

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

May 20–21, 2014

The 83rd meeting of the National Advisory Council for Nursing Research (NACNR) was convened on Tuesday, May 20, 2014, 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 5:00 p.m. The closed session of the meeting, which included consideration of grant applications, was convened on Wednesday, May 21, 2014, 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.

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 83rd meeting of the NACNR to order, and welcomed all Council members, visitors, and staff. She introduced three new Council members: Mr. James Corbett, Dr. Nancy Redeker, and Dr. Meredith A. Rowe. Council members Drs. Rowe, Schoneboom, Lyder, and Tomic-Canic were absent. Dr. Alt-White was absent for the open session but was available for the closed session.

Conflict of Interest and Confidentiality Statement

Dr. Ann Knebel, Executive Secretary, NACNR, and Deputy Director, NINR, noted that NIH is a smoke-free campus. She stated that the meeting would be recorded for purposes of the minutes and that audio recordings would be destroyed once the minutes were completed. Dr. Knebel informed the Council that the presentations were being videotaped and would be posted on the NINR website (www.ninr.nih.gov). She asked Council members to update their addresses on the meeting roster that would be circulated during the meeting. Dr. Knebel reminded the Council that they cannot participate in any lobbying activities while receiving pay from the federal government, and that the complete conflict of interest statement is available to Council members in their meeting materials.

Minutes of the Previous NACNR Meeting

Council members received the minutes of the January 13–14, 2014, NACNR meeting through the Electronic Council Book. 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 permanent record and are posted on the NINR website (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 or Knebel about any conflicts or expected absences.

2014

September 16–17 (Tuesday-Wednesday)

2015

January 27–28 (Tuesday-Wednesday)

May 19–20 (Tuesday-Wednesday)

September 15–16 (Tuesday-Wednesday)

2016

January 26–27 (Tuesday-Wednesday)

May 24–25 (Tuesday-Wednesday)

September 13–14 (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 last Council meeting. Highlights included:

Budget Update—Dr. Grady reviewed recent appropriations history from Fiscal Year (FY) 2013 to the FY2015 President’s Budget. NINR received a 2.4 percent increase from FY2013 levels to its budget in FY2014; NIH had a 2.3 percent increase. Dr. Grady reviewed NINR’s pattern of budget allocation. The President’s Budget for FY2015 keeps funding at FY2014 levels.

HHS News—Sylvia Mathews Burwell has been nominated to become the next HHS Secretary.

HHS' new Global Partnership Against Infectious Diseases serves to prevent, detect, and respond to infectious disease threats on a global level. It establishes national biosecurity systems, public health electronic reporting, and emergency operation centers in countries. HHS released an interactive video to protect research subjects and reduce misconduct (<http://ori.hhs.gov/TheResearchClinic>). A progress report on the status of the 26 leading health indicators identified in *Healthy People 2020* was released in March 2014. There have been improvements in ten of the health indicators. HHS has released the Alzheimer's disease report, which outlines the magnitude of Alzheimer's disease, progress, and promising approaches to address and treat the disease.

NIH News—Dr. Hannah Valentine has been named NIH's first Chief Officer for Scientific Workforce Diversity. NIH has launched the Accelerating Medicines Partnership with several leading pharmaceutical organizations to accelerate work toward developing drugs for chronic diseases such as Alzheimer's disease, type 2 diabetes, lupus, and rheumatoid arthritis. Senator Barbara Mikulski, Chairwoman of the Senate Appropriations Committee, visited the NIH campus. She has taken an active interest in NIH's research activities. NIH celebrated the grand opening of the John Edward Porter Neuroscience Research Center. Dr. John Ruffin, Director of National Institute of Minority Health and Health Disparities (NIMHD), has retired from NIH. Dr. Yvonne Maddox is currently Acting Director of NIMHD; the Institute is searching for a permanent Director.

NIH revised its grant application resubmission policy. Unsuccessful resubmissions (A1) now may be submitted as a new grant (A0) application. The new application does not need to demonstrate substantial redesign in content and scope. The NIH Intramural Research Program has been conducting long-range planning. More details can be found at: <http://irp.nih.gov/>. Dr. Grady highlighted selected NIH-sponsored funding initiatives.

NINR News—Dr. Grady welcomed three new Council members, Mr. Corbett, and Drs. Dowling and Rowe, and recognized the service of the three retiring members, Drs. Dowling, Freeman, and Larson. Dr. Grady highlighted recent NINR activities since January 2014, including the Center for Practical Bioethics' meeting "The State of Palliative Care Across Settings: What Can We Do Together?" and the Aging and Disability Federal Partners Working Group meeting. NINR representatives at recent regional meetings: Southern Nursing Research Society, Midwest Nursing Research Society, Western Institute of Nursing, and Eastern Nursing Research Society. The National Nursing Research Roundtable was held March 6–7, 2014, and focused on the science of caregiving. A meeting summary is being prepared. Dr.

Barbara J. Drew's 2014 NINR Director's Lecture, "Electrocardiographic Monitoring: Two Decades of Discovery," will be posted on the NINR website.

Dr. Grady and Dr. Lisa Lucio Gough's paper "Self-Management: A Comprehensive Approach to Management of Chronic Conditions" was accepted by the *American Journal of Public Health* on April 10, 2014. The article focuses on ways to advance research methods and practical applications of self-management as an approach for treating chronic conditions. Dr. Grady provided brief updates on NINR's partnerships with the NIH Office on Women's Health and the Administration for Community Living.

The NIHSeniorHealth.gov End of Life module provides a resource for aging populations. NINR's pediatric palliative care campaign, Palliative Care: Conversations Matter™, raises awareness of pediatric palliative care and helps patients and health care professionals discuss palliative care earlier.

The Institute's Innovative Questions: Shaping the Future of Nursing Science initiative (<http://ninr.nih.gov/iq>) is engaging the nursing research community to develop questions to focus and further define NINR's scientific agenda. NINR is interested in thoughts and ideas that will encourage new thinking and creativity in nursing science, explore unanswered questions, promote results-oriented research, and guide the science over the next five to ten years. Questions have been posted for the first three workshops: symptom science, wellness, and self-management. An end-of-life and palliative care workshop was held earlier this month, and an innovative technology workshop will be held in June 2014.

The Friends of NINR Ambassador's Program is focused on increasing awareness of nursing research. It is a resource for policymakers concerning NINR's mission, activities, and funding.

Selected NINR funding opportunity announcements are available at:
www.ninr.nih.gov/ResearchAndFunding/DEA/OEP/FundingOpportunities/.

The following NINR staff news was noted:

- The Presidential Early Career Award for Scientists and Engineers was presented to two nurse scientists at the White House on April 14, 2014. Drs. Jessica Gill and Ida Spruiell received the award.
- Dr. Jeri Miller has been named Chief of the Office of End-of-Life and Palliative Care (OEPCR).
- Dr. Leorey Saligan received an award from the Oncology Nursing Society.
- NINR summer intern Ms. Monai Punjabi has been recognized by her home university, Rosalind Franklin University, for her work with NINR.

- Four NINR students presented at the NIH Post Baccalaureate Poster Day.
- Dr. Jessica Gill received the 2014 Distinguished Post-Bac Mentor Award.
- NINR is seeking a new director for the Division of Extramural Science Programs.

Training Opportunities—

- This year's Summer Genetics Institute (SGI) is being held June 2–27, 2014. More information can be found on the SGI website (www.ninr.nih.gov/sgi).
- The NINR Methodologies Boot Camp on Big Data in Symptoms Research will be held July 21–25, 2014 (www.ninr.nih.gov/bootcamp).
- NINR has six fellows currently participating in the Graduate Partnership Program. Ms. Uba Backojona and Ms. Kristin Filler are close to completing their programs.

III. TRANS-NIH PAIN INITIATIVE—Dr. Linda Porter, Pain Policy Advisor, Office of Pain Policy, NIH

Dr. Porter presented an overview of the Trans-NIH Pain Consortium. The NIH Pain Consortium was established in 1996 with the mission to enhance pain research and promote collaboration among researchers across the NIH Institutes and Centers (ICs) that have programs and activities addressing pain. To this end, the Pain Consortium has worked to support targeted research, expand the pain research portfolio, develop clinical research resources, increase visibility of pain research, develop training and educational tools, and apply research to crucial questions.

NIH funding in support of pain research has steadily increased from \$173 million in 2002 to \$402 million in 2013. The publically available Interagency Pain Research Portfolio database (<http://paindatabase.nih.gov>) provides information on pain research and training activities supported by NIH and other Federal Departments and Agencies. Dr. Porter highlighted targeted NIH Pain Consortium funding initiatives.

The Pain Consortium supports 12 NIH-funded Centers of Excellence in Pain Education (CoEPEs) to develop, evaluate, and distribute pain management curriculum resources for medical, nursing, dental, and pharmacy schools to enhance and improve the way health care professionals are taught about pain and the treatment of pain.

The NIH Pain Consortium has partnered with Stanford University on the development of an open-source, centralized pain registry for tracking self-reported outcomes of chronic pain sufferers over time. Registry

data are free and accessible to investigators for outcomes research, comparative effectiveness research, and point-of-care decision-making. Data definitions and standards are being developed in conjunction with the NIH-funded Patient Reported Outcomes Measurement Information System. Full rollout of the registry is targeted for late 2014.

The Chronic Low Back Pain Research Task Force was established to create consistent standards for terminology, classification, data collection, and outcome assessment, and to bring greater consistency to, and ultimately advance, the state of clinical research on low back pain. In April 2014, the Task Force began to release publications on its work, including a definition of chronic low back pain and a uniform minimal data set based on the National Institute of Neurological Diseases and Stroke Common Data Elements. A full report with recommendations on standards was published April 28, 2014, in *The Journal of Pain*.

Dr. Porter reviewed recent conferences sponsored by the NIH Pain Consortium. In 2013, the NIH Pain Consortium Symposium focused on integrated self-management strategies for chronic pain. The 2014 Symposium focus is on the biological and psychological factors that contribute to chronic pain. The 2014 NIH Pathways to Prevention workshop on The Role of Opioids in the Treatment of Chronic Pain, will be held September 29–30, 2014.

The Interagency Pain Research Coordinating Committee (IPRCC) was established to coordinate all efforts within the Department of Health and Human Services and other federal agencies that support research related to pain. The IPRCC and NIH were tasked with addressing core recommendation 2.2 of the *2011 IOM Report: Relieving Pain in America*. To ensure the development of an integrated strategy with practical goals, the IPRCC created an Oversight Panel to coordinate and integrate the efforts of five focused working groups. The working groups are structured to address the objectives outlined in the IOM report that relate to recommendation 2.2.

IV. NINR SYMPTOM SCIENCE PORTFOLIO OVERVIEW—Dr. Martha Matocha, Program Director, Office of Extramural Programs, NINR

Dr. Matocha reviewed NINR-supported research in the areas of symptom assessment, symptom biology, and symptom management. Symptom science is one of four identified scientific focus areas for implementing NINR's strategic plan. This science area focuses on developing personalized strategies to treat and prevent the adverse symptoms of chronic illness across diverse populations and settings. Data from CDC's 2010 National Medical Care Survey show that symptoms are the primary reason for visits to

ambulatory care providers. NINR supports research on various common symptoms, including pain, sleep disturbance, cognitive impairment, fatigue, anxiety, mood disturbance, and dyspnea.

Dr. Matocha highlighted NINR-supported research on symptom assessment in insomnia, pain, and acute coronary events. Studies have been published on the improved understanding of patients' perceptions of insomnia, facial expressions of pain in noncommunicative critically ill patients, and the search for the meaning of myocardial infarction symptoms and delayed treatment in women. NINR has supported symptom biology studies in irritable bowel syndrome (IBS), spinal cord injury, and traumatic brain injury (TBI). Articles on the physiologic parameters associated with IBS symptom frequency, the BDNF receptor contribution to neuropathic pain after spinal cord injury, and the impact of mitochondrial polymorphisms on TBI have been published recently. In the area of symptom management, NINR has funded studies on improved pain-related outcomes in rural, low-socioeconomic-status chronic pain populations; the prevention of neurocognitive decline in children with acute lymphoblastic leukemia (ALL); and improvement of symptom clusters in cancer with cognitive behavior therapy.

There are two NINR P20 Exploratory Centers and 6 NINR P30 Core Centers/Centers of Excellence supporting research in symptom science. NINR supports training of its research community via the NINR Methodologies Boot Camp. This year's Boot Camp, to be held July 21–25, 2014, is on Big Data in Symptoms Research. Dr. Matocha highlighted NINR's current symptom science initiatives:

NINR is poised to continue its support of research on symptom science. The Innovative Questions: Shaping the Future of Nursing Science initiative is engaging the nursing research community to develop questions to focus and further define NINR's scientific agenda. This initiative has generated questions that focus on topics across the spectrum of symptom science.

V. SYMPTOM CLUSTERS RESEARCH—Dr. Angela Starkweather, Associate Professor and Chair, Department of Health and Nursing Systems, Virginia Commonwealth University School of Nursing

Dr. Starkweather gave an overview of symptom clusters research. Multiple cooccurring symptoms (symptom clusters) can have a profound negative impact on the quality of life of patients. Symptom characteristics of fatigue, depression, sleep disturbance, cognitive dysfunction, and pain change over time but are prevalent across stages of cancer and other chronic diseases. A greater number or severity of symptoms at diagnosis is associated with lower function and health-related quality of life during and after treatment.

The science of symptom clusters is important in patient outcomes. Dr. Starkweather reviewed common symptom clusters in patients with HIV, heart failure, chronic graft versus host disease, and chronic liver disease. Symptom clusters can be used to identify risks and guide treatments in conditions such as post-traumatic stress disorder, depression, acute myocardial infarction, and acute pain. Focus areas for symptom clusters research include biological correlates of symptom clusters, putative mechanisms of symptom clusters in women with breast cancer, cancer-related fatigue, the exposome and persistent symptoms, epigenetic influence of persistent symptoms, and persistent low back pain. Dr. Starkweather highlighted selected research in these focus areas.

VI. OVERVIEW OF DECEMBER 2013 PLANNING MEETING—Dr. Julie Anderson, Associate Professor, College of Nursing, University of North Dakota

Dr. Anderson gave an overview of the NINR December 2013 Planning Meeting. The goals of this meeting were to identify scientific gaps and opportunities relative to the mission of NINR and to develop a list of ideas, known as “concepts,” that have potential to move nursing science forward. Based on feedback and discussions, some pre-concepts were further developed into concepts. The concepts are being presented to the Council today.

VII. CONCEPT PRESENTATION AND DISCUSSION—Dr. Linda Weglicki, Chief, Office of Extramural Programs, NINR facilitated Council members’ discussion of the six concepts

Self-Management for Asthma Associated with Sleep Apnea Across the Lifespan A scientific gap exists in the self-management of asthma in children. However, self-management for children with asthma is also a family issue; the concept language does not address this. Council suggested narrowing the concept to focus only on sleep apnea in children and adolescents. Council discussed environmental contributors to asthma as these may differ in diverse populations, depending upon where they live. Council concluded that there are interesting elements in this concept, but it needs further refinement.

Prevention Research in Mid-Life-Stage Adults

Council recommended: adapting behavior modification protocols for midlevel providers in community-based settings; looking at built environment and ecological factors and their effect on mid-life health; and expanding the age range. The concept needs more emphasis on health disparities. Council suggested adding mediating and moderating variables into intervention studies, and evaluation of interventions in settings other than the clinic.

Functional Wellness in HIV: Maximizing the Treatment Cascade Council recommended changing the concept title to focus on minimizing the treatment cascade. This concept also applies to hypertension and diabetes; there is tremendous generalizability beyond HIV. Council recommended a focus on research that looks at systems of care and care delivery, not just care for individuals.

Personalized Strategies to Manage Symptoms of Cancer Survivors

This concept could be expanded to include survivors of other chronic illnesses. The current definition of cancer survivor is problematic. Council cautioned not to focus on individual symptoms.

Self-Management for Health in Chronic Illness

Council recommended clarifying the use of technology in the concept; the poor and vulnerable have access issues. Incorporating resiliency is one of the most important objectives. This concept seems like another version of the functional wellness concept and requires further clarification. Council suggested creating a framework of categories that will be included.

Biobehavioral Interventions Affecting the Trajectory of Cognitive Decline in Individuals with Dementia

Council recommended clarifying definitions. Common data elements are key to this concept. Methods of modeling trajectories, statistical methods, etc., should be discussed. Council suggested focusing on other outcomes (function, management, quality of life) and not only cognitive decline. Use of the term “biobehavioral interventions,” rather than interventions in general, limits the concept. Council recommended including more emphasis on caregivers and their changing role over the trajectory of cognitive decline.

Dr. Grady thanked participants and attendees and adjourned the open session of the meeting.

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 conflict of interest either real or potential. Members were asked to sign a statement to this effect.

REVIEW OF APPLICATIONS

NACNR members considered 115 research and training grant applications on which NINR was the primary Institute; these applications requested a total of \$30,634,848 (direct costs year 01). The Council also considered 368 applications on which another Institute/Center was primary and NINR was secondary. These applications requested a total of \$172,311,025 (direct costs year 01). The Council concurred with the Initial Review Group recommendations for these 483 applications.

ADJOURNMENT

The 83rd meeting of the NACNR was adjourned at 1:00 p.m. on May 21, 2014.

CERTIFICATION

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

Patricia A. Grady, Ph.D., R.N., F.A.A.N.
Chair
National Advisory Council for Nursing
Research

Ann R. Knebel, Ph.D., R.N., F.A.A.N.
Executive Secretary
National Advisory Council for Nursing Research

COUNCIL MEMBERS PRESENT

Dr. Patricia A. Grady, Chair
Dr. Ann Knebel, Executive Secretary
Dr. Anna Alt-White, *Ex Officio*
Dr. Julie Anderson
Dr. Cynthia Barnes-Boyd
Dr. James Corbett
Dr. Susan Gennaro
Dr. Donna Hathaway
Dr. William Holzemer
Dr. Jillian Inouye
Dr. Kenton R. Kaufman

Dr. Elaine Larson
Dr. Bernadette Mazurek Melnyk
Dr. Nancy Redeker
Dr. Anne Rosenfeld
Dr. James Tulskey

MEMBERS OF THE PUBLIC PRESENT

Ms. Beth Jameson, Rutgers University
Dr. Sue Weaver, Rutgers University
Ms. Jamie Smith, Rutgers University
Dr. Leslie Davis, University of North Carolina, Greensboro
Dr. Susan Dorsey, University of Maryland
Dr. Angela Starkweather, Virginia Commonwealth University
Ms. Hee Jun Kim, University of Maryland
Ms. Seo Yoon Chung, University of Maryland
Ms. Eun Hahm, University of Maryland
Ms. Natacha Pierre-Lynch, Marquette University
Ms. Lyungeh An, Virginia Commonwealth University
Ms. Michelle Wright, Virginia Commonwealth University
Ms. Lathika Mohan Ray, Virginia Commonwealth University
Dr. Louise Rosenbaum, Virginia Commonwealth University
Ms. Taryn Quinlan, NOVA Research Company

FEDERAL EMPLOYEES PRESENT

Mr. Brian Albertini, NINR/NIH
Dr. David Banks, NINR/NIH
Ms. Melissa Barrett, NINR/NIH
Ms. Karen Bashir, NINR/NIH
Mr. Nathan Brown, NINR/NIH
Ms. Adrienne Burroughs, NINR/NIH
Dr. Ann Cashion, NINR/NIH
Ms. Ana Ferreira, NINR/NIH

Ms. Kerry Gastley, NINR/NIH
Dr. Lisa Gough, NINR/NIH
Dr. John Grason, NINR/NIH
Dr. Chris Hafner-Eaton, NINR/NIH
Dr. Lynda Hardy, NINR/NIH
Ms. Deborah Jennings Cudjoe, NINR/NIH
Mr. Kenton Kaufman, NINR/NIH
Ms. Mary A. Kelly, NINR/NIH
Dr. Weiqun Li, NINR/NIH
Dr. Yujing Lui, NINR/NIH
Dr. Donna Jo McCloskey, NINR/NIH
Dr. Jessica McIlvane, NINR/NIH
Ms. Wendy Massias-Burnett, NHLBI/NIH
Dr. Martha Matocha, NINR/NIH
Ms. Deborah Mellman, NINR/NIH
Dr. Arthur Meltzer, NINR/NIH
Ms. Archana Mohale, NINR/NIH
Ms. Mary Murray, NINR/NIH
Dr. Linda Porter, NINDS/NIH
Dr. Mario Rinaudo, NINR/NIH
Dr. Mary C. Roary, NINR/NIH
Ms. Priya Shanker, NINR/NIH
Ms. Bonnie Snyder, OD/NIH
Mr. Pasquale Speranza, OD/NIH
Dr. Catherine Timura, NINR/NIH
Dr. Lois Tully, NINR/NIH
Dr. Linda S. Weglicki, NINR/NIH
Mr. Kevin G. Wilson, NINR/NIH
Ms. Natalie Zeigler, NINR/NIH