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 13-14, 2014

The 82nd meeting of the National Advisory Council for Nursing Research (NACNR) was convened on Monday, January 13, 2014, at 1:00 p.m. in Conference Room 10, 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 4:22 p.m. The closed session of the meeting, which included consideration of grant applications, was convened on Tuesday, January 14, 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 82nd meeting of the NACNR to order, and welcomed all Council members, visitors, and staff. Council members Drs. Freeman, Lyder, and Schoneboom were unable to participate in the open and closed sessions. Dr. James Tulsky was unable to participate in the open session but was available for the closed session. Dr. Grady recognized retiring members Drs. Dowling, Freeman, and Larson.

Conflict of Interest and Confidentiality Statement

Dr. Ann Knebel, Executive Secretary, NACNR, and Deputy Director, 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. Dr. Knebel informed the Council that three of 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 also reminded Council members of their status as special federal employees while serving on the Council and that as special government employees, Council members cannot engage in lobbying activities while receiving payment from the government

Minutes of the Previous NACNR Meeting

Council members received the minutes of the September 17–18, 2013, NACNR meeting by email. 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 and Knebel about any conflicts or expected absences.

2014

May 20-21 (Tuesday-Wednesday) September 16-17 (Tuesday-Wednesday)

2015 January 27-28 (Tuesday-Wednesday) May 19-20 (Tuesday-Wednesday) September 15-16 (Tuesday-Wednesday)

Dr. Knebel noted that the January 27-28, 2015, meeting will be held in the Neuroscience Center Building, not Building 31, on the NIH campus. Additional information will be sent to Council members closer to the meeting date.

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—The federal government is operating on a Continuing Resolution (CR) until January 15, 2014. The President's fiscal year (FY) 2014 budget provides a 1 percent increase over NINR's FY2012 budget level. Congress has not yet made a decision regarding what funding levels the government will operate once the CR expires. Dr. Grady reviewed NINR patterns of investment. In FY2013, the majority of NINR's budget went to research project grants (RPGs), which include Small Business Grants, to support research and training. The intramural program comprised approximately 6 percent of the NINR budget.

HHS News—HHS Secretary Kathleen Sebelius announced funding to help veterans advance in nursing careers by building on their combat medical skills and experience and awarding academic credit for prior military training and experience. Over four years, these grants will enable more than 1,000 veterans to obtain baccalaureate nursing degrees. HHS awarded funding in FY2013 to strengthen training for health professionals and increase the size of America's health care workforce. The Patient-Centered Outcomes Research Institute (PCORI) Methodology Report was revised to address extensive feedback received from the healthcare community during a public comment period that followed the July 2012 release of a draft. Dr. Grady reviewed PCORI funding opportunities relevant to nursing.

NIH News—Dr. George Koob has been named Director of the National Institute on Alcohol Abuse and Alcoholism (NIAAA). NIH named Dr. Philip Bourne its first Associate Director for Data Science. President Obama announced that NIH plans to redirect AIDS research funds to expand support for research directed toward a cure for HIV. NIH plans to invest an additional \$100 million over the next three fiscal years on this increasingly promising area of HIV/AIDS research. NIH and the Centers for Disease Control and Prevention (CDC) launched the Sudden Death in the Young Registry, which focuses on deaths from conditions such as heart disease and epilepsy. The Registry will track all sudden, unexpected deaths in youths up to age 24 in as many as 15 states or major metropolitan areas. NIH has announced new funding opportunities to support President Obama's Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative (http://www.nih.gov/science/brain/index.htm). NIH held its annual Leadership Forum the week of January 6, 2014, to discuss issues of common interest such as review, training, and infrastructure. Selected NIH-sponsored funding opportunities that may be of interest to nurse scientists are available at http://grants.nih.gov/grants/guide.

NINR News—NINR launched the new Palliative Care: Conversations Matter campaign (<u>www.ninr.nih.gov/conversationsmatter</u>) to help ensure that children with serious illnesses and their families get supportive care. The campaign aims to increase the use of palliative care—comprehensive treatment of the discomfort, symptoms, and stress of serious illness—for pediatric patients with serious illness.

The Innovative Questions (IQ) initiative is the next step in the implementation of NINR's Strategic Plan. IQ is an interactive, collaborative initiative designed to stimulate a dialogue among the scientific community, professional organizations, and the public through a series of workshops and the IQ website (www.ninr.nih.gov/IQ). 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.

The Friends of the NINR (FNINR) Ambassadors are a group of committed individuals willing to serve as advocates of NINR. Chosen through an application process, these selected Ambassadors will work as advocates for the goals and vision of NINR. The number of individuals with this elite designation will be limited. The deadline for applying for the FNINR Ambassadors Program is January 15, 2014.

The Robert Wood Johnson Foundation's Interdisciplinary Nursing Quality Research Initiative (INQRI) is a research program that quantifies the role of nurses in improving patient care. The Initiative aims to improve patient care by examining the role nurses play in improving the quality of care.

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

The following NINR staff news was noted:

- Dr. Ann Cashion has been appointed Scientific Director of the Intramural Program.
- Dr. Carolyn Sampselle has been named Senior Advisor to the Director.
- Mr. Brian Albertini and Dr. Paul Cotton received the 2013 NIH Group Honor Award for their work with the Small Business Innovation Research (SBIR) program.

Training Opportunities—

- The application deadline for this year's Summer Genetics Institute (SGI) is March 1, 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). The application is open April 1-May 20, 2014.
- Dr. Katy Meilleur, Principal Investigator in NINR's Muscle Disease Unit, received the NIH Benchto-Bedside (B2B) program award for her work on children with congenital neuromuscular disorders.
- Two NINR nurse scientists received the Presidential Early Career Award for scientists and engineers: Drs. Jessica Gill and Ida Spruill.

III. NIH SBIR/STTR PROGRAM UPDATE—Dr. Matthew Portnoy, SBIR/STTR Program Coordinator, Office of Extramural Research, NIH

The SBIR and Small Business Technology Transfer (STTR) programs are congressionally mandated setaside programs with potential for commercialization. SBIR is a set-aside program for small business concerns to engage in federal research and development. STTR is a set-aside program to facilitate cooperative research and development between small business concerns and U.S. research institutions.

NIH is one of 11 federal agencies involved in the SBIR-STTR program; its involvement accounts for about 25 percent of the overall program. The NIH SBIT/STTR is a three-phase program: Phase I is Feasibility; Phase II is Full Research/Research and Development; Phase IIB is Competing Renewal/Research and Development; and Phase III is Commercialization. By law, agencies are not allowed to spend SBIR/STTR funding on Phase III. The eligibility criteria for SBIR grants have changed for the January 28, 2013 funding opportunity announcements going forward. In addition to previous criteria, applicants which are more than 50% owned by multiple venture capital operating companies, hedge funds, private equity firms, or any combination of these are eligible to apply after July 2013. The critical differences between SBIR and STTR grants is that SBIR permits partnering, while the STTR requires partnering with a research institution. Additionally, the primary employment of the principal investigator (PI) on an SBIR grant must be with the small business concern; for STTR, the PI may be employed by either the research institution or the small business concern. For both programs, the award is always made to the small business concern.

Information about funding is posted on the NIH SBIR website (<u>http://sbir.nih.gov</u>). Key provisions of the SBIR/STTR programs reauthorization (<u>http://grants.nih.gov/grants/funding/sbir/reauthorization.htm</u>) are the increase in set-aside requirements for agencies over the next four years and hard budgets caps on the programs.

Questions, Comments, and Discussion Points Included:

• How do you measure the success of grants?

Success is measured in several ways. The law requires that certain outcome measures be collected. The number of jobs created is one measure used to evaluate success. The Small Business Administration (SBA) is building a commercialization database to track those SBIR/STTR grants that have moved successfully to the commercialization stage (Phase III).

How do you generate ideas for areas of interest?

We conduct an annual process whereby the Institutes and Centers (ICs) update their topics of interest.

• Does the business community weigh in on the areas of interest?

Not in a formal manner, but business community members contact their program officers in the ICs to offer input on the selection of topics of interest.

IV. A NURSING SCIENCE APPROACH TO BIG DATA —Dr. Patricia Brennan, University of Wisconsin-Madison

The mission of the NIH Big Data to Knowledge (BD2K) initiative is to enable biomedical scientists to capitalize more fully on the Big Data being generated by research communities. Big data come from three key sources: projects funded to produce important resources for the research community; large data sets useful for individual projects; and small data sets whose value can be amplified by aggregating or integrating them with other data. Big Data are big because of unaccountable elements and the high variety of data types and sources (diversity of data). NIH held three BD2K workshops in 2013 focused on enhancing training for biomedical big data, enabling research use of clinical data, and frameworks for community-based standards efforts.

Big data might advance nursing science through informatics training to complement statistical training, a team science approach, embedded laboratory partnerships, and more varied research methodologies. The nursing research workforce should comprise nurse data scientists, nurse scientists with data sophistication, and data-intensive nurses in practice. There should be four types of talent development investment: (1) information at the point of care (visualization utilities, analytics, capture tools); (2) information at the point of knowledge generation (data management and analytics); (3) workforce development (big data investigators); and (4) involvement of nurses in big data discussions.

Questions, Comments, and Discussion Points Included:

• At the first BD2K workshop on training, there was a huge divide between what clinicians needed and what data science people thought the clinicians needed. What are we going to do to get students, junior faculty, and ourselves up to speed on big data to be able to have a seat at the table?

Nurses already have a unique set of skills—ethics, inquiry, analysis, and communication. We need to embed students and trainees in those groups focused on big data, and we need to embed ourselves in teams on a project-to-project basis. Broadly, scientific journals need to understand that exploration in new fields is a reason to publish. We need the top leadership to constantly be asking the question: What is nursing's role?

• The strategies you are proposing are similar to the strategies used to incorporate genetics into nursing science. In your view, what are the similarities or differences?

We had a compelling reason to understand genetics, but we do not have a compelling reason to understand big data, which means we need to think about it differently. We need to have nursing involved in lots of research all the time—a model where you rotate to different project teams. Computational tools are difficult to learn, but it is harder to teach which tools to use and why. We need to think about an efficient strategy for our discipline as a whole. The funding and risks are different between genetics and big data, but the strategies will not be that different. Currently, resources are not at the level that they need to be—nurses are not prepared with the level of quantitative thinking necessary to address the big data issue.

• How do you deal with Health Insurance Portability and Accountability Act (HIPAA) regulations?

One of the ways to deal with HIPAA is the approach with which we think about those regulations. We need to be looking at more fundamental science framing for research activities—a tolerance that information has a level of uncertainty embedded within it. We are looking at time-variant data. There are a lot of exploratory approaches occurring, but the questions need to be asked before data are examined.

• Early literature on data mining suggests that the question-first approach does not work. Could you comment on this?

The big data training nurses need will require a combination of approaches. One resource nurse scientists should look at is the funding opportunities for training and curricula development being released from the NIH BD2K initiative.

V. NINR TECHNOLOGY SCIENCE PORTFOLIO—Dr. Paul Cotton, Program Director, Technology, NINR

NINR is incorporating the use of cutting-edge technology to improve patient outcomes in the areas of symptom science, wellness, self-management, end-of-life and palliative care, and the SBIR/STTR programs. The number of NINR-supported technology-based research awards increased from FY2008 to FY2012. Innovative technologies play a critical role in advancing health care, and nursing science can provide the foundation for developing novel, culturally sensitive interventions for patients, families, clinicians, and communities. Current technology-based funding opportunities include the BD2K initiative, mHealth tools, and the BRAIN Initiative. In the future, NINR plans to train young and early-stage investigators in nursing science and technology, incorporate stakeholders in technology, link to basic science, and develop sustainable programs such as public-private partnerships.

VI. **REVIEW OF THE STATEMENT OF UNDERSTANDING**—Dr. Ann Knebel, Executive Secretary, NACNR, and Deputy Director, NINR

Dr. Knebel reminded the Council that the Memorandum of Understanding (MOU) serves as a contract between NINR and Council members about what is presented during the closed session. She also noted that NACNR must review the MOU each year. Council members were given the memorandum in their electronic Council books and should have had an opportunity to review it. A motion to accept the two changes to the Statement of Understanding was made, seconded, and approved unanimously.

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

REVIEW OF APPLICATIONS

NACNR members considered <u>91</u> research and training grant applications on which NINR was the primary Institute; these applications requested a total of <u>\$26,008,013</u> (direct costs year 01). The Council also considered <u>400</u> applications on which another Institute/Center was primary and NINR was secondary. These applications requested a total of <u>\$100,896,477</u> (direct costs year 01). The Council concurred with the IRG recommendations on these <u>491</u> applications.

ADJOURNMENT

The 82nd meeting of the NACNR was adjourned at 1:00 p.m. on January 14, 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

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. Glenna A. Dowling Dr. Susan Gennaro Dr. Donna Hathaway Dr. William Holzemer Dr. Jillian Inouye Dr. Kenton R. Kaufman Dr. Elaine Larson Dr. Bernadette Mazurek Melnyk Dr. Anne Rosenfeld Dr. Marjana Tomic-Canic Dr. James Tulsky

MEMBERS OF THE PUBLIC PRESENT

Dr. Patricia Brennan, University of Wisconsin-MadisonMs. Susan Dove, Friends of the National Institute of Nursing ResearchDr. Karen Drenkard, Friends of the National Institute of Nursing Research

Ms. Alisha Hackney, University of Maryland, Baltimore
Ms. Stacey Iobst, University of Maryland, Baltimore
Ms. Kate McElroy, University of Maryland, Baltimore
Ms. Teresa Morris, Friends of the National Institute of Nursing Research
Dr. Janice Phillips, Commission on Graduates from Foreign Nursing Schools (CGFNS) International
Dr. Mary Regan, University of Maryland, Baltimore
Ms. Taryn Quinlan, NOVA Research Company

FEDERAL EMPLOYEES PRESENT

Dr. Noreen Aziz, NINR/NIH Dr. David Banks, NINR/NIH Ms. Karen Bashir, NINR/NIH Mr. Austin R. Blackert, OD/NIH Ms. Alycia Jackson Booth, OD/NIH Ms. Sharhaina Brown, OD/NIH Dr. Yvonne E. Bryan, NINR/NIH Dr. Ann Cashion, NINR/NIH Ms. Amanda Jean Clatterbaugh, OD/NIH Ms. Rachel Cooke, OD/NIH Dr. Paul A. Cotton, NINR/NIH Dr. Marguerite M. Engler, NINR/NIH Dr. Mary B. Engler, NINR/NIH Ms. Ana Ferreira, NINR/NIH Ms. Kerry Gastley, NINR/NIH Dr. Amanda L. Greene, NINR/NIH Ms. Lydia H. Greene, OD/NIH Dr. Chris Hafner-Eaton, NINR/NIH Dr. Lynda Hardy, NINR/NIH Ms. Mary A. Kelly, NINR/NIH Dr. Weiqun Li, NINR/NIH Dr. Yujing Lui, NINR/NIH Dr. Martha Matocha, NINR/NIH Dr. Donna Jo McCloskey, NINR/NIH

Dr. Arthur Meltzer, NINR/NIH Dr. Jeri L. Miller, NINR/NIH Ms. Archana Mohale, NINR/NIH Dr. Priscah Mujuru, CSR/NIH Ms. Mary Murray, NINR/NIH Dr. Mary C. Roary, NINR/NIH Mr. Chip Rose, NINR/NIH Dr. Lois Tully, NINR/NIH Dr. Linda S. Weglicki, NINR/NIH Mr. Kevin G. Wilson, NINR/NIH