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, 2003

The 50th meeting of the National Advisory Council for Nursing Research (NACNR) was convened on Tuesday, May 20, 2003, 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 adjourned at approximately 5 p.m. The closed session of the meeting, which included consideration of grant applications, began at 9 a.m. on Wednesday, May 21 and adjourned at 12:45 p.m. on the same day. Dr. Patricia A. Grady, Chair of the NACNR, presided over both sessions.

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OPEN SESSION

I. CALL TO ORDER, OPENING REMARKS, COUNCIL PROCEDURES, AND RELATED MATTERS

Dr. Grady called the 50th meeting of the NACNR to order, welcoming all Council members, visitors, and staff. Dr. Grady also welcomed and introduced three new Council members. Rosemary Crisp, R.N., a consultant from Marion, IL, is active in a number of groups and associations that are dedicated to advancing health and wellness. Ms. Crisp's background includes pediatric nursing, and her primary area of interest is women's health. Joyce Newman Giger, Ed.D., R.N., F.A.A.N., Professor, School of Nursing, University of Alabama at Birmingham, has expertise in health promotion strategies for culturally diverse populations. The third new Council member, Frances Munet-Vilaro, Ph.D., R.N., an Associate Professor at the University of Washington School of Nursing, is active in family health care research in Latino populations. Dr. Grady also announced the retirement of *ex officio* member Dr. Paulette Cournoyer from the Council. Dr. Cournoyer was a member of the original Council and has served on the Council since 1986.

Conflict of Interest and Confidentiality Statement

Dr. Mary Leveck, Executive Secretary of NACNR, reminded attendees that the standard rules of conflict of interest applied throughout the Council meeting. Briefly, all closed session material is privileged, and all communications from investigators to Council members regarding any actions on applications being considered during the Council should be referred to National Institute of Nursing Research (NINR) staff. In addition, during either the open or the closed session of the meeting, Council members with a conflict of interest with respect to any topics or any application must excuse themselves from the room and sign a statement attesting to their absence

during the discussion of that application. Dr. Leveck also reminded NACNR members of their status as special Federal employees while serving on the Council and that the law prohibits the use of any funds to pay the salary or expenses of any Federal employee to influence State legislatures or Congress. Specific policies and procedures were reviewed in more detail at the beginning of the closed session and were available in the Council notebooks.

Minutes of Previous Meeting

Council members received a copy of the minutes of the January 28–29, 2003, Council meeting by electronic mail. One correction received prior to the May meeting was incorporated into the minutes included in the Council notebooks. A motion to approve the minutes of the January 28–29, 2003, Council meeting was made and approved unanimously. The minutes of each quarterly NACNR meeting are posted on the NINR Web Site (www.nih.gov/ninr).

Dates of Future Council Meetings

Dates for meetings in 2003 and 2004 have been approved and confirmed. Meeting dates in 2005 were announced during the May Council meeting. Council members should contact Dr. Grady or Dr. Leveck regarding any conflicts or expected absences.

2003
- September 16–17 (Tuesday–Wednesday)

2004
- January 27–28 (Tuesday–Wednesday)
- May 19–20 (Wednesday–Thursday)
- September 14–15 (Tuesday–Wednesday)

2005
- January 25–26 (Tuesday–Wednesday)
- May 17–18 (Tuesday–Wednesday)
- September 13–14 (Tuesday–Wednesday)

II. REPORT OF THE DIRECTOR, NINR (Dr. Patricia A. Grady, Director, NINR)

The Director's report focused on updates since the last Council meeting and on current and impending activities related to budget, NIH, and NINR. Dr. Grady opened her talk by noting that the three logos representing NINR, NIH, and the Department of Health and Human Services (DHHS) now appear on Institute and Center (IC) publications, notices, releases, and other materials. Use of the different logos is aimed at increasing name recognition of and associations among these institutions. In marking NACNR's 50th meeting, Dr. Grady thanked the many individuals who have served on the NACNR in the past 17 years and who have contributed to the legacy of NINR.

Budget Updates

Dr. Grady reviewed recent NINR and NIH budgets, noting that finalization and approval of the fiscal year (FY) 2004 budget are pending. The President's Budget calls for a 1.8 percent

increase in the overall NIH budget and a slightly higher increase of 2.3 percent in the NINR appropriation, which would bring NINR's allocation to $134.579 million. As Dr. Grady pointed out, the current fiscal year is the final year of Congress's 5-year plan to double the NIH budget; NINR's budget also has doubled during this time.

The proposed increase in the NINR budget is commensurate with proposed increases for most of the other ICs across NIH. The largest budget increases are for biodefense research, allocated primarily to the National Institute of Allergy and Infectious Diseases (NIAID); for building constuction; for special National Cancer Institute (NCI) programs; and for the National Center on Minority Health and Health Disparities, which, as a new center, receives higher-than-average funding to allow for the establishment of core scientific, administrative, and personnel programs. Dr. Grady noted that in recent years approval of the budget bill has increasingly occurred later into the FY. The timing of the signing of the bill, in turn, affects the time frame for funding new awards and initiatives.

The largest proportion of the NINR budget, estimated at approximately 76 percent in FY 2003, supports extramural research project grants (RPGs). Operating funds (i.e., grants management and review, workshops, meetings) account for about 6 percent of the NINR budget; research and development constitutes 2 percent; the intramural program represents 1-2 percent; training accounts for about 7 percent, which is almost twice the NIH average; the Centers program (P20s, P30s) constitutes about 5 percent; and other research activities (e.g., career awards) represent 2 percent. The relatively higher training allocation represents NINR's commitment to building the cadre of nurse researchers needed for the future. With modest budget increases, the proportions allocated to each activity, program, or function are expected to remain relatively constant.

Extramural funds are used to award competingand noncompeting research grants, Small Business Innovation Research and Small Business Technology Transfer Research (SBIR/STTR) grants, and training grants. The smallest number of awards is made to the SBIR/STTR Program, to which a proportion of each IC budget is mandated. During the past several years, NINR consistently has funded approximately 10 SBIR/STTR grants annually. The profile of the program has changed, however, as these research projects transition from the smaller, pilot Phase I studies to the larger Phase II investigations. A slight drop in the number of research training awards made in FY 2003 is expected because stipends have increased to become more competitive with other training awards and to meet cost-of-living expenses, as recommended by the National Academy of Sciences, NIH, NACNR, and others. Not including the SBIR/STTR awards, the number of competing plus noncompeting grants represents the total research project grant awards made by NINR each year. Noncompeting applications comprise the majority of awards and account for approximately 60–75 percent of the funding pool; awards are in place for an average of 4 years. Only the first year of funding of multiple-year awards is considered competing. Budget increases represent the increase over baseline funding; the increased funding is put toward new and competing applications. A certain percentage of the noncompeting pool turns over each year and becomes available.

Dr. Grady next discussed RPG success rates for NINR and NIH as a whole. She noted that in FY 2000, NINR was in equipoise with the NIH average success rate, which consistently is about 30–32 percent. A significant 28 percent increase in the NINR budget that year allowed NINR to

fund about one-third of its applications in FY 2000. The subsequent years, however, show the more typical funding pattern for NINR, which falls somewhat below the NIH average. The overall NINR success rate for competing applications for FY 2004 is projected to be approximately 18 percent, based on the President's Budget, which is a notable drop from the 23 percent of applications that are expected to be funded in FY 2003. The projected success rate for NIH overall is 30 percent for both FY 2003 and FY 2004. The anticipated decreased success rate for NINR can be attributed to an increase in applications combined with a much smaller budget increase than in prior years. Dr. Grady pointed out, however, that the rates estimated early in the FY may be lower than the actual rates at the end of the year.

NIH Updates

Dr. Raynard Kington, M.D., Ph.D., has been named the new NIH Deputy Director. Dr. Kington previously was the Director of the Office of Behavioral and Social Sciences Research and served as Acting Director of the National Institute on Alcoholism and Alcohol Abuse. He is familiar with NINR's goals and research activities, and he participated in NINR's research theme meetings in early 2003.

In other news, Dr. Grady reported that the Congressional NIH appropriations hearings were held during the first 2 weeks of April. The House hearings were held on April 2, 8, and 9, and the Senate hearings were held on April 8. Dr. Grady's testimony, in support of the President's proposed NINR budget, described overall progress made in nursing research, higlighted major findings from the past year, and identified promising areas to pursue to justify the budget. The testimony and the justification for the budget may be found on the NINR Web Site.

NINR Updates and Outreach

Dr. Grady reviewed three areas of research opportunity for FY 2004, which the Council helped to develop 2 years ago. The areas of opportunity and the related Program Announcements (PAs) and other activities, such as workshops, released or planned, thus far include:

Chronic Illnesses or Conditions
- Chronic illness self-management and quality of life: children and adolescents

Behavioral Changes and Interventions
- Decreasing low birth weight (LBW) infants among minority populations
- Enhancing health promotion among minority men

Responding to Compelling Public Health Concerns
- End of life: Research on dying children and their families (followup to the Institute of Medicine (IOM) report with the same title)
- Nursing research training and centers

In an update on the evaluation of NINR research training programs, Dr. Grady first reviewed the profile of fellowships awarded since 1986. During the first few years, the largest proportion of awards were made to individuals (F31s, F32s); over time, however, the proportion has shifted so that a larger number of fellows have been supported by institutional training grants (T32s), compared to the individual awards. Also, as the NINR has grown, the number of postdoctoral

fellows has increased. However, the Institute still supports a greater number of predoctoral than postdoctoral fellows, at a ratio of about 3:1. More specifically, for the past 3 years the number of predoctoral F31 fellows is slightly higher than the number of institutional predoctoral fellows. Postdoctoral fellows are largely supported by institutional training grants (T32s), with only a handful of postdoctoral F32/33 grants awarded each year.

A 10-year follow-up analysis of subsequent funding to the 1,441 individuals who received either pre- or postdoctoral funding from NINR was conducted. The analysis revealed that fellows supported by the F31 or F32 mechanism (rather than the T32 mechanism) had a greater success rate as defined by subsequent R or K series funding. More detailed analyses that grouped fellows according to a wide range of subsets, such as early versus late awardees, did not vary the findings or identify any explanatory variables.

Dr. Grady identified some conclusions and reminders of interest not only to NINR, but to the larger research community as well. For example, peer reviewers evaluating competing applications for insitutional awards (T32s) are charged with examining the "success" of graduates with respect to subsequent funding, jobs, and career tracks. NINR needs to ensure that these data are available to the reviewers. Characteristics of the fellow and research training environment also play a role in future success. The match between the sponsor or mentor and the fellow is a critical component of this environment. As suggested by the analysis, pursuit of early doctoral education and funding appear to be reliable indicators of future success for a career in nursing research; thus, such pursuits should be encouraged by faculty and institutions.

In other news, NINR has supported several outreach activities since the last Council meeting. NINR was a cosponsor of the symposium "Linking the Double Helix With Health: Genetics in Nursing Research" to celebrate the 50-year anniversary of the discovery of the double helix. The symposium, which covered a broad range of topics, was held on April 13, 2003; the meeting was well attended and well received. In conjunction with the FY 2004 areas of opportunities, NINR convened a workshop titled "Optimizing Pregnancy Outcomes in Minority Populations" on March 3–4, 2003. Dr. Grady provided testimony on April 2, 2003, to the National Research Council (NRC) in support of its regularly released report "Monitoring the Changing Needs for Biomedical and Behavioral Research Personnel." The NRC will release its recommendations on this issue in the future. One prior recommendation was to facilitate early entry into research careers. Another report, IOM's "Describing Death in America: What We Need to Know," was developed in conjunction with an IOM-based NCI policy advisory board; NINR has worked with the board and with IOM on this report, which is highly relevant to end-of-life issues.

Dr. Grady also announced that Dr. Linda Aiken received AcademyHealth's "Research Paper of the Year" award for her publication in *The Journal of the American Medical Association* on hospital nurse staffing and patient mortality, nurse burnout, and job dissatisfaction (Aiken et al., *JAMA* 288:1987-1993, 2002). The AcademyHealth is the primary organization for health services research and the award is a highly recognized accomplishment.

Upcoming NINR events include the 4th Annual Summer Genetics Institute, to be held June 1–July 25, 2003, on the NIH Campus. Dr. Mindy Tinkle and her associates are responsible for the Institute, which is an intensive, 8-week classroom and laboratory course. Expansion and

incorporation of the course to nursing curricula across the country is the ultimate objective. Finally, NINR will cosponsor the Second Conference of the Council for the Advancement of Nursing Science entitled "Promoting Research Intensive Environments in Clinical Settings," which will be held on September 11–12, 2003 on the NIH campus.

In closing the Director's Report, Dr. Grady mentioned Dr. Hilary Sigmon's transfer to the Center for Scientific Research after a 13-year tenure at NINR. Dr. Grady again welcomed new Council members Ms. Rosemary Crisp and Drs. Joyce Newman Giger and Munet-Vilaro. She also recognized Dr. Cournoyer's departure from the Council and thanked her for her enthusiastic support and ongoing contributions to NACNR. On behalf of the Council, Dr. Grady presented Dr. Cournoyer with a certificate of appreciation for her many years of service to NINR and the Council.

III. THE NIH ROADMAP AND NINR'S RESEARCH THEMES FOR THE FUTURE

(Dr. Grady)

NIH Director Dr. Elias Zerhouni's vision and strategic positioning of NIH over the next 5 years will be founded in part on a "Roadmap" generated through a series of activities that coincide with the doubling of the NIH budget at the end of FY 2003. The activities have fostered communication between intramural and extramural researchers regarding important gaps in science and the identification of directions for the future. NINR has been engaged in NIH-wide Roadmap activites.

Among the evolving scientific and medical challenges facing the Nation and NIH are a shift from acute to chronic diseases, an aging population, health disparities, emerging diseases, and biodefense. The NIH Roadmap is driven by several factors in conjunction with these evolving challenges. The pace of discoveries in the life sciences has been rapid, but needs to be accelerated further as a national priority to address problems facing the Nation and the world. More rapid translational processes also are needed, from findings to practice and from bedside to bench. More effective and novel approaches to solving scientific and health issues are needed with respect to factors such as methodological strategies, clinical practice, cultural issues, and research designs to meet current and future demands.

The NIH Roadmap is being developed by expert panels representing a variety of backgrounds and settings including academia, industry, professional societies, other Federal agencies, and patient advocacy groups. The initial questions addressed by NIH Roadmap participants were:

- What are today's scientific challenges?
- What are the roadblocks to progress?
- What do we need to overcome roadblocks?
- What cannot be accomplished by any single IC, but is the responsibility of NIH as a whole? What can be done as an aggregate that cannot be done individually?

As the groups met, three cross-cutting themes emerged, with subthemes unfolding under each major theme:

New Pathways to Discovery (new ways to conduct science, obtain knowledge, and unlock mysteries)

- Approaches: Develop a comprehensive set of building blocks for biology ; improve understanding of how biological pathways, networks, and systems function together; and expand the field of regenerative medicine in relation to the recovery of function.
- Technologies: Structural biology; bioinformatics and computational biology; molecular libraties; nanotechnology; and molecular imaging (for screening, diagnosis, and therapeutics). Also develop systems that allow for access to resources and information.

Research Teams of the Future (based on increased collaborations, multiple disciplines, technology, basic bench science, and large- and small-scale clinical research)

- Multidisciplinary teams.
- Private-public partnerships.
- Identify and characterize "high-risk" research.

Re-engineering the Clinical Research Enterprise

- National clinical research networks.
- New strategies to facilitate translational research and bridge gaps between clinical and basic research.
- Clinical research workforce training for the future
- Medical informatics, including incorporating telehealth and other information transmission modes into study designs.
- Public trust, including engaging the public in the research enterprise.

NIH currently has 16 working groups that are assessing and compiling information to draft ideas and suggestions that will be the foundation of the NIH Roadmap. Dr. Leveck is a member of the Clinical Workforce Training group, Dr. Claudette Varricchio is a member of the Clinical Networks group, and Dr. Grady is a member of the Multidsiplinary group. Dr. Zerhouni and the IC Directors will attend a retreat in June to review the working groups' ideas.

NINR has been engaged in the process of developing research themes that characterize the research it supports. These themes will also link to the NIH Roadmap activities. As part of this effort, several groups that totalled more than 100 individuals have met since last fall. The Office of Science Policy and Public Liaison assisted the effort by tracking the multitude of ideas generated. Themes and subthemes under development are based on compilations of discussions by these groups. The initial concepts were presented to NACNR and the National Nursing Research Roundtable (which represents about 30 of the most nursing research-intensive societies across the country) for comment. Themes will be presented in their present form to NACNR during this May Council Meeting for further review and discussion (see Section IV). Themes will be revised per the Council's comments and posted on the NINR Web Site for public comment.

The research themes identifed thus far are as follows:

- ♦ Changing lifestyle behaviors for better health
- ♦ Managing the effects of chronic illness to improve quality of life
- ♦ Identifying effective strategies to reduce health disparities

- Harnassing advanced technologies to serve human needs
- Enhancing the end-of-life experience for patients and their families

Dr. Grady noted that these themes were well received by Dr. Zerhouni.

Part of NINR's efforts involve linking NINR's themes to the NIH Roadmap. Among the matches are the NIH theme of new pathways to discovery and the NINR theme of research to incorporate or harness innovative technologies to improve health; NIH's theme of research teams of the future and NINR's subtheme of using multidisciplinary teams to study broader issues such as end-of-life care and experiences; and the NIH theme of re-engineering the Clinical Research Enterprise and the overarching clinical research issues associated with a large proportion of NINR-funded initiatives.

Questions/Comments

A council member asked whether the outcomes identified through the NIH Roadmap will be incentivized (e.g., as an overlay onto PAs and initiatives). Dr. Grady explained that the NIH Director's budget involves resources including a discretionary fund and a 1 percent transfer authority to address special projects and issues such as the Roadmap themes and the prior director's "areas of emphasis." Not all of the incentives will be financial, however.

In response to another question, Dr. Grady commented that part of the rapid translation theme under the NIH Roadmap is to address translation into the consumer arena, and the intention of the working group is to ensure that translation to consumers remains one of the stated goals.

Because the NINR themes appear to be more content driven (around biobehavioral research) than the NIH themes, it may be useful to determine how the NINR themes lead to the NIH themes (e.g., how do the NINR themes lead to new pathways of discovery with an emphasis on multidisciplinary teams and help re-engineer clinical research) rather than to match the NINR themes directly to the NIH themes.

IV. NINR RESEARCH THEMES FOR THE FUTURE (Dr. Grady and Council Discussants)

Five research themes have been identified for NINR emphasis. These themes are part of NINR's planning for the future and will complement the Roadmap developed by NIH and the NINR strategic plan. Each of the five larger research themes presented to the Council for discussion included a list of bulleted research subthemes. The full text of the report, "Research Themes for the Future," including background information and the research subthemes, may be found on the NINR Web Site (www.nih.gov/ninr).

Changing Lifestyle Behaviors for Better Health (Dr. Dolores Sands, Council Discussant)

Dr. Sands commented that this is a challenging, complex research theme that has the potential to be of great benefit to society. The largest gains in life expectancy have come from public health advances at the macro or aggregate level, not at the individual level. One recent DHHS report

noted that individual, unhealthy behaviors account for up to 40 percent of early premature deaths. The worthiness of this research theme is evident, but the theme carries with it several inherent difficulties, including the concept of free will, which can limit individual variance. An array of theories guides this research, including decision theory, change theories, motivation theory, habit-formation theory, health-promotion theory, goal-attainment theory, and others. Research related to this theme may have some overriding methodological issues. For example, benefits of this research may not be evident for several years. Longitudinal designs, in turn, must address special human subjects concerns and long-term access to participants. The benefits for children's health promotion in particular are far reaching, however; studies begun in preschool or elementary school could continue into middle and high school. Measurements must be made over time to determine the incidence and duration of benefits and lifestyle behaviors. In addition, populations that are the most difficult to reach may require novel, interdisciplinary approaches that include cultural anthropologists, social workers, sociologists, teachers, and others.

Questions/Comments

Researchers under this theme also may wish to access grass-roots, community-based groups as part of outreach efforts in addition to those cited above.

Expanding on Dr. Sands' comments about the importance of longitudinal studies to observe a benefit of lifestyle changes on health, one Council member noted that it might take generations to affect a real change within some groups or in relation to certain behaviors. Many habits are learned within families starting from a very young age and time is required to dispel behaviors that are rooted in upbringing and tradition as well as within communities and cultures. Timeframes and intermediate and final endpoints should be identified in study designs. Another Council member commented that the dynamic between the desire to reduce health disparities and changing behaviors also is influenced in part by biology; however, much of it is behavioral as well.

In addressing the theme of new technologies and approaches, this theme may involve identifying new markers of lifestyle behaviors. Investigators tend to consider a behavior "all or none," but modest behavioral changes can have a significant impact on health outcomes (e.g., a 5 percent weight loss and improved status in diabetes). It may behoove researchers to take advantage of this concept.

The emphasis of the theme should convey "action," as exemplified in the first bullet, which supports research with an increased emphasis on changing or stopping unhealthy behaviors and starting or maintaining healthy behaviors.

A general comment was made about the importance of biobehavioral research and public health and how successes in subgroups, not just the general public, demonstrate the strength of the research. These successes, in turn, may be translated to other research areas and/or ICs. Furthermore, it is important to relay successes to the public and to Congress as a demonstration of the impact of nursing research.

Managing the Effects of Chronic Illness To Improve Quality of Life (Dr. Mary Naylor, Council Discussant)

Dr. Naylor commented that this is a very important area of research, particularly given the aging population and the growing number of older persons that will comprise this group. The emphasis on "health in illness" is especially relevant. IOM recently published its list of national health priorities and the top 2 out of 20 cross-cutting issues address persons with chronic illnesses and care coordination and symptom management. The IOM report discusses the need for system interventions as well as individual interventions. Much of this NINR theme emphasizes a continued focus on change at the individual level and at the caregiver level. The theme and subthemes should be expanded to address cultural issues and the context of care and how to embrace multilevel interventions, which could be considered a new path of discovery. In addition, although the research subthemes suggest that much is known in this field, many questions still remain regarding transitions in health throughout the lifespan and overall care and transitions in care over time.

Another approach that may lead to new paths of discovery or to new discoveries is to examine closely the state-of-the-science of the biological, social, and behavioral factors that contribute to positive or negative outcomes in chronic illness. One strategy to accomplish this goal might be to use meta-analyses and integrated reviews to answer questions in chronically ill populations, such as whether interventions in one group work in another group. Answers to this and similar questions also could lead to another type of "translation" of data.

Dr. Naylor also commented that related research efforts should move beyond simply managing the "effects" of chronic illness to managing the illness itself to improve quality of life. The clinical goal should be to try to minimize the negative effects through early interventions and preventive measures rather than managing what happens once the illness begins to progress. This approach, in turn, may alter patient outcomes considerably.

Dr. Naylor noted further that NINR has funded a body of work in chronic illness to improve quality of life that is now at a sophisticated level in many areas in many populations. She suggested that the Institute capitalize on this investment through the translation theme. A tie-in to NIH themes also could be made through the creation of a database on chronic illness (e.g., longitudinal care, different levels of care, and interventions at multiple time points).

Questions/Comments

This theme should perhaps focus on more than just quality of life, because interventions may also improve disease outcomes, and for some diseases, one feature should not be traded for the other (e.g., with diabetes, both quality of life and metabolic outcome are simultaneously important). Thus, this theme may be strengthened by also capturing outcomes for functional status.

Regarding the aging of the population, statistics indicate that women continue to live longer than men in this culture. Thus, NINR might specify women and other populations as of special interest. Council members also commented that there are significant gaps in knowledge about

gender differences in this area. Considerable information is known about prevalence, but little is known, for example, about the factors that influence outcomes. It may therefore be prudent to consider addressing the absence of information in this research area.

One strategy that might address the comments above is to identify factors or influences ("clusters") that are common across illnesses and populations, rather than considering each illness individually. For example, if a 5-percent weight loss improves metabolic function in diabetes, what impact, if any, does this loss have on cardiovascular disease (CVD) risk or on the metabolic factors that influence CVD risk?

Compelling points in the first summary paragraph of this theme are the estimated 100 million persons with some type of chronic disease and the approximately 20 percent of the U.S. population that is expected to be older than 65 by the year 2030. These numbers strongly support the suggestion to move beyond the caregiver-patient relationship to public health. The bioinformatics and biomarkers research resources discussed earlier are favorable matches for these numbers and chronic illness information attached to these populations. In addition, the magnitude and scope of these issues is of great interest to Congress, which NINR should not overlook.

Identifying Effective Strategies To Reduce Health Disparities (Dr. Rosanne Harrigan, Council Discussant)

Dr. Harrigan noted that this is a highly significant area for NINR and across NIH as well. She noted some considerations in how this theme currently is presented. Regarding the statement in the opening summary paragraph, "Each person must have an equal opportunity to attain and maintain optimal health," Dr. Harrigan commented that this may be an overly optimistic goal given uneven playing fields in areas of insurance, accessibility to health care, and other issues. These are national issues challenged by increasingly limited time and resources and that likely contribute to some degree to existing health disparities. As a result, optimal health cannot be guaranteed.

In addition, Dr. Harrigan noted that populations identified as having health disparities should self-determine if and how they are to be studied, and how they would participate in such investigations; they should have a voice in identifying their health concerns as a group. Dr. Harrigan also recommended that cultural self-determination and community-based decisionmaking be incorporated into this theme. This theme also could be strengthened by addressing the issue of "proxy measures." For example, health services research focused on health disparities and access is based on models that assume 80 percent adherence rates. The impact of such assumptions and measures should be viewed carefully.

Other suggestions included reframing to reflect more action-oriented research investigations, distinguishing more carefully between prevention and treatment, documenting and incorporating disease progression into the theme where relevant, adding women to the list of groups in the second bullet about community interventions, proposing that more descriptive work in this area be conducted, incorporating longitudinal studies into this research theme (e.g., what are the

factors that reduce health disparities), and incorporating cost components into all research activities.

Questions/Comments

One Council member noted the importance of developing and ultimately implementing culturally competent and effective interventions that are targeted toward preventing the expression of medical conditions and illnesses typically seen in certain groups (e.g., hypertension in African Americans). Thus, "action verbs" for at least some of the proposed research may not be currently appropriate. In addition, with respect to health disparities in ethnic minorities, if access is not an issue, researchers need to identify the obstacles and factors that lead to the observed health disparities.

Another Council member raised an overriding concern related to three research subthemes: (1) culturally sensitive interventions to modify health disparities; (2) disparities in various groups (e.g., infants, the elderly, rural populations); and (3) stressors in the development of health disparities such as lack of access to care. The Council member noted that effective interventions may be known, but they may not be available through or offered by insurance providers or clinicians. Thus, the larger system likely needs repair with respect to a variety of issues such as financial limitations and lack of racial and ethnic competence to improve translation of existing (and future) knowledge.

These issues fit well with the public-partnership theme. Research efforts are needed that target systemic infrastructural changes to enable the delivery of effective interventions. Approaches that may facilitate these changes include the development of innovative incentives (e.g., to insurance companies) and increased participation and education of persons who receive services about these issues.

Regarding cost issues and interventions, one Council member suggested that the nursing community explore and take greater advantage of economic incentives in conjunction with behaviors and outcomes for a more rapid impact on health and lifestyle. Another member noted that incentives must be used judiciously depending on the issue and the target population.

<u>Harnessing Advanced Technologies To Serve Human Needs</u> (Dr. Dan Hanley, Council Discussant)

Dr. Hanley viewed this research as an important link to the new pathways to discovery theme. He noted that nurses are at both ends of the research; they develop and test devices and they also implement them. The focus on devices and communications works well. To strengthen this theme, NINR should pursue interagency collaborations, i.e., the Institute could explore the recent significant spikes in funding to NIAID for biodefenseand; the Department of Defense- Defense Advanced Research Projects Agency initiatives on human performance monitoring; and the Veterans Administration, which may involve implementation more than development.

Concepts which address telehealth and the use of the Internet to improve health and health care delivery are a possible new path to discovery and these mechanisms can readily generate new

data and information about health, disease, interventions, and other issues. Assessment of these data could, in turn, result in the development and testing of best practices.

With respect to the genetics aspect of this theme, Dr. Hanley commented that the research still is in its early stages in many areas, such as identifying subpopulations (whether for disparity or phenotype). Nurse researchers and nurse clinicians are in a unique position because of the extent of their direct contact with patients and families that is not shared by others in the medical field. The nursing community may be able to apply this exposure to various aspects of genetic research such as identifying genetic patterns of disease risk.

Questions/Comments

Council members commented on the specific role of nursing research in the testing and development of devices, informatics, and other technologies. This area of research is prime for exploring private-industry partnerships. The biotechnologies area could include not only intervention, but also assessment. Decisionmaking should be built into the bioinformatics area. Another suggestion was to expand the physiologic function concept to include devices that address and support cognitive function, mobility, and other processes that already exist and/or are being tested. Nurse researchers should be involved in the testing and utilization of these devices. Finally, this theme should ensure that nursing research clearly is involved in all phases of design and testing of the simpler as well as the more advanced technologies.

Enhancing the End-of-Life Experience for Patients and Their Families (Dr. Lou Burgio, Council Discussant)

Dr. Burgio noted that most Americans support improvements in end-of-life care. However, the cultural mindset in this country is challenged by death and end-of-life experiences. Similarly, health care professionals as a whole have difficulty addressing these issues. This theme should be expanded to include nursing homes and possibly other settings. Dr. Burgio noted that approximately 30 percent of individuals in this country die in nursing homes and that this percentage is on the rise. Additional data show that nursing home residents who receive palliative care have better outcomes at the end of life (e.g., improved pain management, decreased hospitalizations).

There is a need to raise public awareness of palliative care since the general public knows very little about this issue. The focus on improving the management of symptoms and patient comfort at the end of life from a physiological perspective is important. However, Dr. Burgio noted that management of suffering as a psychosocial construct—independent of symptom management—also is critical. Many descriptive and qualitative studies demonstrate that competent patients with terminal illness may choose to live with some pain as long as they can retain the ability to interact with their family and friends. Thus, the concept of suffering includes not only pain, but also a range of spiritual and existential factors that could be incorporated into this area. It was also pointed out that the term "advance directives" may be replaced with "advance care planning."

Questions/Comments

Research on models for palliative care and interactions with the patient should include approaches and attitudes that may be part of a particular culture, race, or ethnicity. For example, some data suggest that African Americans and Mexicans prefer to live longer without palliative care than be pain free and possibly have a shorter life. Advance care planning also appears to vary by culture and ethnicity. Thus, groups seem to define "quality of life" very differently. However, these findings are limited, warrant further study, and should be integrated into this theme.

This theme also could be strengthened by incorporating spirituality and the interface between one's belief system and the delivery or acceptance of various aspects of care. In addition, because bereavement can begin with diagnosis, "bereavement issues" could be rephrased as "bereavement process."

Dr. Grady requested that additional comments and suggestions on any of the themes to be forwarded directly to her or Dr. Leveck.

V. NINR RESEARCH ACTIVITIES: IMPROVING PREGNANCY OUTCOMES

(Dr. Yvonne Bryan, Program Director, NINR)

From its earliest days, NINR has focused on and supported the study of pregnancy outcomes. In January 1988, the newly established National Center on Nursing Research (NCNR) identified "Low Birth Weight: Mothers and Infants" as one of seven research priorities. One of NCNR's first PAs, "Neonatal Nursing Care of Low Birth Weight Infants," was published in 1989. A subsequent PA on "Prevention of Low Birth Weight" was published in 1991. In 1992, NINR released a Request for Applications on "Cooperative Community-Based Perinatal Studies and Interventions in Minority Populations."

Dr. Bryan highlighted findings from some early NINR-supported research projects in the area of maternal reproductive health. One study of more than 1,000 low-income women in Memphis, Tennessee, found that home visits by nurses improved the health and quality of life of low-income mothers and their children. As part of The Malama Project in Hawaii, culturally based perinatal programs were found to improve LBW outcomes in a group of women at high risk of preterm deliveries.

NINR's current portfolio in maternal reproductive health and preterm/LBW includes three major research areas: (1) optimizing maternal health and pregnancy outcomes; (2) care delivery issues associated with pregnancy and the postpartum; and (3) infant health and development, care of infants, and parenting. Dr. Bryan provided a sampling of recent studies in the three areas of the portfolio. Under optimizing maternal health and pregnancy outcomes, research studies have focused on:

- Interventions to prevent LBW in minority populations
- The effects of moderate exercise on pregnancy complications, i.e., to reduce pre-eclampsia in high-risk women
- Reducing unhealthy behaviors in low-income pregnant women
- Interventions to improve maternal and infant outcomes for high-risk women

Care delivery studies associated with pregnancy and the postpartum issues have investigated:

- Neuroendocrine and immunological responses to stress in lactating women
- Culturally sensitive interventions for rural African-American mothers of preterm infants

Research in the infant health and development, care of infants, and parenting area of the portfolio includes:

- An ongoing investigation of long-term effects of LBW on child development that has run for 7 years and plans to continue further into the participants' lives
- Early interventions for irritable and intrauterine drug-exposed infants
- A study on breast- and bottle-feeding readiness in high-risk infants
- Community-based partnership research to promote breastfeeding

Dr. Bryan also highlighted findings under each area in the research portfolio. One 5-year study of women at increased risk of delivering a LBW infant or having a preterm birth found that simple nursing interventions, such as regular telephone monitoring and followup, led to marked decreases in the rates of both LBW babies and babies born before term (Moore et al., *Image: J of Nurs Sch* 31:340-354, 1999). Another study similarly showed that nurse specialist home care interventions reduced prenatal hospitalizations, postpartum rehospitalization days, and the number of preterm infants in women with high-risk pregnancies (Brooten et al., *Am J Managed Care* 7:793-803, 2001). Cost of care also differed significantly between women in the control versus the intervention groups; total costs for the control group were approximately $4.18 million, in contrast with $1.68 million for the intervention group. One review of more than 20,000 hospital records of deliveries and births found increasing relative risk (RR) of uterine rupture following a prior Cesarean delivery with subsequent spontaneous labor (RR, 3.3 percent), induced labor without prostaglandins (RR, 4.9 percent), and induced labor with prostaglandins (RR, 15.6 percent) (Lyndon-Rochelle, *NEJM* 345:3-26, 2001). Another study tracked postpartum maternal factors such as sleep and smoking patterns and habits to identify factors that contribute to optimizing health behaviors in high-risk mothers (Gennaro et al., *Fam Comm Health* 22:16-26, 2000).

Recent initiatives and collaborations include the FY 2004 area of opportunity, "Low Birth Weight in Minority Populations," which was the topic of a recent NINR-sponsored, multidisciplinary state-of-the-science workshop (as described in Section VI of this report), and the FY 2002 PA, "The Role of Gene/Environment Interactions Underlying the Health Disparity of Premature Birth," which NINR cosponsored. Future research in NINR's portfolio on maternal and infant health will focus on optimizing pregnancy outcomes by focusing on underserved populations, identifying and investigating biologic indicators and psychosocial and behavioral antecedents of preterm birth and LBW, and reducing maternal high-risk behaviors.

VI. REPORT ON NINR WORKSHOP: OPTIMIZING PREGNANCY OUTCOMES IN MINORITY POPULATIONS (Dr. Dorothy Powell, Council Discussant)

LBW infants have been an area of interest for NINR since its inception 15 years ago. During that time, as the field has evolved and certain problems occurred at a greater incidence among minority groups, interest shifted from issues within the general population to those within minority populations. In continuing its commitment to studying and identifying interventions that improve pregnancy outcomes, NINR convened a 1½-day workshop titled "Optimizing Pregnancy Outcomes in Minority Populations" on March 3–4, 2003. The workshop united investigators from a range of basic and clinical research fields in a collaborative, multidisciplinary approach to address this issue and formulate future research strategies. Goals of the workshop included reviewing the state-of-the-science of research on pregnancy outcomes in minority populations, fostering new collaborative relationships, identifying research gaps, and proposing novel science to address gaps.

A considerable body of literature relates LBW and very LBW to socioeconomic status and developmental outcomes. However, the underlying biological mechanisms associated with these relationships are not clear. Workshop attendees generated a list of suggested research topics under the areas of biological science, stress, environment, genetics, research techniques and measures, psychology, health behaviors, health care delivery systems, and epidemiology. Key to the application of these suggestions to reduce disparities in pregnancy outcomes in minority populations is a multidisciplinary approach that facilitates the crossfertilization of ideas, perspectives, and expertise. For example, research in one area, such as stress and stressors in the psychosocial context, can build on research in another area, such as biological responses to stress, to elucidate more fully how stress influences poor pregnancy outcomes.

Dr. Powell cited three overarching messages from the workshop: (1) consider study designs that blend biopsychosocial factors, (2) address the need to improve the understanding of race as a factor or contributor to pregnancy outcomes, and (3) identify more clearly the contribution of genetics to these outcomes. Interdisciplinary research will be instrumental in addressing these issues.

The executive summary of the workshop detailing all recommendations is posted on the NINR Web Site at http://www.nih.gov.ninr/news-info/pregnancy.doc.

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Following this final discussion, Dr. Grady adjourned the open session of the meeting and thanked those in attendance for their participation.

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, US Code, and Section 10(d) of the Federal Advisory Committee Act, as amended (5, USC Appendix 2).

Members excused 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, either real or apparent. Members were asked to sign a statement to this effect.

REVIEW OF APPLICATIONS

The members of the NACNR considered 367 research and career development grant applications requesting $82,267,977 in direct costs. (Data obtained from IMPAC II / QVR on May 14, 2003; includes all primary and dual applications; excludes F31, F32, F33, and R03 applications.)

OTHER ITEMS FOR CLOSED SESSION: EXECUTIVE SESSION

The closed session concluded with brief discussion of personnel and proprietary items.

ADJOURNMENT

The 50th meeting of the NACNR was adjourned at 12:45 p.m. on May 21, 2003.

CERTIFICATION

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

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

MEMBERS PRESENT

Dr. Patricia A. Grady, Chair
Dr. Mary Leveck, Executive Secretary
Dr. Peter Buerhaus
Dr. Louis Burgio
Ms. Rosemary Crisp
Dr. Jacqueline Dunbar-Jacob
Dr. Joyce Newman Giger
Dr. Margaret Grey
Dr. David Hanley
Dr. Rosanne Harrigan
Dr. Frances Munet-Vilaro
Dr. Mary Naylor
Dr. Dorothy Powell
Dr. Dolores Sands
Dr. Joan Shaver
Dr. David Ward
Dr. Paulette Cournoyer, *Ex Officio*

MEMBERS OF THE PUBLIC PRESENT

Ms. Debbie Campbell, AACN
Ms. Mary Cerny, SCG, Inc.
Ms. Debra Hall, NIH COPR and University of Kentucky
Ms. Allison Webel, AACN

FEDERAL EMPLOYEES PRESENT

Dr. Nell Armstrong, NINR/NIH
Mr. Ray Bingham, NINR/NIH
Dr. Yvonne Bryan, NINR/NIH
Ms. Linda Cook, NINR/NIH
Ms. Janet Craigie, NHLBI/NIH
Mrs. Diane Drew, NINR/NIH
Ms. Robin Gruber, NINR/NIH
Dr. J. Taylor Harden, NIA/NIH
Dr. Martha Hare, NINR/NIH
Dr. Karin Helmers, CSR/NIH
Dr. Carole Hudgings, NINR/NIH
Ms. Samantha Jarvis, NINR/NIH
Ms. Kai Lakeman, NINR/NIH
Dr. June Lunney, NINR/NIH
Dr. Donna McCarthy, NINR/NIH
Ms. Cindy McDermott, NINR/NIH
Dr. Gertrude McFarland, CSR/NIH
Mrs. Tara Mowery, NINR/NIH
Mr. Daniel O'Neal, NINR/NIH
Dr. Janice Phillips, NINR/NIH
Mr. Eddie Rivera, NINR/NIH
Ms. Siobhan Robinson, NINR/NIH
Dr. Hilary Sigmon, CSR/NIH
Ms. Arlene Simmons, NINR/NIH
Dr. Mindy Tinkle, NINR/NIH
Mr. Mark Waldo, NINR/NIH
Mrs. Sally York, NINR/NIH