

**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 29–30, 2019

The 97<sup>th</sup> meeting of the National Advisory Council for Nursing Research (NACNR) was convened on Tuesday, January 29, 2019, at 1:00 p.m. in Conference Room D, Building 45, National Institutes of Health (NIH), Bethesda, Maryland. The first day of the meeting was an open session and adjourned that same day at 3:55 p.m. The closed session of the meeting, which included consideration of grant applications, was convened via WebEx on Wednesday, January 30, 2019, at 9:00 a.m. and continued until adjournment at 1:00 p.m. Dr. Ann Cashion, Acting 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. Ann Cashion, Acting Director, National Institute of Nursing Research (NINR)

Dr. Cashion called the 97<sup>th</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 4–5, 2018, NACNR meeting via 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 Dr. Kearney about any conflicts or expected absences.

#### 2019

May 21–22 (Tuesday–Wednesday)

September 17–18 (Tuesday–Wednesday)

#### 2020

January 14–15 (Tuesday–Wednesday)

May 19–20 (Tuesday–Wednesday)

September 15–16 (Tuesday–Wednesday)

## **II. REPORT OF THE DIRECTOR, NINR—Dr. Ann Cashion, Acting 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. Cashion’s report included:

**Budget Update**—Dr. Cashion reviewed recent appropriations history. Funding for Fiscal Year (FY) 2019 has been in place for NIH and most of HHS since September 2018. NINR received a 3.1 percent increase and NIH, an increase of nearly 5 percent, much of which was allocated to large initiatives such as Brain Research through Advancing Innovative Neurotechnologies (BRAIN), Alzheimer’s disease (AD) research, and the “All of Us” program.

NINR distribution of funds for FY2018 (the most recent completed FY) shows the Institute’s strong commitments to training and investigator-initiated research.

**HHS and NIH News**—Dr. Cashion reported that Dr. Stephen Katz, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), passed away suddenly in December.

Dr. Robert Carter has been named Acting Director of NIAMS. Dr. Bruce J. Tromberg has joined NIH as the new Director of the National Institute of Biomedical Imaging and Bioengineering (NIBIB).

NIH has announced new funding opportunities for Basic Experimental Studies Involving Humans; that is, studies that meet the definition of basic research and also are subject to clinical trials policies based on the NIH definition of a clinical trial.

More than 30 new NIH funding announcements have been released to solicit innovative research ideas through the NIH HEAL (Helping to End Addiction Long-term) Initiative, a trans-agency effort to speed solutions to stem the national opioid public health crisis.

NIH, the African Academy of Sciences, and the Bill & Melinda Gates Foundation are collaborating to fund the African Postdoctoral Training Initiative, which is designed to build research capacity in African countries and develop ongoing scientific partnerships. Ten scientists have been selected for training at NIH. NINR is hosting Dr. Markos Tesfaye Woldeyohannes, who will be working with Dr. Paule Joseph and continuing the collaboration after his return to Africa.

Dr. Cashion mentioned a selection of NIH funding opportunities in which NINR participates; topics include diet and physical activity assessment methods, improving patient adherence to treatment and prevention regimens, early-stage clinical trials for AD and age-related cognitive decline, and self-management of chronic pain. Announcements are available at <http://grants.nih.gov/grants/guide>.

**NINR News**—Dr. Cashion acknowledged three Council members who will be retiring after the January 2019 Council meeting: Dr. George Demiris, University of Pennsylvania; Dr. Alexa Stuijbergen, University of Texas at Austin School of Nursing; and Dr. Jennifer Temel, Harvard Medical School/Massachusetts General Hospital/Dana-Farber.

Dr. Colleen Conway-Welch, founder of the Friends of NINR, died in October following a battle with cancer. Long-time Dean of the Vanderbilt University School of Nursing, Dr. Conway-Welch was nationally recognized for encouraging innovative ways to utilize nurses to improve healthcare.

Upcoming NINR Director's Lectures will feature Dr. Arlene Butz (March 7) and Dr. Eun-Ok Im (April 25). Videos of the fall 2018 Director's Lectures—Dr. Ann Marie McCarthy (September 25) and Dr. Christopher Lee (November 14)—are available on the NINR YouTube channel.

Dr. Cashion presented the Gawlinski Research Scholar Award Lecture at the UCLA Research and Evidence-Based Practice Conference. She highlighted the unique role of nursing science in addressing the needs of individuals, families, and communities to improve health and quality of life.

NINR-funded T32 Program Directors from 14 universities held their first meeting in September to exchange information and discuss training pipeline concerns, recruitment and retention of diverse candidates, individualized development plans, and plans for future T32 discussion.

On January 10, 2019, the National Academies of Science, Engineering and Medicine Roundtable on Quality Care for People with Serious Illness released proceedings of a public workshop on integration of healthcare and social services for people with serious illness. Dr. Jeri Miller, Chief of NINR's Office of

End-of-Life and Palliative Care Research, moderated the session “Providing Supportive Services: Exploring the Key Role and Unique Needs of Caregivers” with panel speakers that included several NINR-affiliated researchers.

NINR has created an online Pediatric Palliative Care Toolkit to encourage healthcare providers to give presentations to their colleagues highlighting Palliative Care: Conversations Matter® materials. In addition, the Conversations Matter® provider tear-off pad has been updated to reflect the most recent research, terminology, and practices; the revised publication is available in English and Spanish.

A new NINR informational brochure outlines the role of nursing science, describes the Institute, and provides examples of NINR-supported science. The brochure is available on the NINR website.

In December 2018, NINR participated in a site visit for scientific review of the NINR Division of Intramural Research (DIR), which supports rigorous research on symptom science that complements extramural community efforts.

A video exploring the work of NINR Deputy Scientific Director Jessica Gill to identify those at risk for ongoing complications from traumatic brain injury is available on NINR’s YouTube channel.

NINR partnered with the Safe to Sleep® campaign to update a continuing education activity for nurses, “Risk Reduction for Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death.” The activity explains ways nurses can communicate risk-reduction messages to parents and caregivers and describes modeling safe infant sleep practices.

In October, NINR funded five new Centers: three P20 Exploratory Centers and two P30 Centers of Excellence. The P20 Centers are the Center for Advancing Multimorbidity Science: Profiling Risk and Symptom Expression to Develop Customized Therapies for Adults with Multiple Chronic Conditions (CAMS) at the University of Iowa, the Exploratory Center for Precision Health in Diverse Populations at New York University, and the Center for Improving Palliative Care for Vulnerable Adults with MCC (CIPC) at Columbia University. The P30 Centers of Excellence are The Center for the Study of Symptom Science, Metabolomics and Multiple Chronic Conditions at Emory University and the Hopkins Center to Promote Resilience in Persons and Families Living with Multiple Chronic Conditions (the PROMOTE Center) at the Johns Hopkins University.

**NINR-Funded Science Advances**— Dr. Cashion highlighted recently published findings from research conducted by NINR extramural grantees in cardiovascular health, hypertension, pain, and sleep apnea. Secondary outcomes of depression and fatigue improved in a multisite randomized clinical trial (RCT) comparing collaborative versus usual care in patients with chronic heart failure. Another study reported evidence that diet quality plays an important, independent role in heart failure outcomes. A study

concluded that perceived discrimination appears to heighten levels of inflammation before and after acute stress exposure in women at risk for cardiovascular disease. A randomized, double-blind crossover intervention study reported that short-term use of a portable air filtration system reduced personal exposure to particulate matter in the air and reduced systolic blood pressure among older adults living in typical U.S. urban areas. A communication study focused on chronic pain and opioids showed that training programs that help physicians negotiate disagreements about pain management have potential to improve visit experience ratings for patients and physicians. An investigation of hippocampal sub-regional injury in obstructive sleep apnea showed lateralized and sex-specific regional volume differences that may contribute to sex-related expression of symptoms in the sleep disorder.

Dr. Cashion noted the range of NINR-sponsored funding opportunities includes obesity, telomeres, tailored palliative and end-of-life care, and addressing caregiver symptoms. Funding announcements are available at [www.ninr.nih.gov/ResearchAndFunding/DEA/OEP/FundingOpportunities/](http://www.ninr.nih.gov/ResearchAndFunding/DEA/OEP/FundingOpportunities/).

**NINR Training Opportunities**—Dr. Cashion described two upcoming NINR training activities: the Summer Genetics Institute (June 3–28, 2019), the NINR Methodologies Boot Camp (July 15–29, 2019) “Precision Health: Smart Technologies, Smart Health.”

**Staff News**—Dr. Cashion announced that Dr. Marguerite Kearney is retiring from federal service at the end of the week and thanked her for her contributions to NINR; Dr. Kearney has led NINR’s Division of Extramural Science Programs (DESP) since 2015. Dr. Pamela Tamez has been named Training Director in the DIR Office of Training Program. The search for an NINR Director is ongoing, with a goal of having the position filled by September 1, 2019.

**III. OVERVIEW OF THE NINR TECHNOLOGY SCIENCE PORTFOLIO**—Dr. Augie Diana, Program Director, NINR [coordinates NINR SBIR and STTR]

Dr. Diana presented an overview of the NINR technology science portfolio, including the Small Business Innovation Research (SBIR) and Small Technology Transfer Research (STTR) grant programs.

NINR’s Innovative Questions (IQ) initiative identified several areas of technology-focused research, including mechanisms by which innovative technologies (robots, games, avatars) can be used to facilitate behavior change and decrease burden of illness and how IT can promote health behavior change and reduce disease risk by engaging individuals to reinforce health care provider messages. Current NINR technology-specific program announcements (PAs) include mHealth tools for chronic conditions, self-management interventions, and technology designed to enhance patient outcomes, address caregiver symptoms, attenuate cognitive decline, and optimize functional capabilities.

NIH SBIR/STTR funding aims to stimulate technological innovation, use small business to meet federal research and development needs, and increase private-sector commercialization of innovations derived from federal research and development. Each year, NIH Institutes provide a list of Institute priorities in the small business and technology areas; in the case of NINR, topics are selected in consultation with NINR Program staff and leadership.

Examples from the NINR technology portfolio include a fully-automated face and body skeleton tracking system aimed toward developing a method for pain detection and assessment; in-home sensing technologies for early detection of health changes during aging to support functional independence, improve self-management of chronic or acute conditions, and improve quality of life; Type 2 Diabetes education and support in a virtual environment; a pneumatically-actuated power-assist walker robotic platform; and a computer-vision-based active learning co-robot wheelchair.

Current priority areas of need include assessment and management of symptoms, enhancement of self-management and clinical care, health promotion and disease prevention, and end-of-life and palliative care.

#### **IV. ANNOUNCEMENT OF VISITORS**

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

#### **V. DEVELOPMENT OF NOVEL, BIOPHYSICALLY DESIGNED FLUIDS FOR SWALLOWING DISORDERS**—Dr. JoAnne Robbins, Professor Emerita, University of Washington School of Medicine and Public Health; Mr. Eric Horler, President and CEO, Swallow Solutions

Dr. Robbins presented an overview of her work with swallowing disorders and efforts to move research from the lab into patients' hands via a ladder of scientific funding formed by NIH and the Veterans Administration.

Swallowing disorders are a growing global health problem lacking in diagnostic and treatment methods. The effects of these disorders lead to malnutrition and dehydration, pneumonia, reduced rehabilitation potential, and increased hospital stays. Dr. Robbins' research addressed lack of diagnostic and treatment standards, beverage rheology studies, and product acceptability necessary to support patient adherence. The increased need for protein among seniors led to identification of whey protein as easier, and faster to break down. Ultimately, Dr. Robbins and her team developed biophysically designed beverages for people with dysphagia that create “matched” standards for diagnosis and treatment and address

sarcopenia. Based on research, the beverages are safe for individuals with mild to severe dysphagia, appropriate as a primary source of hydration and as a protein supplement, and offer excellent sensory attributes for adherence without artificial colors, flavors, or sweeteners.

Mr. Horler described key considerations for commercializing a product. Developers must find a way to get their product to patients so that the research makes a difference; build understanding of the market, distribution, and supply chain; and continually collect the voice of the customer through qualitative interviews, quantitative value proposition surveys, prototype studies, and formal market research.

**VI. DEVELOPMENT OF PATIENT-CENTERED TECHNOLOGIES TO PROVIDE SUPPORTIVE TREATMENT SUPERVISION**—Dr. Sarah Jo Iribarren, Assistant Professor, University of Washington School of Medicine

Dr. Iribarren summarized the trajectory of her research in mobile interventions for tuberculosis (TB) treatment adherence. Mobile interventions hold great promise as a cost-effective means for improving health outcomes and increasing patient engagement in self-management. TB treatment adherence offers an important use case due to its disproportionate impact on marginalized groups, its requirement for a long-term commitment to treatment, and decreasing treatment success rates.

Dr. Iribarren gained research experience and contextual understanding as an NIH Fogarty International Clinical Research Scholar studying TB treatment success in Buenos Aires, Argentina. She received an F31 award from NINR to develop educational messages and pilot a texting intervention, TextTB; findings demonstrated intervention feasibility and acceptability and led to improved treatment outcomes versus historic rates. A T32 postdoctoral award from NINR supported further skill development while she conducted an evaluation of the TB mobile landscape; none of the 24 mobile apps she evaluated focused on supporting patient treatment progression. To address this gap, Dr. Iribarren applied for and received a K23 award to develop and evaluate an interactive mHealth intervention to support individuals with active TB. Using principles of iterative/agile design, she aimed to convert and expand TextTB into a mobile-optimized app; refine and enhance the app with patients; and pilot an RCT. Focus groups and field testing indicated that users found the app to be useful and relevant and provided recommendations to simplify reporting, link to resources, and add interactivity with others. The app is being built in a modular fashion using open-source software components and open standards to allow for future integration into healthcare systems. Future plans include further refining the app and evaluating its impact in a pragmatic RCT

**VII. PANEL Q&A**—Drs. Diana, Iribarren, and Robbins and Mr. Horler

Council members asked presenters about the challenges of working in the technology space when technology is continually changing. Responses included: moving from one tech to the next was not

difficult; nimble software and using an agile development framework were key. A similar trajectory, translating paper or manual interventions to CD ROM, DVD, web, and now mobile—as long as there is evidence behind the intervention, was described.

Further, it was noted that grant reviewers need to see that the new technology will advance the field and applicants would be prudent to focus on adapting technology for that purpose rather than on advancing the technology for its own sake.

**VIII. REVIEW OF THE STATEMENT OF UNDERSTANDING AND REPORT ON INCLUSION OF WOMEN AND MINORITIES IN CLINICAL RESEARCH—Dr.**

Marguerite Kearney, Executive Secretary, NACNR, and Director, Division of Extramural Science Programs, NINR

Dr. Kearney drew Council attention to the Statement of Understanding. The statement outlines Council member responsibilities for grant application review. Council raised no questions regarding the statement.

Dr. Kearney summarized the *NINR Report, Monitoring Adherence to the NIH Policy on the Inclusion of Women and Minorities in Clinical Research as Reported in FY 2016 – FY 2018*. NINR must prepare and submit a report every three years.

NINR is performing per expectations in relation to sex, gender, race, and/or ethnicity. Report highlights include an increase in total enrollment for all NIH-defined clinical research from 79,618 in FY16 to 279,760 in FY18. Minority enrollment increased from 26,012 (32.7 percent) in FY 2016 to 97,471 (34.8 percent) in FY 2018. Enrollment in intramural clinical research grew from 680 in FY16 to 961 in FY 2018, reflecting increased productivity in those protocols.

A motion to approve the report was made, seconded, and approved unanimously.

**IX. ADJOURNMENT—Dr. Ann Cashion, Acting Director, NINR**

Dr. Cashion thanked meeting attendees and adjourned the open session of the meeting at 3:55 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 125 research and training grant applications on which NINR was the primary Institute; these applications requested a total of \$34,102,297 (direct costs year 01). The Council also considered 233 applications on which another Institute/Center was primary and NINR was secondary. These applications requested a total of \$96,202,454 (direct costs year 01). The Council concurred with the Institutional Review Group recommendations on these 358 applications.

## **ADJOURNMENT**

The 97<sup>th</sup> meeting of the NACNR was adjourned at 1:00 p.m. on Wednesday, January 30, 2019.

## **CERTIFICATION**

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

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Ann Cashion, Ph.D., R.N., F.A.A.N.  
Acting Chair  
National Advisory Council for Nursing Research

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Nara Gavini, PhD, MPhil  
Acting Executive Secretary  
National Advisory Council for Nursing Research

## **COUNCIL MEMBERS PRESENT**

Dr. Ann Cashion, Acting Chair  
Dr. Marguerite Kearney, Acting Executive Secretary  
Dr. Kathryn H. Bowles  
Dr. Yvette Conley  
Dr. George Demiris  
Dr. Audwin Fletcher  
Dr. Deborah Koniak-Griffin  
Dr. Ida Moore  
Dr. Shirley Moore  
Dr. Nilda Peragallo-Montano  
Dr. Rita Pickler  
Dr. Alexa K. Stuijbergen  
Dr. Jennifer Temel  
Dr. JoEllen Wilbur

## **MEMBERS OF THE PUBLIC PRESENT**

Ms. Amber Cassady, Lewis-Burke Associates LLC  
Ms. Marlena Fisher, Johns Hopkins School of Nursing  
Ms. Mary Ann Fullon, Social & Scientific Systems, Inc.

Mr. Nick Giordano, University of Pennsylvania  
Ms. Melissa Hearrell  
Mr. Eric Horler, Swallow Solutions  
Dr. Sarah Jo Iribarren, University of Washington School of Medicine  
Dr. Robert McLinden  
Dr. JoAnne Robbins, University of Washington School of Medicine and Public Health  
Ms. Kathy Sedgwick, NOVA Research Company  
Dr. Paula Tanabe, Duke University School of Medicine

#### **FEDERAL EMPLOYEES PRESENT**

Dr. Lynn Adams, NINR/NIH  
Dr. David Banks, NINR/NIH  
Ms. Catherine Blumhorst, NINR/NIH  
Mr. Nathan Brown, NINR/NIH  
Dr. Yvonne Bryan, NINR/NIH  
Dr. Edmond Byrnes, NINR/NIH  
Mr. Aaron Condon, NINR/NIH  
Dr. Augie Diana, NINR/NIH  
Ms. Ana Ferreira, 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. Doug Hussey, NINR/NIH  
Dr. Paule Joseph, NINR/NIH  
Dr. Emma Kurnat-Thoma, NINR/NIH  
Ms. Alison Lemon, NINR/NIH  
Dr. Weiqun Li, NINR/NIH  
Ms. Reena Masih, NINR/NIH  
Dr. Martha Matocha, NINR/NIH  
Dr. Jeri Miller, NINR/NIH  
Ms. Cathy Mutta, NCI/NIH  
Dr. Cheryl Nordstrom, CSR/NIH  
Dr. Ananya Paria, NINR/NIH  
Dr. Rebekah Rasooly, NINR/NIH  
Dr. Louise Rosenbaum, NINR/NIH  
Dr. Pamela Tamez, NINR/NIH  
Dr. Lois Tully, NINR/NIH  
Mr. Kevin G. Wilson, NINR/NIH  
Dr. Sue Wingate, NINR/NIH  
Dr. Lichen Xiang, NINR/NIH