cigarette smoking behaviors through cigarette discount coupons. The availability of the coupons on the internet were associated with higher probabilities of smoking progression and continuation and revealed themselves to be an important component of marketing for the tobacco industry since widespread prohibition of advertising on television and in print.

### **Division of Intramural Research Updates**

- Captain Anthony Johnson serves as the Scientific Advisor and Training Director for NIMHD's Division of Intramural Research. CAPT Johnson has helped coordinate NIMHD's training program and attended the Columbia University Mailman School of Public Health Career Forum in New York to recruit graduate and doctoral professionals for NIMHD fellowships.
- Dr. Pérez-Stable congratulated 14 NIMHD Research Trainees from the 2023 NIH Postbaccalaureate Poster Day.

### **Invited Presentations**



**Digital NIH Strategy, Patricia Flatley Brennan, RN, Ph.D., Director, National Library of Medicine, National Institutes of Health**

<https://videocast.nih.gov/watch=49533&start=5605>

The National Library of Medicine (NLM) was established in 1836 with roots in the office of the U.S. Army Surgeon General. Congressional authorization moved NLM to the Public Health Service and charged it with collecting information and data about medicine to transmit and share, with the building opening its doors on the NIH campus in Bethesda, MD in 1965. Between 1968 and 2000, NLM saw the emergence of computing as the basis of a modern library, as well as the creation of two of its research institutions: The Lister Hill National Center for Biomedical Communications and the National Center for Biotechnology Information. Since 2000, NLM has positioned itself as the 21st Century Library. It conducts research, it disseminates information, knowledge, and data, and it reaches into the community using NLM's 8,000 points of presence around the country in hospital libraries, public libraries, and specialty libraries that allow the public to make use of its resources. Millions of people make use of NLM's resources every day to access research literature, biomedical tools, library resources, health standards, and consumer health services, making NLM highly dependent on informational technology (IT).

Over the past two years NLM has been working across NIH to create the vision of Digital NIH, which will accelerate science through innovation, technology, and computation. The conduct of modern science requires technology, and advancing the promise of technology requires new approaches from the NIH campus to funding and governance. NIH's traditional approach has created a great deal of disparity for its information services, as well as an elevated risk when security is of preeminent importance in healthcare research. The vision of Digital NIH is of an adaptive governance model that aligns Institute and Center-specific (IC) technology investments with trans-NIH investments and its mission. The strategy reflects contributions of over 400 NIH staff members and 19 leading sector organizations. Digital NIH will champion a new, more enterprise-savvy approach to technology governance and decision-making that reflects holistic, integrated planning across NIH. False boundaries between disciplines and areas of research need to be eliminated through technology. Digital NIH aims to provide rapid computational services with flexible data storage, to enable all ICs to be on the forefront of the technologies relevant to their research mission, to maximize operational efficiency of scientific processes and technologies, and to develop innovative frameworks that deliver faster, more automated approaches to digital technologies. Digital NIH is a framework to develop high-priority capabilities and manage NIH technology investments across functional areas common to all ICs, including extramural research management, intramural clinical and basic research, as well as administration and management. Increasing extramural research management capabilities requires an enhanced Electronic Research Administration, new technologies to implement critical policies in compliance and fraud detection and creating artificial intelligence and machine learning algorithms. Intramural research requires a collaboration portal for researchers to connect on related data sets, broadly accessible licensure for commonly used scientific software, a suite of tools to support clinical trial management, and increased computing power for large, complex data sets. Administration and Management at NIH will be enabled through management platforms that can be tailored to IC's unique needs; analytics, reporting, and

visualization tools that allow decisions to be made more transparently; automated and digitized workflows; and learning systems and tools. With these improvements, NIH is expected to see reduced researcher and staff burden, a more supportive, secure, and flexible environment for research technology, improved patient interactions, and optimized and efficient business processes. Dr. Brennan suggested a common digital architecture across NIH to enable integration; cutting-edge storage, analytics, and computation infrastructure; an increasingly technically competent workforce; and risk-based, embedded cybersecurity protections to modernize technical solutions for all NIH ICs.

Digital NIH is envisioned as a five-year plan that will iteratively explore solutions to prioritize capabilities over the coming years. The implementation planning process is well underway with over 100 staff members working on it. The Office of Data Science Strategy (ODSS) is concurrently developing a strategic plan for data science. Digital NIH will provide the light-weight infrastructure needed to modernize the NIH biomedical data-resource ecosystem for the NIH 2023-2028 Strategic Plan for Data Science. Dr. Brennan emphasized integrating ethics, policy, health equity and transparency in the development of data science methods and tools.

Common Data Elements (CDEs) are a combination of a defined variable or question paired with a specified set of similarly coded permissible responses to questions. CDEs are common to multiple data sets or designated for use across different studies, and they can be structured as a single data element or a collection of data elements to compute a survey score (e.g., PHQ-9). NIH plans on building quality into data acquisition, which means having researchers collect the same concept of data in the same manner in a consistent fashion. NIH is committed to building CDEs that are relevant and germane to Institute-specific research or initiatives. The CDE Taskforce, through a governance subcommittee, endorses NIH-designated CDEs that are shown to meet specified criteria. This taskforce reports CDEs to the BioMedical Information Coordinating Committee (BMICC), which reports it to the Scientific Data Council, which reports it to the Steering Committee.

Collected data need to be reusable in a protected and secured fashion. When data are initially being gathered, planning for data sharing begins in the design phase by using CDEs when possible and employing standard terms and formats (e.g., SNOMED nomenclature, or the FHIR interoperability standards). Consent also needs to be obtained for sharing and re-use. For future researchers, the priority is allowing them the ability to discover and evaluate relevant data and comply with existing stipulations, indicating that they have the right to use the data and it's properly supervised. The NIH has four data life cycle initiatives that include its (1) Recommendations for Open Access Data Repositories like PubMed Central or generalist repositories, (2) Controlled Access Data Management which requires all data to be accessible and managed and for most data to be shared, (3) the 2023 Data Management and Sharing Plan, and (4) innovations in NIH data repositories. For instance, NIH currently spends \$8.5 million storing genomic data in the Sequence Read Archive. NIH spends \$1.8 billion a year on data and information technology, and the better it's managed, the better it will be able to meet future needs.

Dr. Long asked if there are plans for other government agencies to share their data sets and make them interoperable with Digital NIH. Dr. Brennan mentioned the Department of Veterans Affairs, the National

Oceanic and Atmospheric Administration, and the Department of Energy as collaborators with NIH, and that NIH's data plan rolls up into HHS's broader strategy and ultimately into the trans government plan. Dr. Elliott asked about reducing redundancy and safeguarding data in working with other agencies. Dr. Brennan's strategy is to use her formal role as a NIH leader and relations with her colleagues and Dr. Tabak and Dr. Schwetz to seek governance levers within the institution to provide coordination while respecting local control. Dr. Southerland asked about algorithmic bias and the injection of the bias of the individual developer or investigator into the algorithm. Dr. Brennan referenced Diana Forsythe's ethnographic work and the National Institute for Standards and Technology (NIST) AI Management Risk Framework but noted that the mitigation of bias is dependent on the awareness by all parties of its presence at every step of an investigation. She cautioned that the risk with AI and recent algorithms is that they are driven more by data than individual investigators, and that unstructured data sets can be processed by neural nets or large language models in ways that are not always human interpretable. Dr. Aguila asked about lower-resourced universities and colleges and minority-serving institutions making use of NIH data without always having expertise or training. Dr. Brennan recommended the NIH's data sharing site which has links to training and analytics tools, and that training modules are currently being built that will provide in-the-moment coaching, but that ultimately data science training needs to occur earlier in every student's education.

**Impacts of Discrimination on Brain Health in Older African Americans, Lisa Barnes, Ph.D., The Alla V. and Solomon Jesmer Professor of Gerontology and Geriatric Medicine, RUSH Medical College**  
<https://videocast.nih.gov/watch=49533&start=8175>

Alzheimer's Dementia (AD) is among the most feared diseases of old age, being one of the leading causes of death and the only one that cannot be slowed, cured, or prevented. More than six million adults aged 65+ had clinical AD in 2020, which will increase to 13.85 million in 2060. The backdrop for this public health crisis is an aging and rapidly diversifying population, with African Americans being twice as likely as White Americans to have AD. Age-standardized dementia incidence rates indicated that African Americans alongside American Indians and Alaska Natives had the highest incidence rates for AD, with Asian Americans being somewhat protected. Dr. Barnes spoke about four challenges faced as a field of study in understanding AD. First, recruitment practices have been largely passive strategies not centered in communities of color. Recruiting is often done from well-resourced clinics in academic medical centers, and inclusion/exclusion criteria tend to favor White participants, selecting for individuals with few chronic co-morbidities and access to transportation. In an analysis of eight to ten recent AD studies, 79% of participants were White. This disparity persists in National Institute on Aging (NIA) funded clinical trials where new AD therapeutics are being developed and tested, with private industry funded trials even less diverse. The second challenge is a lack of trust by the African American community. The Alzheimer's Association held several focus groups that demonstrated that Black Americans were the most likely to believe medical research is biased against people of color and the least likely to trust an Alzheimer's cure will be shared equally regardless of race, color, or ethnicity. Another challenge is the cross-sectional design of AD diagnosis, which relies heavily on cognitive test performance that is correlated with education but influenced by many other factors, including race. This

"snapshot" cross-sectional design needs to be complemented with longitudinal designs that study the changes of aging over time. The final challenge was the missing narrative of those most at risk for the disease who are being left out of studies and research because they fall outside the group most likely to be reported on when it comes to AD.

The objective of Dr. Barnes's program of research is to build an infrastructure and resource for investigators interested in understanding the aging profile of older African Americans, primarily to understand cognitive aging but also to give voice to those historically excluded from critical AD studies and identify risk/protective factors for cognitive decline and AD. The Minority Aging Research Study (MARS) began enrollment in August 2004 and now comprises more than 800 African Americans over 65 years of age, who enrolled without dementia. Participants were recruited in their communities from churches, senior buildings, and organizations in Chicago, and MARS staff assembles a team of professionals to go to the participants' homes for annual cognitive testing, risk factor assessment, and blood draws. The follow up rate is excellent, greater than 90% for survivors, and recruitment for brain autopsies began in 2011 with 160 autopsies to date. As all participants enrolled without AD and 10% have since developed the disease over the course of the study, these brain autopsies will be an important resource for understanding the neurobiology of AD. To conduct a study like this requires intense and continuous community engagement, which Dr. Barnes detailed. Consistent with most aging research MARS is composed primarily of women, since women tend to volunteer for longer and more men die before the age of 65. About half of the cohort has agreed to brain donation, and since the study is approaching its 20th year, ancillary studies making use of MARS participants and data include brain imaging, decision making, SMART homes, nutrition, and Medicare. A study complementary to MARS is the Rush Memory and Aging Project which is made up of 2,000 older persons without dementia throughout Chicago and northeast Illinois, about 91% White, who all agreed to clinical evaluations, risk factor assessments, blood draws, and organ donation at death. Since MARS is exclusively African American, the Rush Memory and Aging Project allows for research into the differences and similarities between Black and White participants. Comparing data between the two studies showed wide heterogeneity in the rates of decline among individuals, but remarkable similarity across races in the slope of decline at different ages, even as a gap remains between Black and White performance on cognitive tests.

To better understand the gap between races, defined as a social/political construct, rooted in cultural identity, and shaped by historic events. Dr. Barnes asked, how do social determinants influence brain health? She asked MARS participants, who would all have come of age in a time with more overt and pervasive discrimination, where they were born. Those born in the South, where racism was more intense earlier in the 20th century, or who lived in the South at 12 years old, performed worse on cognitive function tests than African Americans raised in the North. Segregation in education was the norm for many participants who came to Chicago from the South in their childhood, and a notable fact is that participants who attended legally desegregated schools in the South had lower late-life cognition than those who attended segregated schools. Discrimination can be described as a psychosocial stressor that affects many areas of mental health, cognitive function, and neuropathology. People who report higher levels of perceived stress also have faster rates of decline in episodic memory and visuospatial

ability. Concluding, Dr. Barnes suggested NIH needs studies that include under-represented populations that incorporate social determinants. Not only could this advance science and move towards health equity, but it could set the stage for future intervention and policy work to eliminate disparities.

Dr. Johnson and Dr. Pérez-Stable discussed with Dr. Barnes representation in clinical trials, and the need for at-risk populations for a disease to be over-represented in studies on that disease, particularly in industry funded trials. Dr. Aguila asked about the gap in cognitive tests for White participants with similar or less education than Black participants in MARS which Dr. Barnes said she would study, and they discussed the role of occupation as a protective factor for AD. Dr. Resnicow asked what interventions could be attempted to mitigate the psychosocial and physiological effects of discrimination throughout an individual's life. Dr. Barnes responded that beyond fixing systemic issues that create discrimination, teaching better coping skills for minoritized populations could relieve some of the harm that arises through discrimination, adversity, and poor treatment. Dr. Southerland asked what the rate of AD at brain autopsy was for MARS participants, and Dr. Barnes said that beyond the 10% who displayed clinical symptoms during life, around 30% had the underlying pathology that defined AD upon autopsy. Jennifer Webster-Cyriaque, Deputy Director of the National Institute of Dental and Craniofacial Research, suggested stratifying based on oral health and periodontal disease, as older African Americans suffer significant oral health disparities that are associated with systemic inflammation and other co-morbidities with AD. Dr. Barnes responded that she was very open to collaborating with someone with the expertise to assess participants' oral health.

## **Approval of Concepts**

### **Multilevel Pathways and Interventions to Promote Vaccine Uptake among Populations Experiencing Health Disparities; Presenter: Dr. Deborah Linares**

<https://videocast.nih.gov/watch=49533&start=11560>

The objective of this initiative is to support research examining multilevel pathways and interventions to promote vaccine uptake among populations experiencing health disparities. Vaccines provide multiple benefits for the prevention and reduction of disease and serious illness or death while also providing protection against transmission. Despite the multiple benefits of vaccination, disparities exist and continue to grow for vaccine uptake among adult and child populations of racial and ethnic minority persons, people with low Socioeconomic Status (SES), as well as SGM persons, and individuals living in rural areas. Because many of these statuses intersect among these populations, it is important for NIHMD to understand why these disparities exist and to develop effective strategies. Vaccine hesitancy varies across vaccine, may vary across time, and can be influenced by cultural and religious factors, lack of accurate information, or exposure to misinformation and disinformation. Upstream social determinants, such as out-of-pocket-cost or having a primary care provider, can serve as barriers or facilitators to vaccine access. A portfolio analysis on NIH funded research project grants on vaccines in FY2017-22 found 470 funded studies including populations experiencing health disparities. There were few studies on mechanisms and interventions to promote vaccine updates, but instead focused on

vaccine development and response to vaccines. NIH funded 45 grants for three different types of studies: vaccine intervention, the etiology of vaccine uptake, and the Rapid Acceleration of Diagnostics-Underserved Populations (RADx-UP) initiative. NIMHD issued three Notices of Special Interest (NOSIs) on community-based interventions promoting vaccine uptake during FY21-23 and has funded 12 R01 grants through these NOSIs, however most studies focused on vaccine uptake among adults and NIMHD would like to expand its research on other vaccines and all ages. Several studies are working within the community or through community-based organizations, but few studies have focused on American Indians/Alaska Natives, SGM individuals, groups with intersecting minority status, as well as children and parents.

Critical gaps persist among populations experiencing health disparities and Dr. Linares proposed an initiative to solicit multidisciplinary projects examining mechanisms and interventions at multiple levels to promote vaccine uptake in those groups. Intervention studies in the initiative would involve community-engaged and culturally tailored approaches at a systems level in various settings, especially healthcare, to address barriers to vaccine access, with the potential to utilize digital interventions and artificial intelligence. Potential research topics may include evaluations of the effectiveness and optimal timeframe for policy-based and community-based interventions to promote vaccine uptake in community settings and front-line clinical sites.

Dr. Resnicow suggested that studies on single level factors influencing vaccine hesitancy may occasionally be appropriate and that research may be warranted on whether the COVID-19 vaccine has specific barriers to vaccine uptake that other vaccines do not possess. He also pointed out the difference between African Americans who initially occupied a "wait and see" category regarding vaccination that eventually ended up receiving the vaccine in large numbers, and White Americans who were more heavily loaded into the "never ever" category who still mostly refuse to be vaccinated. Dr. Trinh-Severin appreciated the emphasis on multilevel, multidomain interventions that proved effective during the pandemic and the inclusion of studies on social media's role in quickly spreading disinformation and misinformation reducing trust in vaccines. In the post-pandemic phase, there is a heightened mistrust of science, particularly among minoritized populations, and encouraging strong community-engagement programs is key. Dr. Trinh-Severin also said that disaggregating data in the Asian and Native Hawaiian and Pacific Islander category may reveal distinctions within ethnic subpopulations.

Dr. Trinh-Severin made a motion to support moving the concept forward for funding opportunity announcement (FOA) development. Dr. Barnes seconded the motion. The council passed the motion unanimously.

**Interventions to Reduce Sleep Health Disparities; Presenter: Dr. Arielle Gillman**

<https://videocast.nih.gov/watch=49533&start=12685>

The objective of the proposed initiative is to support the development and testing of multilevel, multidomain, non-pharmacological interventions to promote sleep health, reduce sleep health

disparities, and examine sleep as a modifiable factor to reduce health disparities for other health outcomes. Sleep deficiencies, which include insufficient or long sleep duration, poor sleep quality, irregular timing of sleep, and circadian disorders, are disproportionately distributed among populations that experience health disparities and are influenced by social determinants of health. From 2017 to 2022, NIMHD collaborated with various other ICs at NIH to promote mechanistic and observational sleep health disparities research through PAR-17-234/235 which were reissued as PAR-20-164. These funding opportunities promoted research to understand the underlying causes of sleep health disparities in populations experiencing health disparities with a focus on how social determinants of health influence sleep and distal health outcomes. 24 grants were funded across NIH ICs, nine of which were funded by NIMHD. In 2018, NIMHD in collaboration with the National Heart, Lung, and Blood Institute (NHLBI) and the Office of Behavioral and Social Sciences Research (OBSSR) held a workshop to identify strategies to address sleep health disparities. A portfolio analysis of sleep interventions funded across NIH from 2018 to 2022 showed that less 20% focused on populations experiencing health disparities with some groups not represented at all, and that three-fourths focused on adults even though sleep disparities emerge as early as very early childhood.

Interventions in this initiative must focus on one or more NIH-designated population that experiences health disparities and the dissemination of information discovered to those communities is to be encouraged. The initiative emphasizes non-pharmacological interventions that focus on modifying social, behavioral, environmental, and structural determinants of health. Study topics may include methods to encourage healthy sleep behavior or treat specific sleep disorders like insomnia or sleep apnea. Interventions should consider work, family, and community context, as well as age and comorbidities, and they should also consider multiple facets of sleep health, such as quality, quantity, efficiency, and timing. Finally, interventions should be built upon a theoretical or conceptual model and clearly articulate and examine the mechanisms by which the intervention influences the health outcomes of interest. Some research priorities may include evaluation of policies and practices that promote healthy sleep; evidence-based, culturally appropriate interventions for specific vulnerable populations across the lifespan or at key transition points; or investigations on sleep as primary prevention for negative physical and mental health outcomes for people with observed health disparities.

Dr. Elliott commended the initiative's specific targeting of sleep as a primary means of intervention to affect other health outcomes. One item that will be important to consider as the concept is developed is that research on sleep interventions must occur outside of normal appointment hours, and Dr. Elliott wondered whether other entities like home visitation programs may be able to integrate such interventions into their service delivery models. Dr. Johnson said it was important that the research is not solely focused on the proximal outcomes of increased sleep duration or improved sleep quality but also on the distal measures of health outcomes for people experiencing health disparities and patients for whom there are an intersection of contextual factors, such as shift work and comorbidities.

Dr. Elliott made a motion to support moving the concept forward for FOA development. Dr. Johnson seconded the motion. The council passed the motion unanimously.

## **Healthcare Worker Burnout in Populations Experiencing Health Disparities; Presenter:**

**Dr. Carolina Solis Sanabria**

<https://videocast.nih.gov/watch=49533&start=13640>

The goals of this initiative are to (1) understand the etiological factors contributing to healthcare worker well-being and workforce challenges in settings serving populations that experience health disparities; (2) support research that evaluates the impact of healthcare worker burnout on the health of these populations and the mechanisms through which this impact occurs; and (3) support targeted multi-level interventions that address workforce challenges and promote well-being in healthcare settings and facilities serving these populations. These factors may exacerbate healthcare worker burnout, an occupational syndrome characterized by a high degree of emotional exhaustion, depersonalization, and a low sense of personal accomplishment at work. Although COVID-19 worsened the situation, burnout is an issue pre-existing the pandemic, with 35-54% of nurses and physicians and 45-60% of medical students and residents reporting symptoms of burnout to the National Academies of Medicine prior to the arrival of the virus. A portfolio analysis of grants showed that only two of the nine burnout-related grants awarded by NIH pertained to health disparities; both were funded by NIMHD, and both were LRP grants by the same PI about the impact of burnout on health outcomes.

This initiative will focus on research involving longitudinal studies, clinical trials, natural experiments, mixed-methods, quasi-experimental designs, and quality improvement studies that focus on understanding the impact of and addressing the workforce challenges of physicians, nurses, social workers, mental health care workers, and any other clinicians having direct patient care interactions with populations experiencing health disparities. Research priorities for this initiative could include studies on the extent and impact of burnout and staff shortages on clinical and disease outcomes, quality of care, access to care, and utilization of healthcare services for populations experiencing health disparities; developing measurements for burnout and examining burnout levels from before and after the pandemic; evaluating organizational and policy-level interventions to burnout and multi-level interventions; and, studies evaluating the impact of burnout on healthcare workers who are themselves members of populations experiencing health disparities, as well as protective factors associated with healthcare worker well-being.

Dr. Johnson recommended providing examples of measurements of well-being and burnout to point investigators towards what they should operationalize or use in thinking about those concepts. Dr. Johnson also appreciated the focus on the healthcare settings in the initiative, such as safety net facilities and community hospitals, and the scope of their operation (inpatient, outpatient, and primary care,). Dr. Calman applauded the broad nature of the concept but objected to the overemphasis on the term of burnout, which belies the systemic issues in healthcare that are the true causes of the workforce problems, including healthcare provider burnout. There is also the issue of less experienced staff being hired at safety net hospitals, acquiring experience, and then leaving for less taxing and more lucrative employment at other institutions. Many of these issues stem from staff turnover and the



underinvestment in those who provide care to those without health insurance and Medicaid recipients. Dr. Calman suggested including the economics of the healthcare system as part of the etiological factors to be researched through this initiative. Dr. Trinh-Severin offered the reminder that small ethnic clinical practices are often the clinicians who care for immigrant populations and may be appropriate subjects of study for research on different healthcare settings and facilities.

Dr. Johnson made a motion to support moving the concept forward for FOA development. Dr. Calman seconded the motion. The council passed the motion unanimously.

### **Closing Remarks and Adjournment**

Retiring council members offered brief reflections of their time serving on NACMHD and, after closing remarks,

Dr. Pérez-Stable adjourned the meeting at 2:11 p.m.

#### **END NOTE: REVIEW OF GRANT APPLICATIONS\_ CLOSED SESSION:**

This portion of the meeting was closed to the public in accordance with the determination that it was concerned with matters exempt from mandatory disclosure under sections 552b(c)(4) and 552b(c)(6), Title 5 U.S.C., and section 1009(d) of the Federal Advisory Committee Act, as amended (5 U.S.C. §§ 1001-1014).

Dr. Pérez-Stable called the Closed Session to order at 1:00 pm, May 22, 2023. Dr. Cotton led the second level review of grant applications submitted to NIMHD programs. Council Members and Staff were instructed on conflict of interest and confidentiality regulations. Members and Staff absented themselves from the meeting room and discussions for which there was a potential conflict of interest, real or apparent. The Council considered 532 competing applications requesting an estimated \$448,851,427 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.

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Eliseo J. Pérez Stable, M.D. Date

Director

National Institute on Minority Health and Health Disparities, NIH

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