

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

September 18–19, 2012

The 78th meeting of the National Advisory Council for Nursing Research (NACNR) was convened on Tuesday, September 18, 2012, at 1:00 p.m. in Conference Room 6C, 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 approximately 5:15 p.m. The closed session of the meeting, which included consideration of grant applications, was convened on Wednesday, September 19, 2012 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. Grady called the 78th meeting of the NACNR to order, welcoming all Council members, visitors, and staff.

Conflict of Interest and Confidentiality Statement

Dr. Ann Knebel, Executive Secretary, NACNR, referred Council members to the Conflict of Interest and Confidentiality Statement. Briefly, Council members should determine whether they have a tangible role in the proposal, a vested interest in the proposal, or an appearance of a conflict in deciding whether they should review applications. To avoid conflicts of interest, or even the perceptions of such, Council members should leave the room during a discussion of applications submitted by their institutions, family members, close associates, or persons with

whom they have had longstanding differences. The Conflict of Interest and Confidentiality Statement also notes that material furnished for review purposes and discussion during the closed session is privileged and can only be discussed with NINR staff under appropriate circumstances. Council members are to be mindful of their status as special Federal employees while serving on the Council and as such, 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 May 15–16, 2012 NACNR meeting by email. A motion to accept these minutes was made, seconded, and approved unanimously.

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.

2013

January 22–23 (Tuesday–Wednesday)

May 21–22 (Tuesday–Wednesday)

September 17–18 (Tuesday–Wednesday)

2014

January 21–22 (Tuesday–Wednesday)

May 20–21 (Tuesday–Wednesday)

September 16–17 (Tuesday–Wednesday)

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

The Director's report focused on the NIH and NINR budgets and on activities and news occurring within NINR, NIH, and the Department of Health and Human Services (HHS) since the last Council meeting.

Budget Update—Dr. Grady reported that Federal agencies are still in a waiting period, although they are anticipating approval of a continuing resolution for 6 months. A continuing resolution typically keeps funding at the same level as it was in FY2012 and restricts agencies from beginning any new major initiatives. Dr. Grady also noted the possibility that the FY2013 budget could be smaller and constrain the ability of NIH to make full awards. Because of the uncertainty for FY2013, NIH Institutes and Centers (ICs) are considering contingency plans for a variety of funding scenarios. However, Dr. Grady noted that although NIH and the Federal government are facing difficult times, discussions on Capitol Hill tend to be positive, and recognize NIH as a valued institution.

NINR continues to grow at approximately the same rate as NIH does, and in the past its budget has increased by the same or slightly higher percentage of the NIH budget. The NINR budget constitutes 0.5% of the overall NIH budget. Most of its funds, about 72%, support extramural research. Approximate proportional funding includes the following: training is funded at 6% of the NINR budget, other awards such as K awards are funded at 2%, centers and program projects are funded at 4%, and the NINR Intramural Research Program (IRP) is funded at 4%. Dr. Grady reminded the Council that the proportion of the NINR budget devoted to training is twice the average across NIH, while the proportion devoted to IRP is a little less than half the average proportion for intramural programs across NIH.

HHS News—Many changes are taking place in universities and health care centers as a result of the Patient Protection and Affordable Care Act (ACA), with the most important change being a reorienting of the system more toward prevention than to cure. The National Prevention Council, an Office of the Surgeon General initiative that comprises 17 Federal departments and agencies, has issued an action plan to promote wellness and increase the number of Americans who are healthy at every stage of life.

In line with the action plan, the Science of Eliminating Health Disparities Summit, which has expanded from an NIH initiative to one encompassing the entire Department, gathers leaders and experts and explores the state of the science in health disparities. The next Summit will be held October 31–November 3, 2012. NIH and HHS also hosted the Alzheimer’s Disease Summit to unveil a new national plan not only for curing this disease, but for addressing aspects such as caregiving.

NIH News—Dr. Grady announced that NIH has a new logo, designed to be simpler and to reflect science pointing the way forward. NIH also has a new website emphasizing the impact and importance of both NIH and biomedical research in general. One large area of emphasis involves the impact of investments in NIH; for example, every dollar spent on NIH reaps \$2.20 in the local economy.

Dr. Grady noted a recent event, A Celebration of Science, which was organized through partnerships among NIH, FasterCures, and the Milken Institute to renew America’s commitment toward biomedical science. This event brought together political leaders, advocates, government funders, academia, and private industry and presented strong, clear messages about the value of science to America. Dr. Grady encouraged Council members to visit the website for A

Celebration of Science and cited the event as a model for presenting complicated material in a clear and straightforward way.

Dr. Grady also reported that:

- In line with the NIH Reauthorization Act of 2006, NIH has created the Office for Emergency Care Research, which will reside in the National Institute of General Medical Sciences. The Office will operate along the same lines as the Trans-NIH Pain Committee by assessing existing research and identifying gaps, synergies, and ways to stimulate research in important areas. Dr. Grady serves on a steering committee for the Office, and Dr. Karen Huss will represent NINR in the Office's operations.
- NIH has selected 11 Centers of Excellence in Pain Education to address the limited attention to pain in existing medical school curricula and training programs. All the centers are interdisciplinary, although each center's partnerships are specific to that center's environment.
- The NIH-wide End-of-Life and Palliative Care Lecture series, continues to bring stimulating speakers and generate wide interest. The lectures are archived, and information about the lecture and the speaker's expertise is included in the archive.
- Dr. Janine Clayton has been named as the Director of the NIH Office of Research on Women's Health (ORWH). Dr. Clayton was the Deputy Director for ORWH and before that was active on committees to improve the environment and attract more women scientists into intramural research at NIH. She has served as Acting Director of ORWH since Dr. Vivian Pinn, founding Director, retired.
- Dr. David Murray has been named as the Director of the NIH Office of Disease Prevention (ODP), which addresses issues in disease prevention, health promotion, and dissemination of

prevention research to increase impact. Dr. Murray comes to NIH from Ohio State University, where he was the Chair and Professor in the Division of Epidemiology, within the College of Public Health.

- Dr. Catherine Bushnell, the new Scientific Director of the Division of Intramural Research at the National Center for Complementary and Alternative Medicine, is leading a multidisciplinary program on pain.
- Three new members have been named to the NIH Advisory Committee on Women's Health: Dr. Afaf Meleis, the Margaret Simon Bond Dean of Nursing at the University of Pennsylvania School of Nursing; Dr. Heidi Nelson, research professor of medical informatics, clinical epidemiology, and medicine at the Oregon Health & Science University; and Dr. Gerson Weiss, Professor and Chair of obstetrics and gynecology at the New Jersey Medical School, Newark.

NINR News—The NINR website includes a Spotlight on Pain Research, which highlights Institute activities focusing on pain. The website also boasts a new feature, Because of Nursing Research, consistent with efforts to disseminate not only the results of NINR-supported research but also the importance and impact of that research to the public. For example, this feature highlights Dr. Bernadette Melnyk's work in helping families of premature infants and in reducing the length of stay in neonatal intensive care units. In addition, Dr. Grady and Dr. Pamela Mitchell were recently featured in a *Nature Medicine* article about the importance of nurses in clinical trials and the leadership role of nurses in scientific studies.

NINR is also continuing its palliative care campaign, as recommended by the Science of Compassion Summit. A pilot campaign focused on pediatric palliative care will begin later in

September, with an actual launch expected in summer 2013. *Nursing Outlook* is publishing a special issue dedicated to end-of-life and palliative care, as an outcome of the Summit.

NINR held its most recent State of the Science Congress and Friends of the NINR Nightingala, which was attended by approximately 1,200 people. Major General Patricia Horoho, the first nurse and woman to be appointed as the Army Surgeon General, gave the keynote presentation and acknowledged the Friends of the NINR for its work in organizing the event.

Dr. Grady announced that Dr. Jessica Gill, who had worked in the NINR IRP as a fellow, is one of the first recipients of the new NIH Lasker Clinical Research Scholar award. This program, a joint effort between NIH and the Lasker Foundation, supports a 5-year fellowship in the tenure track in the intramural program at NIH, at the end of which the awardee can stay or go to another institution. Dr. Gill comes to NIH from George Mason University, and her research focuses on post-traumatic stress disorder and traumatic brain injury.

Dr. Grady also reported that she received the Sterling Award from the University of California, Los Angeles School of Nursing at its recent commencement exercises. She also acknowledged Dr. Mary Engler, who as IRP Training Director oversees the mentoring of junior researchers, and Dr. Marguerite Engler, who is serving as Deputy Science Director. Both have taken on these responsibilities in addition to conducting research in vascular biology. Dr. Grady announced that Dr. Ann Cashion is the Acting Scientific Director for IRP and that Ms. Ana Ferreira, who has been with NINR for about 12 years, was selected as Executive Officer at NINR.

The Graduate Partnership Program is now accepting applications for 2013. The deadline is January 3, 2013. Dr. Grady also reported that the Summer Genetics Institute was again a success and that application success rates are measurably higher among former Institute participants. In addition, NINR has continued its symptom methodology boot camps, with the most recent camp

focused on sleep and fatigue. Dr. Grady noted that enrollment for these boot camps fills pretty quickly.

Dr. Grady closed her presentation by highlighting selected funding opportunities in behavioral interventions to address multiple chronic health conditions in primary care, improving diet and physical activity assessment, and research supplements to promote diversity in health-related research. She also invited Council members and visitors to visit the NINR website.

III. NIH COMMON FUND—Dr. James Anderson, Director, NIH Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI)

Dr. Anderson began his presentation by noting that DPCPSI and the Common Fund had their origins in 2004 with the NIH Roadmap, an initiative put forward by former NIH Director Elias Zerhouni to coordinate trans-NIH research. In the NIH Reauthorization Act of 2006, Congress built on this initiative by creating DPCPSI, with a separate appropriation for the Common Fund so that it no longer took a percentage of funds from each IC. DPCPSI got up and running in 2008 and is still evolving.

The Common Fund creates a space where all ICs can identify big scientific opportunities and address them together. Ideal opportunities are those that create new technologies, models, or datasets that multiple Institutes and Centers (IC) can use to overcome obstacles. They are broad in scope, complex, and often expensive, and therefore would not appear in the portfolio of an individual IC. Common Fund projects must be transformative, unique, cross-cutting, and synergistic. Importantly, the Common Fund is a catalytic activity and incubator. Development of an initiative includes a scientific business plan, wherein an IC must be willing to administer and

support the project after 5 to 10 years in the Common Fund. Dr. Anderson emphasized that if the obstacle is “only money,” then the project does not qualify as a Common Fund project.

The Common Fund now supports 29 programs that vary significantly in the size of budget, depending on the obstacle NIH is trying to overcome. One example is the Human Microbiome Project (HMP), which takes advantage of advances in sequencing to identify and characterize the thousands of microbes that live on and within the human body. The Project has recently published a series of transformative papers, including a description of reference microbiome sequences from more than 200 healthy adults. This project is already successful, garnering a large amount of press coverage and creating references anyone can use, and it does not require continued infrastructure investment. Another example is the Molecular Libraries Project, which has established centers to help investigators develop assays for high-throughput screening. These centers have become so popular that some are funded by individual R01s. Other projects included the Knockout Mouse Phenotyping Project; the Epigenomics Project; and the Clinical and Translational Science Awards program, which was funded by the original NIH Roadmap and is now a part of the new National Center for Advancing Translational Science (NCATS). Clinically oriented initiatives include the Health Maintenance Organization Collaboratory project, which aims to enable the participation of health care systems and their large patient populations in clinical research, and the Patient-Reported Outcomes Measurement Information System, which has standardized reporting of symptoms and patient-reported conditions.

Dr. Anderson pointed out that the majority of these projects are top-down initiatives developed in response to community input. However, some Common Fund programs, such as the Transformative R01, Early Independence Award, and New Innovators program, support investigator-initiated research in a different way than traditional NIH grant programs do, thus

encouraging high-risk, high-reward science. Applications for these programs are evaluated in a to-step process that assesses whether they are transformative yet feasible.

The process by which DPCPSI identifies and develop potential Common Fund projects has evolved over the years. The current iteration begins with a generation of ideas by soliciting input from the community through social media and requests for information. The initial list of ideas is vetted by the Council of Councils, the NIH Director, and IC Directors, who narrow the list down to a workable number. The Office of Portfolio Analysis, another office within DPCPSI, then analyzes what has already been done for each idea and where the best investments would be, and this analysis yields the final set of potential Common Fund projects. For the current round, a list of 70 initial ideas was narrowed to 37 unique ideas that were presented to the Council of Councils, which cleared 26 as fulfilling Common Fund criteria. Further assessment by IC directors yielded 12 ideas that are now undergoing further development. Two of these initiatives, one focused on extracellular RNA communication and a continuation of the Undiagnosed Diseases Program, will be funded in FY2013.

IV. UPDATE ON NINR GLOBAL/INTERNATIONAL HEALTH RESEARCH

PORTFOLIO—Dr. Lynda Hardy, Office of Extramural Programs, NINR

“Global health” is defined by NIH as “health problems, issues, and concerns that transcend national boundaries, may be influenced by experiences or circumstances in other countries, and are best addressed by cooperative actions and solutions.” Many health problems seen worldwide, such as child malnutrition and food insecurity, maternal mortality rates, HIV infection, tuberculosis, and non-communicable diseases such as cardiovascular disease, are also seen in the United States.

In 2009, NIH Director Francis Collins outlined four goals for global health: cutting-edge advances, linking measures to strengthen and sustain research capacity in low- and middle-income countries, finding synergies and partnerships with international counterparts, and linking academic networks to major intervention programs to link research with practice. The Fogarty International Center (FIC) leads NIH efforts in global health, although several ICs, including NINR, collaborate on research addressing such topics as malaria, chronic non-communicable diseases, tuberculosis, mobile health, bioethics, and implementation science.

NINR has funded research in the Dominican Republic, Argentina, South Korea, China, and many African countries. NINR-supported global health projects include:

- A project that incorporates a mixed-methods approach to determine the efficacy of new interventions and assess community perceptions of social support and stigma for children infected with HIV. This project was initially done in China, but UNICEF has asked the investigators to evaluate children in Ethiopia to determine the possibility of applying the project model there.
- A large clinical trial evaluating user preferences for pre-exposure HIV therapy in serodiscordant couples to permit safer conception and prevent HIV transmission. These results are particularly important in light of the recent U.S. Food and Drug Administration's (FDA) approval of Truvada, a combination of two antiretroviral drugs, for HIV prevention. This project was presented at the 2012 International AIDS Symposium in July.
- A project using a mixed methods approach to assess correlations of depression in HIV-infected patients seeking care and barriers that prevent the integration of depression screening into HIV care in India.

- A global initiative to develop foreign investigators from low- or middle-income countries and build long-term scientific capacity to address HIV/AIDS in Chile, Indonesia, and Malawi. This project represents a collaboration between NINR and FIC and one between the School of Public Health and the College of Nursing at the University of Illinois.
- Six raining awards supported with funds from the American Recovery and Reinvestment Act (ARRA).

A Small Business Technology Transfer (STTR) project was discussed in more detail in another presentation (see summary of Dr. Sia's presentation, elsewhere in this document). NINR's efforts in global health have led to several publications. In addition, NINR continues to welcome applications on reducing disease burden in underserved populations. Dr. Hardy closed her presentation by emphasizing that disease prevention is based on a combination of biomedical and biobehavioral research, that NIH invests in capacity building to enable countries to conduct their own research, that NINR works with investigators on global research that is generalizable and applicable worldwide, and that NINR-supported scientists are essential contributors to global health issues.

V. LEVERAGING POINT-OF-CARE DETECTION TECHNOLOGIES TO IMPROVE PATIENT CARE—Dr. Samuel Sia, Department of Biomedical Engineering, Columbia University

In resource-limited settings, patients often see health professionals who are not physicians. Patient records are not on site, and laboratory testing is not available. Thus, when patients present with non-specific symptoms, professionals do not have the benefit of a laboratory or sophisticated diagnostic resources, and they traditionally manage patients based on their

symptoms. Dr. Sia and his colleagues have developed a low-cost device that can aid professionals in making more precise diagnoses on site, thus improving treatment.

Initial projections suggest that the device is cost-effective and achieves a public health impact similar to that seen with immunization or rehydration therapy. It also provides a clinical benefit by helping clinicians to provide correct treatments within a single visit and by reducing the patient anxiety associated with waiting for test results. Dr. Sia's work has received press coverage from the *Washington Post* and the *Wall Street Journal*. In addition, his interdisciplinary collaboration, which includes the Rwandan Ministry of Health, the International Center for AIDS Care and Treatment Programs, industrial designers, and economists, has been instrumental in developing a business case for use of the device in African settings.

Dr. Sia noted that global health research is valuable because it has a large public health impact that is easily understood both abroad and in the United States. His work has been successful because he and his partners went to and worked with sites where the need was and because an engineering point of view forced them to keep costs low. However, although validation is required for a real impact, it remains a challenge because fewer investors are interested in it.

Questions, Comments, and Discussion Points Included:

- A brief discussion of possible benefits of this technology in the field of viral infection, particularly in influenza testing.
- A note that readouts for this technology are comparable to those seen with ELISA, but at lower cost.
- The importance of transparency in managing potential conflicts of interest.
- The potential utility of this point-of-care technology in the United States, particularly for providers with limited resources.

VI. OVERVIEW OF STRATEGIC PLANNING RETREAT—Dr. Linda Weglicki, Office of Extramural Programs, NINR

Dr. Weglicki reminded the Council that planning retreats, to which Council members are invited, are held to identify gaps and opportunities related to NINR's mission and to develop a list of ideas that can move nursing science forward. At the December 2011 retreat, NINR considered pre-concepts in all four of NINR's research emphasis areas: health promotion, disease prevention, and quality of life; palliative and end-of-life care; innovation; and investments in nurse scientists. Concepts that were chosen were discussed at the June 2012 Planning Retreat and are being presented at this NACNR meeting. Concepts that move forward may form the basis for initiatives in FY2013 or FY2014.

VII. CONCEPT PRESENTATION, AND DISCUSSION—Dr. Linda Weglicki, Office of Extramural Programs, NINR

Council members presented the concepts to the NACNR and led the discussion. Fourteen concepts were presented and discussed.

1. Interventions to Reduce Asthma Health Disparities Among Ethnic Minority Children

Although progress has been made in reducing asthma in children, guidelines for asthma management have not been applied as successfully in ethnic minority children. The proposed concept aims to understand why these guidelines have not been adopted for this population and to design or tailor culturally and ethnically appropriate interventions.

Questions, Comments, and Discussion Points included:

- The importance of this issue is consistent with the enormous health disparities seen
- Potential linkages to assessments of genetic and environmental factors.

2. The Role of Stress in Sleep Disturbances in Adolescents

Stress and anxiety are associated with multiple areas of dysfunction in adolescence. For many adolescents, it is a painful time, with conflicting demands and stress from several sources.

Although individuals spend a third of their lifetimes in sleep, and although some work has been done on sleep disturbance in adults, little is known about adolescent sleep disturbance or the dynamic relationship between the complexities of stress and sleep disturbance in adolescents.

Council noted that NINR has many potential partners for this concept, and endorsed the concept as a good and timely opportunity. Noted were social behavioral factors, in the form of social networking and text messaging, as emerging factors that could affect sleep processes. It was also suggested that the concept consider age, sex and gender, economic and social factors, disease burden, and clinical consequences.

Questions, Comments, and Discussion Points included:

- Differences between adults and adolescents. It was noted that circadian rhythms are disturbed during adolescence and that the top three areas of sleep disturbance seen in adults are not seen in adolescents.
- Discussed were ways to focus the concept, as sleep disturbance and stress are both broad, generic concepts.

3. Global Partnership in Women's Health: Focus on Chronic Diseases

This concept addresses the significant and growing escalation of chronic diseases, also called non-communicable diseases, in low- and middle-income countries, with emphases on the disproportionate burden on women and on the role of women in culture and the community.

Council noted that these emphases are powerful because many preventive measures focus on factors, such as diet and exercise, which women often control. It was suggested that the proposed concept could present an opportunity to develop nurse scientists worldwide and that the D43 mechanism could be used to partner with FIC and build training programs.

Questions, Comments, and Discussion Points included:

- The need to include adolescent girls, as well as women.

4. Patient-Centered Outcomes Research and Interdisciplinary Partnerships in Chronic Illness

The proposed concept seeks to foster interdisciplinary collaboration while incorporating patient-reported illness into research. Importantly, it provides nurse scientists at the beginning of their careers an opportunity to join a research team. Council pointed out that the concept title and context do not match and that adding nurses after a trial has begun is challenging. A title change was suggested to reflect the focus on building interdisciplinary partnerships centered on patient outcomes.

5. Promoting Optimal Health Outcomes for Ethnic Minority Populations with Multiple Chronic Conditions

Although the likelihood of having a chronic condition increases with older age, the rates of chronic conditions are considerably higher among ethnic minorities and other underserved populations. In addition, management of multiple chronic conditions constitutes a large burden to the individual, family, and health care system. The proposed concept aims to promote optimal health outcomes, specifically by measuring and defining health outcome assessments, identifying determinants and predictors of health status, and developing and evaluating new models of care. The concept also includes the development and use of economic models, which are important

because of the cost burden associated with multiple chronic conditions. Council was enthusiastic about the concept and noted that it aligns with both the NIH and NINR strategic plans.

Questions, Comments, and Discussion Points included:

- A question of whether to include sickle cell disease, as the age of this population has increased but no studies have focused on long-term effects.

6. Addressing Symptom Management in HIV-Infected Individuals with Comorbid Conditions

Through a confluence of several events, HIV infection is now viewed as a chronic condition. Individuals infected with HIV are living longer and are relatively healthy, but age-associated conditions appear to be exacerbated by HIV infection. In addition, 21% of new infections occur in individual older than 50 years. Council suggested that the concept could be strengthened by the addition of symptom-related biomarkers and considerations of psychological and mental health comorbidities. There was discussion of whether the concept could increase individuals' capacity in self-care and resilience, because self-care and resilience are not always linked and because, from a cultural perspective, self care is often equal to family care. It was noted that efforts to decrease reliance on others, particularly in light of the continuing stigma associated with HIV, that there was a need for more open communication as well as a need for more resources as individual age.

7. Synergizing Omic and Symptom Science

The proposed concept is a large, expansive initiative that will use systems biology approaches to relate biological processes to particular symptoms of a disease or condition. Council noted that the concept aligns well with the NINR strategic plan, the NINR intramural program, and the Summer Genetics Institute and that it also could link with the Common Fund, which has projects

focused on epigenomics and metabolomics. It was pointed out that even though the field of “omics” has grown to the point of having its own journal, nursing has not been included. Thus the concept presents a unique opportunity. Consideration should be given to a focus on acute symptom management as well as on chronic illness.

Questions, Comments, and Discussion Points included:

- The applicability of this concept across ICs.
- Noted that this concept will require a long-term view and the inclusion of appropriate statistical expertise in study teams.
- This concept is important in the development of the next generation of nurse scientists.

8. Prevention and Management of Symptoms in Chronic Illness Through Innovative Research Methods

Council expressed enthusiasm for this concept, which will address the limitations of randomized controlled trials by using innovative methods such as sequential multiple assignment randomization trials (SMART), where dosage or components of an intervention can be changed or individuals re-randomized to another group based on their responses. It was noted that the use of innovative methods could improve enrollment, that the methodologies studied in this concept could be applied broadly, and that the concept could be linked with the Common Fund. There was less enthusiasm about data mining from electronic health records and that perhaps it was not an innovative approach.

Questions, Comments, and Discussion Points included:

- Suggestion to incorporate new research methodologies into doctoral programs.

- Suggestion that the concept address how these innovations can be used to answer questions more efficiently.

9. Building Evidence: Effective Palliative/End-of-Life Care Interventions

This concept responds to the NINR Summit on Palliative and End-of-Life Care (Summit on the Science of Compassion), which called for immediate and substantial research on innovative care models. Council noted that in hospice there is a large need to understand what the key patient and family outcomes are. There was a desire that the concept explore appropriate outcomes across a range of ages. For example, it was noted that children are often caregivers for young and middle-aged persons with neurodegenerative diseases. It was emphasized that outcomes explored by the concept should not be restricted to how long a patient survives. It was suggested that the concept look at populations, ethnocultural and community factors, and stigma or situations where family support is not present.

Questions, Comments, and Discussion Points included:

- A suggestion that the concept seek to increase awareness, particularly among ethnic minorities, of shared decision-making.

10. Examining Innovative Approaches to Manage Complex Comorbidities

This concept focuses on comorbidities in the presence of life-limiting diagnoses. Medical care for multiple comorbidities, which is already complex, adds a substantial burden to patients, families, and the health care system when it is performed at the end of life. Council noted that the concept and its objectives focus more on individual patients or a particular population. It was suggested that attention be paid to the issue of caregivers, especially because the number of able-bodied laypeople able to serve as caregivers will decline as our society ages. Suggestions included a focus of care in the home, incorporation of issues related to care coordination,

particularly with multiple discharges and readmissions, as well as the ethics surrounding decision-making about transitions to hospice care. Also, AHRQ be added as a collaborator in the area of systems science.

Questions, Comments, and Discussion Points included:

- Combining similar concepts, for example those focused on systems approaches to explore decision-making, into one concept. Requests for applications or proposals for this concept should state clearly the types of studies NINR is seeking.

11. Family-Centered Decision-Making in End-of-Life Palliative Care

The proposed concept responds to the 2011 Summit on the Science of Compassion, which called for research on communication with family at the end of a patient's life. This issue was raised in an editorial calling for research on the role emotion plays for physicians and other health care staff responding to patients and families, as well as in work identifying the many informal roles within the family. Council identified that the proposed concept aligns with NINR's mission and could improve the quality of life and the quality of care for patients, families, and caregivers. It was suggested that concept should consider decision-making models and list bioethical considerations as a separate objective. Further, it was noted that within the objective, that the incorporation of patients and self-management appears to take away from the overall emphasis on family decision-making. Additional suggestions included separation of end-of-life and palliative care and that the concept move beyond description to an emphasis on models that drive intervention.

Questions, Comments, and Discussion Points included:

- A call for awareness that families have many ways of composing themselves, and a reminder that in some cases, caregivers are actually minors.
- A suggestion to focus not only on traditional family, but also on diverse composites of family.

12. The Influence of the Microbiome in Preterm Birth

Highlighted were the consequences of preterm birth – that are long lasting, can be devastating, and the most expensive (neonatal intensive care unit) in the United States. About 20% to 40% of preterm births are related to infection, for example bacterial vaginosis. Until recently, however, studying the organisms involved was difficult because of technical challenges, choosing the appropriate treatments was difficult as providers often did not know what kinds of infection patients had. The proposed concept aims to leverage work on the human microbiome to understand more about the infections leading to preterm birth. Council agreed that this is an important research area with many questions yet to be addressed, such as the effects of treatment modalities such as probiotics, the effects or implications of microbes from other sites on the human body appearing in the vagina during pregnancy, and the role of inflammation in preterm birth.

Questions, Comments, and Discussion Points included:

- An emphasis on partnerships and training to ensure that enough scientists with the appropriate skills are available for these kinds of studies.

13. Innovative Measurement Tools for Community-Engaged Research Efforts

Traditional outcomes measures, such as patient satisfaction, morbidity, and mortality, are not useful at the community level. The proposed concept therefore seeks to develop reliable and valid tools for community-engaged research in disease prevention and health promotion. Council

noted that the concept is highly appropriate and relevant. It was suggested that it be expanded beyond the development of tools to research that helps to define the personality of a community, including its values, elements of trust, and environmental factors. Understanding the personality of a community will be critical before tools are developed.

Questions, Comments, and Discussion Points included:

- Noted was that all communities are not the same and that the concept seeks to build and develop the skills needed to learn about the personality of a community.
- There was a suggestion to leverage or refer to existing work on community readiness
- Suggestion that investigators should engage with the community to see how it defines itself, rather than defining the community and issues before engaging with it.
- A suggestion that tools should focus both on data gathering/collection and storage.

14. Nanotechnology for Advancing Nursing Science

This concept seeks to gather information and lay a foundation for future work, through the development of an Expert Panel on Nanotechnology and a request for information. Council identified that this concept is timely, because the Common Fund nanomedicine initiative has reached its seventh year. It was noted that the concept has the potential to be a unique, transformative, and synergistic opportunity for NINR and will provide a lot of useful information. As nanotechnology is a broad area, it was suggested that the NINR concept focus be clear and perhaps expanded to include microscale technology.

Questions, Comments, and Discussion Points included:

- A suggestion to define clearly what NINR means by “nanotechnology,” because different individuals have different ideas of what it is.

- A call for partnerships and training to ensure that enough scientists with the appropriate skills are available to explore this concept.
 - A suggestion that convening an expert panel could create enthusiasm and expand involvement of potential colleagues.
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Following these discussions, Dr. Grady thanked participants and attendees for their time and engagement and adjourned the open session of the meeting. Council members and visitors stayed to watch a video highlighting the October, 2011 Celebration of Science meeting.

CLOSED SESSION

This portion of the meeting was closed to the public in accordance with the determination that this session was concerned with 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

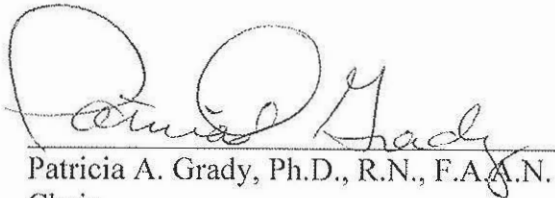
The members of the NACNR considered 197 research and training grant applications on which NINR was the primary Institute; these applications requested a total of \$54,130,941 (direct costs year 01). The Council also considered 392 applications on which another Institute/Center was primary and NINR was secondary. These applications requested a total of \$99,992,234 (direct costs year 01). The Council concurred with the IRG recommendations on these 589 applications.

ADJOURNMENT

The 78th meeting of the NACNR was adjourned at 1:00 p.m. on September 19, 2012.

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 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. Susan Gennaro
Dr. Barbara Guthrie
Dr. William Holzemer
Dr. Kenton Kaufman
Dr. Elaine Larson
Dr. Courtney Lyder
Dr. Kathleen Potempa
Dr. Anne Rosenfeld
COL Bruce Schoneboom, Ph.D., *Ex Officio*
Dr. Gail Stuart
Dr. Janet Williams

MEMBERS OF THE PUBLIC PRESENT

Mr. Brian Burke, University of Maryland School of Nursing
Mr. Benjamin Canha, University of Maryland School of Nursing
Ms. Jooyoung Chen, University of Maryland School of Nursing
Ms. Valerie Dernetz, University of Maryland School of Nursing
Dr. Susan Dorsey, University of Maryland School of Nursing
Ms. Mazen El Ghazari, University of Maryland School of Nursing

Ms. Mari Griffioen, University of Maryland School of Nursing
Ms. Hee Jun Kim, University of Maryland School of Nursing
Dr. Jane Lipscomb, University of Maryland School of Nursing
Ms. Katie McElroy, University of Maryland School of Nursing
Dr. Alison Montpetit, University of Maryland School of Nursing
Ms. Eyad Mussalam, University of Maryland School of Nursing
Dr. Eun-Shin Nahm, University of Maryland School of Nursing
Dr. Mary Regan, University of Maryland School of Nursing
Dr. Cynthia Renn, University of Maryland School of Nursing
Dr. Samuel Sia, Columbia University
Dr. Angela Starkweather, Virginia Commonwealth University School of Nursing
Ms. Tracy Zvenyach, University of Maryland School of Nursing

FEDERAL EMPLOYEES PRESENT

Mr. Brian Albertini, NINR/NIH
Dr. James Anderson, DPCPSI/NIH
Ms. Maria Araneta, NINR/NIH
Dr. Noreen Aziz, NINR/NIH
Dr. David Banks, NINR/NIH
Ms. Melissa Barrett, NINR/NIH
Ms. Karen Bashir, NINR/NIH
Mr. Brian Beckham, NINR/NIH
Dr. Yvonne Bryan, NINR/NIH
Dr. Ann Cashion, NINR/NIH
Ms. Andi Cimino, NINR/NIH
Dr. Marguerite Engler, NINR/NIH
Dr. Mary Engler, NINR/NIH
Ms. Ana Ferreira, NINR/NIH
Dr. John Grason, NINR/NIH
Dr. Amanda Green, NINR/NIH
Mr. Kevin Green, NINR/NIH
Ms. Jennifer Greene, NINR/NIH
Dr. Chris Hafner-Eaton, NINR/NIH
Dr. Lynda Hardy, NINR/NIH
Dr. Rebecca Hawes, NINR/NIH
Dr. Karen Huss, NINR/NIH
Mr. Doug Hussey, NINR/NIH
Ms. Deborah Jennings, NINR/NIH
Ms. Ellie Johnson, NINR/NIH
Ms. Mary Kelly, NINR/NIH
Dr. Weiqun Li, NINR/NIH
Dr. Yujing Liu, NINR/NIH
Dr. Sue Marden, NINR/NIH
Ms. Angela Marshall, NINR/NIH
Dr. Donna Jo McCloskey, NINR/NIH

Dr. Arthur Meltzer, NINR/NIH
Ms. Archana Mohale, NINR/NIH
Ms. Mary Murray, NINR/NIH
Ms. Shashi Ravindran, NINR/NIH
Dr. Mario Rinaudo, NINR/NIH
Mr. Charles Rose, NINR/NIH
Dr. Kathy Salaita, CSR/NIH
Mr. Mark Schaaf, NINR/NIH
Ms. Candice Scott, NINR/NIH
Ms. Tara Schwetz, NINR/NIH
Mr. Shawn Stocking, NINR/NIH
Mr. Roberto Tellez, NINR/NIH
Dr. Chelvi Thyagarajan, NINR/NIH
Dr. Xenia Tigno, NINR/NIH
Dr. Catherine Timura, OD/NIH
Dr. Lois Tully, NINR/NIH
Dr. Linda Weglicki, NINR/NIH
Mr. Kevin Wilson, NINR/NIH
Mr. Ronald Wolff, NINR/NIH
Mr. Bryson Young, NINR/NIH