

**Department of Health and Human Services**  
**National Institutes of Health**  
**National Institute of Nursing Research**  
**Minutes of the National Advisory Council for Nursing Research**

January 24–25, 2017

The 91<sup>st</sup> meeting of the National Advisory Council for Nursing Research (NACNR) was convened on Tuesday, January 24, 2017, at 1:00 p.m. in Conference Room 6, Building 31, National Institutes of Health (NIH), Bethesda, Maryland. The first day of the meeting was an open session and adjourned that same day at 4:45 p.m. The closed session of the meeting, which included consideration of grant applications, was convened on Wednesday, January 25, 2017, at 9:00 a.m. and continued until adjournment at 1:00 p.m. Dr. Patricia A. Grady, Chair, NACNR, presided over both sessions of the meeting.

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**OPEN SESSION**

**I. CALL TO ORDER, OPENING REMARKS, COUNCIL PROCEDURES, AND RELATED MATTERS**—Dr. Patricia Grady, Director, National Institute of Nursing Research (NINR)

Dr. Grady called the 91<sup>st</sup> meeting of the NACNR to order and welcomed all Council members, visitors, and staff.

Conflict of Interest and Confidentiality Statement

Dr. Marguerite Kearney, Acting Executive Secretary, NACNR, and Director, Division of Extramural Science Programs, NINR, noted that the meeting would be recorded for purposes of the minutes and that audio recordings would be destroyed once the minutes were completed. She reminded attendees that NIH is a smoke-free campus. She asked Council members to update their addresses on the meeting roster that would be circulated during the meeting. Dr. Kearney referred to the conflict of interest and confidentiality statements provided in the Council materials and indicated that specific instructions would be provided at the beginning of the closed session on Wednesday.

Minutes of the Previous NACNR Meeting

Council members received the minutes of the September 13–14, 2016, NACNR meeting through the electronic council book (ECB). A motion to accept these minutes was made, seconded, and approved

unanimously. The approved minutes of each NACNR meeting become part of the Institute's official record and are posted on the NINR website ([www.ninr.nih.gov](http://www.ninr.nih.gov)).

#### Dates of Future Council Meetings

Council members were asked to confirm their calendars for the following meeting dates and to contact Drs. Grady and Kearney about any conflicts or expected absences.

#### 2017

May 23–24 (Tuesday–Wednesday)

September 12–13 (Tuesday–Wednesday)

#### 2018

January 23–24 (Tuesday–Wednesday)

May 15–16 (Tuesday–Wednesday)

September 11–12 (Tuesday–Wednesday)

## **II. REPORT OF THE DIRECTOR, NINR**—Dr. Patricia Grady, Director, NINR

The Director's report focused on activities and news from the Department of Health and Human Services (HHS), NIH, and NINR since the Council met in September. Highlights of Dr. Grady's report included:

**Budget Update**—Dr. Grady noted that the federal government is operating under a continuing resolution (CR) that expires April 28, 2017. That CR supports NIH and NINR at fiscal year (FY) 2016 levels until a full year appropriations bill is enacted and makes new funding available to NIH.

Dr. Grady reviewed projected budget allocations, noting that the majority of funds (74 percent) go to support extramural research. Other NINR budget allocations include the intramural program (6 percent), research management support (11 percent), and training (6 percent).

**HHS News**—Dr. Grady reported that key Presidential appointees awaiting confirmation include the nominees for HHS Secretary, Congressman Tom Price, M.D., and the administrator of the Centers for Medicare & Medicaid Services, Seema Verma.

The 21st Century Cures Act earmarks \$4.8 billion for the NIH over the next 10 years for specific initiatives including the Cancer Moonshot, the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, Precision Medicine, and Regenerative Medicine. Additional provisions of the Act include investing in the next generation of researchers; reducing administrative burden for researchers; allowing the NIH Director to require awardees to share data generated from NIH

funded research; supporting high-risk, high-reward research; conducting Eureka prize competitions to advance research and improve health outcomes for serious, high-burden disease in the United States; enhancing the rigor and reproducibility of scientific research; increasing inclusion of underrepresented populations in clinical trials; supporting the National Pediatric Research Network; and emphasizing national and global pediatric research efforts.

In September 2016, HHS issued a final rule designed to make information about clinical trials widely available to the public. The rule specifies requirements for registering certain clinical trials and submitting summary results information to ClinicalTrials.gov. The new rule expands the legal requirements for submitting registration and results information for clinical trials involving U.S. Food and Drug Administration-regulated drug, biological, and device products.

**NIH News**—Dr. Grady reported that President Trump has not announced a nominee for NIH Director. In the meantime, NIH Director Francis Collins continues to serve in that role.

Major General James K. Gilman, M.D., joined NIH as Chief Executive Officer of the Clinical Center.

NIH has issued a number of new requirements for clinical trials. Effective January 1, 2017, investigators involved in NIH-supported clinical trials and staff who design, oversee, manage, or conduct clinical trials must receive training in good clinical practice. Effective January 18, 2017, NIH-supported clinical trials must be registered at ClinicalTrials.gov within 21 days of first patient enrollment and trial results submitted to the website within one year of trial completion. Multisite studies conducting the same protocol must use a single Institutional Review Board (IRB) to carry out ethical review of proposed research; to allow institutions time for planning and implementation, the effective date of this policy has been extended to September 25, 2017.

**NINR News**—Dr. Grady acknowledged the five members of Council who are retiring this year: Drs. Cynthia Alee Barnes-Boyd, Donna Hathaway, Jillian Inouye, Bernadette Melnyk, and Marjana Tomic-Canic. She noted that Dr. Barnes-Boyd is joining the Council of Councils that advises on trans-NIH initiatives at the concept approval stage.

NINR grantee Dr. Jacquelyn Taylor has received a Presidential Early Career Award for Scientists and Engineers, the highest honor bestowed by the U.S. government to outstanding scientists and engineers in early stages their independent research careers. Dr. Taylor is principal investigator (PI) on the NINR-supported Intergenerational Blood Pressure Study to increase understanding of the effect of

psychological, environmental, and genetic factors on blood pressure in African-American women and their young children.

Recent additions to the NINR website include “Stories of Discovery” that spotlight highly productive NINR research programs; a summary of recent NINR activities related to end-of-life and palliative care (EOL/PC) research initiatives; and a series of interviews where pediatric palliative care team members share their experiences as part of the Palliative Care: Conversations Matter® campaign.

On April 25, 2017, NINR’s Intramural Program will host “Symptom Science Research: A Path to Precision Health,” a symposium that will highlight NINR’s scientific collaborations across the NIH and other organizations.

Dr. Grady announced upcoming NINR Director’s Lectures planned for spring 2017. Dr. Linda H. Aiken will present “Nursing’s Impact on Patient Outcomes” on March 2, and Dr. Kate Lorig will present on May 23.

Dr. Jessica Gill, an NIH Lasker Clinical Research Scholar and Chief of NINR’s Brain Injury Unit, is lead author on a study that identified a new biomarker that may help predict recovery time for sports-related concussions. The study, published in *Neurology*, has received a lot of attention from the media, including *Nature*, *Science*, and National Public Radio.

Dr. Grady authored “Advancing Palliative and End-of-Life Science in Cardiorespiratory Populations: The Contributions of Nursing Science,” in *Heart & Lung: The Journal of Acute and Critical Care*.

Dr. Grady mentioned a selection of NINR funding opportunities. Announcements are available at [www.ninr.nih.gov/ResearchAndFunding/DEA/OEP/FundingOpportunities/](http://www.ninr.nih.gov/ResearchAndFunding/DEA/OEP/FundingOpportunities/).

Two new Graduate Partnership Program Fellows have joined NINR’s Division of Intramural Research: Katie Edwards and Stephanie Prescott.

Dr. Grady noted that NINR Scientific Director, Dr. Ann Cashion, co-chaired the NIH Research Festival in September 2016, which included eight posters from the NINR intramural program in addition to the various activities celebrating NINR’s 30<sup>th</sup> anniversary, including release of the NINR strategic plan.

### **Training Opportunities—**

- The 2017 Summer Genetics Institute (SGI), a four-week, eight-credit-hour graduate-level program, is scheduled for June 5–30 on the NIH Campus. The application period closes March 1, 2017. The SGI includes classroom and laboratory components.
- The NINR Methodologies Boot Camp, “Precision Health: From Omics to Data Science,” August 7–11, 2017, will feature lectures by nationally and internationally known scientists, classroom discussion, and lab training. Registration will open in early April.

### **III. FUTURE RESEARCH PRIORITIES FOR MINORITY HEALTH AND HEALTH**

#### **DISPARITIES RESEARCH—**Dr. Eliseo Perez-Stable, Director, National Institute on Minority Health and Health Disparities

Dr. Perez-Stable presented an overview of the National Institute on Minority Health and Health Disparities (NIMHD), including its history, vision, and research agenda. NIMHD’s mission is to lead scientific research that advances understanding of minority health and health disparities. NIMHD supports research in minority health designed to improve understanding of the causes of and reduce health disparities in specific populations and supports training and development of a diverse scientific workforce as part of the broad NIH mandate. NIMHD priorities include defining the science of health disparities and minority health; promoting innovation from extramural scientists in these sciences that lead to R01 applications; establishing health services and research in clinical settings; and promoting diversity in the workforce.

Minority health is defined as the distinctive health characteristics and attributes of the minority racial and/or ethnic groups in the United States. A health disparity is a health difference that adversely affects disadvantaged populations, based on one or more of the following health outcomes: higher incidence or prevalence, burden of disease measured in disability-adjusted life years, premature or excessive mortality in areas where populations differ, and poorer health-related quality of life (QOL) or daily functioning using standardized measures. Health disparity populations include racial/ethnic minorities, underserved rural residents, sexual gender minorities, and those with less-privileged socioeconomic status.

Health disparities research is devoted to advancing scientific knowledge about mechanisms by which health determinants affect disparities and how this knowledge is translated into interventions to reduce disparities. Mechanisms leading to disparities include individual behaviors, lifestyle, beliefs, and response to stress; biological processes, genetics, and epigenetics; physical and cultural environment; and clinical events and health care.

Dr. Perez-Stable noted that, although social justice, good science, and common sense mandate the inclusion of diverse participants in research, all disparities populations historically are underrepresented in biomedical research. Recruiting minorities is challenging and often more resource-intensive; it requires more face time and personal messages, and minority scientists are generally better at it. NIMHD is working with NIH Chief Officer for Scientific Workforce Diversity Hannah Valentine to promote diversity within the NIH scientific workforce, where 68.6 percent of PIs in FY 2015 were white, 17.7 percent were Asian, and 2.2 percent were black or African American. NIMHD PIs that year were 50.8 percent white, 9.5 percent Asian, and 19.6 percent black or African American.

Dr. Perez-Stable outlined clinical topics of mutual interest across NIH and opportunities for synergy, including management of chronic pain; diabetes, which disproportionately affects minorities; asthma among youth; HIV/AIDS; breast and cervical cancer; pre-term birth and low birthweight; and communication. Patient-clinician communication is a critical area for study, with considerations such as racial/ethnic concordance of patients and clinicians; patients with limited English proficiency and use of qualified interpreters; cultural competence/structural racism and implicit bias; numeracy and health literacy; use of jargon; and risk communication.

NIMHD will focus on several new research areas during FY 2017: HIV- infected youth and young adults, immigrant populations, disparities in surgical care, social epigenomics, continued funding of the Caribbean initiative, sleep disparities, liver cancer (in collaboration with the National Cancer Institute and National Institute on Alcohol Abuse and Alcoholism), and research with tribal epidemiology centers, a network funded by the Indian Health Services.

Dr. Perez-Stable described recent NIMHD workshops and research institutes. Efforts to strengthen the NIMHD intramural program include recruitment of a science director and senior scientists, a proposed cohort study, and networking with other NIH intramural programs that have an interest in minority health and health disparities.

**IV. MEASURING DIVERSITY OF THE NINR-FUNDED WORKFORCE**—Dr. Nara Gavini, Chief, Office of Extramural Programs, Division of Extramural Science Programs (DESP), NINR Noting that diverse teams outperform their homogeneous counterparts, Dr. Gavini presented an overview of a systematic analysis designed to measure diversity of the NINR workforce. Self-reported gender, race, and ethnicity of NINR investigators and trainees were collected from the NIH Information for

Management, Planning, Analysis, and Coordination (IMPAC) II database and NINR data for FY 2016 and then analyzed for race diversity.

IMPAC II data were categorized by representation ratio (awards divided by eligible population, overall NIH data). White and black males were equally represented, and white and black females were overrepresented at the postdoctoral and K award levels. At the R01-equivalent level, white males were overrepresented, white females were equally represented, and black males and black females were underrepresented. Thus, race rather than gender appears to be the most significant gap in the R01 awardees.

A snapshot of the FY 2016 NINR portfolio showed a big decrease of diversity from trainees to research project grant (RPG) PIs. Race distribution across reviewers is similar between mechanisms. Training grant diversity showed an increase in the applicant-to-funding ratio (22 percent to 31 percent); however, research project grant diversity showed a decrease in the applicant-to-funding ratio (18 percent to 14 percent).

An analysis of 30-year trends in diversity within the NINR portfolio showed that the percentage of Asian trainees increased at a linear rate and the percentage of black trainees increased at a supralinear rate. For RPGs, the percentage of Asian PIs increased at a supralinear rate and the percentage of black PIs increased at a sublinear rate. Dr. Gavini concluded that diversity has good representation in the NINR training portfolio but is underrepresented in the RPG portfolio.

Dr. Gavini listed available resources to promote a diverse research workforce, including the NIH Diversity Supplement Program, the National Research Mentoring Network, and Building Infrastructure Leading to Diversity (BUILD). NINR is an integral part of targeted programs to support diversity, tracks and analyzes diversity metrics, and views diversity inclusion as a work in progress.

## **V. ANNOUNCEMENT OF VISITORS**

Dr. Grady announced the names of visitors and encouraged attendees to take advantage of the upcoming break to meet with them.

## **VI. NINR HEALTH DISPARITIES RESEARCH: CROSS-CUTTING PROGRAM AREAS—**

Dr. Mary Roary, Program Director, DESP, NINR

Dr. Roary described NINR efforts to address health disparities through training and support of nurse scientists, trans-NIH collaborations, and funding of targeted R-series and training grants. The NINR

health disparities research portfolio cuts across five core program areas: self-management, symptom science, wellness, EOL/PC, and technology and training.

Health disparities research in the self-management core includes projects on adherence to medications, strategies for controlling cardiovascular diseases and reducing risks for cancer that target patients and caregivers, and maintaining asthma control in school-aged children. An example of NINR-supported work in this area is a pilot study of the use and perceptions of mobile and wireless devices for self-monitoring eating and physical activity among rural men who have a high prevalence of cardiovascular disease, diabetes, obesity, cancer, and musculoskeletal conditions. The pilot concluded that the men's desire for daily text messages and the interactive nature of the contact is similar to outcomes of other rural technological trials, with rural adults preferring several contacts with tailored interventions.

In the area of symptom science, health disparities research projects focus on cognitive impairment, cardiac symptoms, sleep disorders, fatigue, and pain. For example, investigators developed a personal patient profile tool to test feasibility of using infographics to improve cancer outcomes of low-literate minority men who have localized prostate cancer. Study findings indicate that the graphical display does improve patient understanding of risk information.

Health disparities research within the wellness program area includes projects on prevention, risk perception, cultural adaptation, and health literacy. A sample project in this area is an interactive video game designed to reduce teen Latina sexual behavior and ultimately reduce their risk for teen pregnancy and sexually transmitted infections.

Health disparities research in the EOL/PC program area includes QOL in patients and caregivers; advanced care planning; enhancement of decision making; and use of patient navigators. For example, a nurse investigator is developing and evaluating a culturally congruent, patient-centered Advanced Care Planning intervention for Alaska Natives and American Indians.

Health disparities research in the technology and training program area includes a personalized bio-behavioral weight loss intervention for African-American women, Internet-based therapy to improve sleep in rural breast cancer survivors, and reduction of health disparities through informatics. Many of the technological grants include communication components to manage disease, including telehealth, smartphone applications, and patient monitoring.

The NINR training portfolio supports nurse scientists at all stages in health disparities research. Examples include a K01 recipient examining the influence of individual, interpersonal, and neighborhood factors on

opiate adherence in African Americans being treated for cancer pain; an F31 training recipient conducting a mixed-methods study to examine African-American family members' perceptions of the factors that influenced the EOL decision-making for their family member who recently died from advanced cancer; and a K01 recipient using community-based participatory research methods together with a randomized controlled trial to develop and test a novel community-partnered, peer-led HIV treatment adherence intervention.

Dr. Roary noted that NINR health disparities research covers a range of disorders, behavioral risk factors, and social determinants and targets racial and ethnic minorities including African Americans, Hispanics/Mexican Americans, Native Americans, and Koreans. However, gaps remain among rural and immigrant populations, those with functional disabilities, and sex and gender minority populations.

**VII. PROSTATE CANCER AND TREATMENT DECISION MAKING**—Dr. Randy Jones, Associate Professor, University of Virginia School of Nursing

Dr. Jones outlined his education and clinical background, which blends mental health and oncology under the umbrella of health disparities.

Prostate cancer is the second leading cause of cancer deaths among all men, and African-American men are nearly twice as likely to have the disease. Further, mortality is two times higher among African-American men than among whites and Hispanics. The reasons for this higher mortality appear to be multifactorial. Cultural beliefs, for example, are important determinants in cancer outcomes and decision making.

In an early study supported by the University of Virginia and NINR, Dr. Jones focused on prostate cancer screening decision-making among rural African-American men. Key themes included a lack of awareness of increased risk of prostate cancer; the importance of family in making prostate cancer screening decisions; and the importance of a trusting relationship and interaction between patient and provider.

Dr. Jones observed a need to improve relations between healthcare providers and the rural African-American community by creating a welcoming environment in which to discuss options without using medical jargon and including families in decision-making.

This work led to subsequent studies in which Dr. Jones developed and evaluated a culturally sensitive decision aid with patients with advanced prostate cancer. The decision aid was shown to help patients better understand treatment decisions and to help patients and their support persons be more involved in

their treatment. Dr. Jones observed that patients valued frequent contact with the study nurse; QOL was deemed more important than quantity of life; and contact with providers influenced decisions.

Dr. Jones has submitted an R01 application to support a multi-arm, multisite randomized controlled study to test the decision aid with patients diagnosed with advanced prostate cancer, a support person, and a community health worker.

Dr. Jones briefly outlined his plans to continue his program of research and involve junior faculty at all levels along with the community. In addition, he continues to serve on interdisciplinary boards to enhance healthcare, research, and collaborations.

**VIII. REVIEW OF THE STATEMENT OF UNDERSTANDING**—Dr. Marguerite Kearney, Acting Executive Secretary, NACNR, and Director, Division of Extramural Science Programs, NINR

Dr. Kearney invited Council members to comment on the Statement of Understanding, which was provided in the electronic Council book. The Statement is a roadmap for how the Council operates and is reviewed annually.

**IX. ADJOURNMENT**—Dr. Patricia Grady, Director, NINR

Dr. Grady thanked participants and attendees and adjourned the open session of the meeting at 4:45 p.m.

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**CLOSED SESSION**

This portion of the meeting was closed to the public in accordance with the determination that this session concerned matters exempt from mandatory disclosure under Sections 552b(c)(4) and 552b(c)(6), Title 5, U.S. Code, and Section 10(d) of the Federal Advisory Committee Act, as amended (5, USC Appendix 2). Members absented themselves from the meeting during discussion of and voting on applications from their own institutions or other applications in which there was a potential conflict of interest, real or apparent. Members were asked to sign a statement to this effect.

**REVIEW OF APPLICATIONS**

NACNR members considered 132 research and training grant applications on which NINR was the primary Institute; these applications requested a total of \$38,550,496 (direct costs year 01). The Council also considered 348 applications on which another Institute/Center was primary and NINR was

secondary. These applications requested a total of \$119,397,882 (direct costs year 01). The Council concurred with the IRG recommendations on these 480 applications.

## **ADJOURNMENT**

The 91<sup>st</sup> meeting of the NACNR was adjourned at 1:00 p.m. on January 25, 2017.

## **CERTIFICATION**

I hereby certify that the foregoing minutes are accurate and complete.

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Patricia A. Grady, Ph.D., R.N., F.A.A.N.

Chair

National Advisory Council for Nursing Research

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Marguerite Kearney, Ph.D., R.N., F.A.A.N.

Acting Executive Secretary

National Advisory Council for Nursing Research

## **COUNCIL MEMBERS PRESENT**

Dr. Patricia Grady, Council Chair  
Dr. Marguerite Kearney, Executive Secretary  
Dr. Cynthia Barnes-Boyd  
Dr. Kathryn Bowles  
Dr. Aaron G. Buseh  
Mr. James Corbett  
Dr. George Demiris  
Dr. Donna Hathaway  
Dr. Jennifer Hatzfeld, Ex Officio  
Dr. Jillian Inouye  
Dr. Deborah Koniak-Griffin  
Dr. Bernadette Melnyk  
Dr. Rita Pickler  
Dr. Nancy Redeker  
Dr. Alexa Stuijbergen  
Dr. Jennifer Temel

## **MEMBERS OF THE PUBLIC PRESENT**

Dr. Whitney Boyd, Rush University  
Ms. Emilia Flores, University of Pennsylvania  
Dr. Rosa M. Gonzalez-Guarda, Duke University  
Dr. Randy Jones, University of Virginia  
Ms. Sue Keim, University of Pennsylvania  
Ms. Kathy Sedgwick, NOVA Research Company  
Dr. Ellen Tilden, Oregon Health & Science University  
Dr. Christina Whitehouse, University of Pennsylvania

## **FEDERAL EMPLOYEES PRESENT**

Dr. Lynn Adams, NINR/NIH  
Dr. David Banks, NINR/NIH  
Ms. Melissa Barrett, NINR/NIH  
Mr. Nathan Brown, NINR/NIH  
Dr. Yvonne Bryan, NINR/NIH  
Dr. Ann Cashion, NINR/NIH  
Dr. Sheila Cox Sullivan, VA  
Dr. Ana Diallo, NINR/NIH  
Dr. Augie Diana, NINR/NIH  
Dr. Mary B. Engler, NINR/NIH  
Ms. Alison Evans  
Ms. Ana Ferreira, NINR/NIH  
Dr. John Grason, NINR/NIH  
Dr. Nara Gavini, NINR/NIH  
Dr. Michelle Hamlet, NINR/NIH  
Dr. Wendy Henderson, NINR/NIH  
Dr. Rebecca Henry, NINR/NIH  
Dr. Karen Huss, NINR/NIH  
Mr. G. Douglas Hussey, Jr., NINR/NIH  
Ms. Deborah Jennings, NINR/NIH  
Dr. Peter G. Kaufmann, NHLBI/NIH  
Dr. Karen Kehl, NINR/NIH  
Ms. Mary A. Kelly, NINR/NIH  
Ms. Diane Kuszewski, NINR/NIH  
Dr. Weiqun Li, NINR/NIH  
Dr. Martha Matocha, NINR/NIH  
Ms. Margie McCambridge, NINR/NIH  
Dr. Arthur Meltzer, NINR/NIH  
Dr. Jeri Miller, NINR/NIH  
Dr. Ananya Paria, NINR/NIH  
Dr. Mary C. Roary, NINR/NIH  
Dr. Becky Roof, NINR/NIH  
Dr. Louise Rosenbaum, NINR/NIH  
Ms. Marisa Sheelor, NINR/NIH  
Dr. Pamela Tamez, NINR/NIH  
Dr. Lois Tully, NINR/NIH  
Mr. Kevin G. Wilson, NINR/NIH  
Mr. Ajay K. Yadava, NINR/NIH  
Dr. Sung “Sarah” Yoon, CSR/NIH