

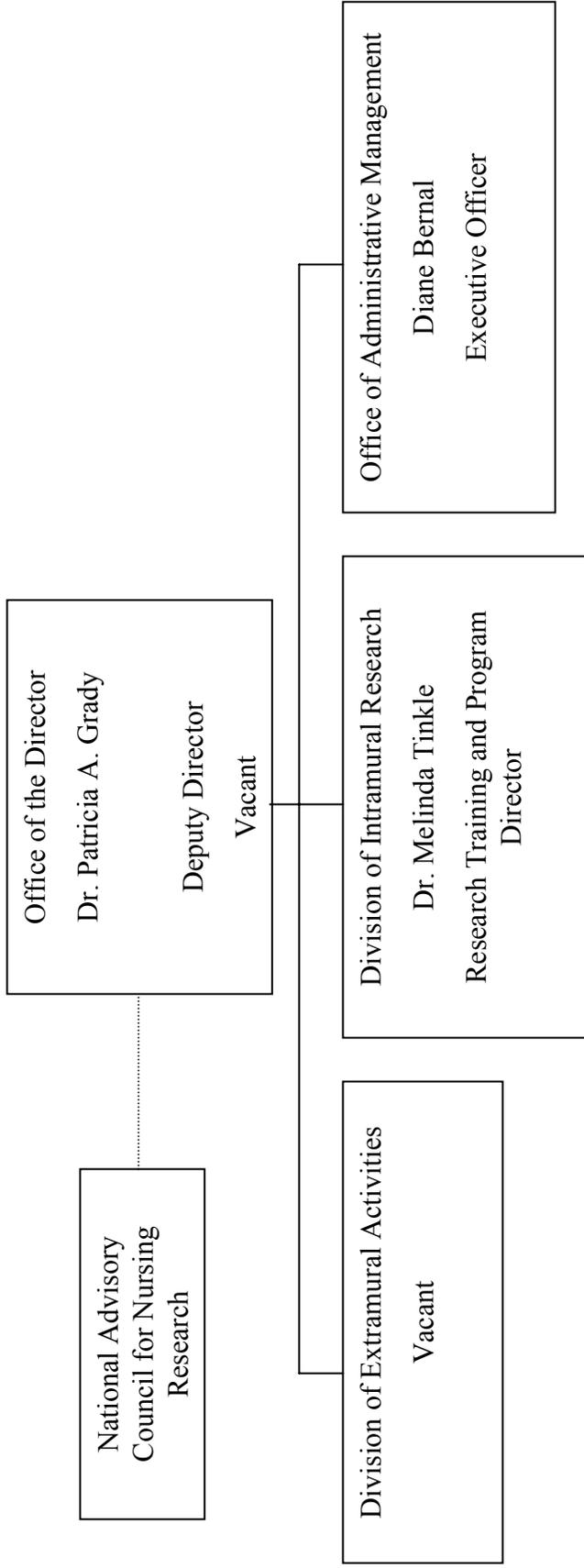
DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research

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National Institutes of Health
National Institute of Nursing Research
Organizational Structure



NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research

For carrying out section 301 and title IV of the Public Health Service Act with respect to nursing research [\$139,198,000] \$138,729,000.

[Department of Labor, Health and Human Services and Related Agencies Appropriations Act, as enacted by the Consolidated Appropriations Act for Fiscal Year 2005]

**National Institutes of Health
National Institute of Nursing Research**

Amounts Available for Obligation 1/

Source of Funding	FY 2004 Actual	FY 2005 Appropriation	FY 2006 Estimate
Appropriation	\$135,555,000	\$139,198,000	\$138,729,000
Enacted Rescissions	(831,000)	(1,126,000)	0
Subtotal, Adjusted Appropriation	134,724,000	138,072,000	138,729,000
Real transfer under NIH Director's one-percent transfer authority to other ICs	(444,000)	0	0
Comparative transfer to NIBIB for Radiology Program	(1,000)	0	0
Comparative transfer to Buildings and Facilities	(22,000)	0	0
Comparative transfer to/from other NIH ICs for NIH Roadmap	444,000	0	0
Subtotal, adjusted budget authority	134,701,000	138,072,000	138,729,000
Unobligated Balance, start of year	0	0	0
Unobligated Balance, end of year	0	0	0
Subtotal, adjusted budget authority	134,701,000	138,072,000	138,729,000
Unobligated balance lapsing	(1,000)	0	0
Total obligations	134,700,000	138,072,000	138,729,000

1/ Excludes the following amounts for reimbursable activities carried out by this account:
FY 2004 - \$72,000 FY 2005 - \$72,000 FY 2006 - \$72,000

**Justification
National Institute of Nursing Research**

Authorizing Legislation: Section 301 and Title IV of the Public Health Service Act, as amended.

Budget Authority:

FY 2004 Actual		FY 2005 Estimate		FY 2006 Estimate		Increase or Decrease	
FTE	BA	FTE	BA	FTE	BA	FTE	BA
35	\$134,701,000	39	\$138,072,000	39	\$138,729,000	0	\$657,000

This document provides justification for the FY 2006 research activities of the National Institute of Nursing Research (NINR), including HIV/AIDS activities. A more detailed description of NIH-wide fiscal year 2006 HIV/AIDS activities can be found in the NIH section entitled "Office of AIDS Research (OAR)".

Introduction

The National Institute of Nursing Research supports clinical and basic research that provides the scientific foundation upon which nurses and other health care professionals base their practice. NINR supports a broad scope of research studies that improve patient, family and community outcomes across the lifespan. NINR's science improves the quality of clinical care in all settings, from hospital to the home, and develops methods to promote healthy lifestyles and reduce risk for diseases and disability. Examples of NINR's research outcomes include: helping people manage symptoms and prevent complications of chronic disease; developing and testing methods to slow the progression of disease; improving diagnosis and treatment of disease by clarifying how disease presentation differs among patient groups; and enhancing understanding of the relationship between nurse staffing and surgical patient mortality. Ultimate outcomes of the science supported by NINR are better quality of life for individuals, their families and caregivers, and the communities in which they live.

Overview

Initiatives to be undertaken in FY 2006 target important national health concerns: an increasing focus on pediatric research in areas such as self-management and quality of life for children and adolescents with chronic diseases, health risk behavior change in children and adolescents especially related to obesity, improving the care of dying children; translating genetics/genomic research into clinical practice; enhancing the self-management of chronic illness in understudied populations; managing clusters of symptoms in patients with cancer and HIV/AIDS; reducing health disparities among minority and underserved women; and continuing NINR's leadership in

end-of-life research with a focus on improving quality of life near the end of life. All of these initiatives include collaboration with other Institutes and Centers across NIH, and with other agencies of the Department of Health and Human Services.

Research training is an important ongoing initiative of NINR. The nation's nursing shortage is compounded by a shortage of nursing faculty. NINR will continue efforts to increase the workforce of nurse investigators to both conduct research and meet the need for nurse faculty. NINR is also working to increase the number of minority nurse researchers and faculty in health disparities research.

The NINR intramural program's laboratory for symptom management is growing. In the past year, this program contributed new knowledge about cachexia and muscle wasting in chronic disease, especially cancer, and about the patterns of decline of function among people at the end of life. Graduates of NINR's *Summer Genetics Institute* continue to incorporate genetic knowledge into extramural settings across the country. Many graduates have published in the scientific literature, submitted research applications which capitalize on their new knowledge in genetics, and integrated content on genetics into university curricula. In 2004, over 1,200 investigators and students completed NINR's online research training course in grantsmanship, designed to help with the submission of successful research applications to NIH.

NINR-supported researchers' publications remain robust, with 298 articles published in FY 2004. A large percentage of all articles captured in FY 2004 from NINR-funded investigators were published in non-nursing journals, an indication of the increasing impact and dissemination of our science.

The Institute continues to have a close working relationship with scientists and clinicians in many disciplines, as well as with those in nursing practice, administration, and education. This year, NINR sponsored the Biobehavioral Research Workshop and the End-of-Life and Palliative Care Research Workshop. NINR also recently co-sponsored a workshop on Cost-Effectiveness Analysis in Research. As a result, we anticipate more research applications from clinical settings and from partnerships between clinical settings and universities, and an increased focus on cost-effectiveness of interventions and clinical trials in the research.

NINR's HIV and AIDS-related research has contributed innovative approaches to complex care problems. A number of studies have focused on how to improve quality of life by managing troublesome symptoms experienced by people with AIDS, particularly weight loss, fatigue, appetite loss, chronic pain, bone loss and other metabolic changes. Methods have been developed and tested that help people with AIDS integrate complex medication regimens into their lives. Still other studies help poor and ethnic minority women with HIV/AIDS manage their disease. Some of these methods promise to reduce health care costs by substituting telephone interventions for visits to providers, while improving both patient motivation and adherence to drug regimens. A number of studies address prevention of infection with HIV, especially among adolescents and youth, and among minority youth and women in particular. NINR's ongoing studies also focus on quality of life among children with HIV. Another

example of NINR's HIV research program in global health is the mentoring of nursing faculty and nurse-midwives from Armenia, Thailand, and southern Africa, in order to develop HIV prevention and HIV-treatment research activities.

Story of Discovery

Science Finds Gender Differences in Recognizing Heart Disease Symptoms

Coronary heart disease (CHD) is still the number one cause of death in the U.S. for both men and women despite the efforts of scientists and healthcare practitioners who continue to explore its causes and effects. However, the mortality rate from CHD has declined by roughly 30% since 1980. Much of this decline can be attributed to research on the value of prevention strategies to reduce or avoid heart disease, including healthy diets to decrease blood levels of lipids and cholesterol, and healthy lifestyles to increase levels of exercise and maintain a healthy body weight. Still, risky behaviors persist in many populations within the US, where obesity, smoking, and sedentary lifestyles often contribute to poor cardiovascular health.

Maintaining a healthy lifestyle is difficult for many people. Recognizing and managing symptoms of heart disease is a major issue for healthcare professionals and patients. Gender and ethnic differences and health disparities need to be better understood in order to address this problem effectively. The National Institute of Nursing Research, since its creation at NIH almost 20 years ago, has been supporting research addressing various aspects of heart disease. Research studies supported by NINR in this area include health promotion and disease prevention, symptom management, and differences in the population's cardiovascular risk according to age, ethnicity and socioeconomic status.

NINR-supported researchers realized early on that poor health habits and dietary patterns, seen even in young children, increased their life-long risk of many forms of cardiovascular disease. One large-scale study established an exercise intervention and conducted long-term follow-up testing for grade school and middle school students. As gender, age, and type of physical activity can have many effects on cardiovascular health, other NINR studies have focused on exercise and diet across these risk factors.

One community-based study related to heart disease and health disparities was a program aimed at young, urban African American men who are at special risk of hypertension. This successful community intervention model brought health care to an underserved population and helped more of these men bring their blood pressure under control.

Research on the symptoms of CHD and myocardial infarction (MI), or heart attack, has often focused on older men, who generally report feeling pain or pressure in the chest. With the increase in NINR research on women's health, several studies have indicated that cardiac-related symptoms in women may be subtle, and that few women understand the health threat of cardiovascular disease. Failure to recognize the meaning and severity of CHD symptoms can lead to a delay in seeking treatment. Since early treatment can help to minimize adverse outcomes of an MI, the National Institutes of Health have placed special research emphasis on the cardiac symptom recognition and treatment-seeking behavior of women.

One research team tackled the issue of symptoms prior to an MI, and how they may differ between men and women. Through a series of preliminary studies, they developed and tested the McSweeney Acute and Prodromal Myocardial Infarction Symptom Survey (MAPMISS) as an instrument to help identify and describe the full range of MI symptoms. First, the researchers interviewed women who had recently suffered an MI and asked them to describe any symptoms experienced prior to, and around the time of, seeking treatment. Further development refined the MAPMISS as a comprehensive, valid, and reliable instrument for health care workers and researchers to use in evaluating both early and acute symptoms of MI for women.

The research team then administered the MAPMISS to over 500 women within 4 to 6 months following an MI. The women averaged 66 years of age, and 44% were low income. Virtually all of the women reported early symptoms in the month prior to their MI. The most severe symptoms were unusual fatigue and sleep disturbance, while others

included shortness of breath, indigestion, and anxiety. Fewer than 30% reported any kind of chest discomfort. Acute symptoms experienced at the time of the MI included shortness of breath, weakness, fatigue, cold sweat, and dizziness. Only 57% reported some degree of pressure, pain, or tightness of the chest at this time. This program of research helped establish that both the early signs of CHD and the acute symptoms of an impending MI may differ between women and men.

The publication of these research results received wide media coverage in several newspapers, including the *New York Post* and the *Chicago Tribune*, and other general public media such as *Reader's Digest*, *Women's Day*, and *Family Circle*. The results were also reported on several television news programs. The principal investigator has been interviewed on the CBS Evening News, and on BBC and NPR radio broadcasts. This article was selected as the American Heart Association Council on Cardiovascular Nursing Research Article of the Year. Translation to practice is being facilitated through adaptation of the research article for Continuing Medical Education (CME) credit and a patient-friendly version of the information has been developed.

Another NINR-supported nurse researcher interviewed women hospitalized with a recent MI to have them describe their decision to seek care. The delay for seeking treatment ranged from 15 minutes to over 2 weeks. Some women knew they would need to seek help, while others tried to manage the symptoms on their own. Even among the group who knew they needed help, many delayed for a variety of reasons. Common symptoms reported by all of the women included chest, jaw, arm, or back pain, along with shortness of breath, fatigue, nausea, and perspiration.

A separate research team interviewed post-MI patients, both men and women, on the cardiac symptoms they experienced prior to their attack, and factors that led them to seek or delay treatment. The sample was 31% female and ranged in age from 21 to 92 years. When first deciding to seek medical treatment, women were more likely than men to believe they were suffering from gastrointestinal distress, stress, or anxiety, and they were more surprised to receive a diagnosis of MI. Women were also less likely than men to be advised by others to seek medical attention. Those who attributed their symptoms to other causes delayed seeking treatment longer than those who recognized the cardiac nature of their problem.

In a related study, a research team looked at gender-related differences peripheral artery disease (PAD), a form of atherosclerosis which often leads to impaired circulation to the legs. They assessed lower extremity circulation, activity tolerance, and quality of life in elders suffering from mild to moderate PAD. All subjects had evidence of diminished leg circulation. On an exercise treadmill test, the walking distance achieved until onset of claudication (leg pain from poor circulation) was not significantly different between men and women. However, the men achieved a greater absolute walking distance than the women. Also, the women reported worse physical functioning, more body pain, and a poorer mood state than the men.

This research contributes to a growing body of evidence to indicate that women experience the symptoms of CHD and other forms of cardiovascular disease differently than men. Women tend to experience a wider range of symptoms, and their symptoms are not as predictable as those of men. More research in this area will elucidate how women with cardiovascular disease view their symptoms and make the decision to seek care. Such findings would help in designing interventions to decrease the delay in seeking treatment, a vital step towards reducing cardiac-related mortality and morbidity for women.

Science Advances

Hygiene: Hygiene practices in the household are important for controlling the transmission of common infectious diseases such as colds, upper respiratory tract infections, and diarrhea. These diseases can place a significant financial burden on families due to missed work or the needs of providing care. This is especially true in the winter season, with the expected prevalence of influenza and common colds, and the current national shortage of the influenza vaccine. However, the prevalence of these infections is difficult to estimate, as most do not come to the attention of a health care provider.

As part of a larger study that took place in an inner-city Hispanic neighborhood in Manhattan, researchers assessed the household characteristics and infectious symptom rates for 238 families, encompassing 1,178 members, over the course of one year. The average family size was 5 members, all lived in apartments, and all had at least one small child. Most families shared a single bathroom and frequently shared towels and washcloths. Family members generally reported they were in good health, but 12% had one or more chronic conditions such as asthma or diabetes. Almost all respondents reported daily bathing and frequent hand washing, and most owned a washing machine and used hot water for laundering whites. During their visits, the researchers found most apartments to be clean. From quarterly interviews, 9 to 12% of family members reported experiencing an infectious symptom within the previous month, with the most common being a cough, runny nose, or fever. Three hygiene factors had a significant relationship with infectious symptoms: families that drank only bottled water had a twofold increase in risk, possibly due to sharing of the bottle, while those that used hot water for laundry or held the belief that germs were mostly likely picked up in the kitchen had lower risks. Knowing what is common practice among households will provide a basis for targeted and culturally appropriate public education campaigns to improve hygiene.

Improving Healthcare Outcomes: NINR-supported clinical trials on the use of Advanced Practice Nurses (APNs) to provide transitional care to bridge the gap between inpatient and home care have demonstrated improved healthcare outcomes, and decreased healthcare costs, for many populations. With the aging of the population in the United States, a greater number of older adults are living longer with chronic health conditions. Elders requiring hospitalization for heart failure have the highest readmission rate of all adult patient groups, indicating a breakdown in care after hospital discharge.

In a randomized, controlled trial, APNs managed the discharge planning and transition to home care for 118 patients aged 65 years and older and hospitalized for heart failure. The APNs coordinated care across different settings, identified patient and caregiver goals, individualized care plans, provided education on medications and treatments, and managed the multiple therapies associated with heart failure. At one year after discharge, patients in the transitional care group had fewer rehospitalizations, hospital days, and deaths, and a lower total cost of care, than patients in a control group who remained in standard care. Providing transitional care for elders with chronic health conditions offers potential benefits to patients for a lower cost. A managed care organization is currently testing this intervention in its system to determine the savings in costs of care.

Self-Care Strategies in Children: In recent years NINR has focused research initiatives on symptom management, pain relief, and palliative and end of life care in children. Pain is a frequent cause for clinical visits. Children often have an impaired ability to express their pain, and this is especially true in those for whom English is not their primary language. One study examined pain experience in minority and majority children with leukemia.

Children with leukemia experience pain from the disease process, treatment, and diagnostic procedures. An NINR study examined children's pain experience, management strategies, and outcomes during the first year after the diagnosis of acute lymphocytic leukemia (ALL) with 95 Spanish- and English-speaking children and their parents. For the children experiencing pain,

the most commonly identified sites were the legs, abdomen, head and neck, and back. Coping and management strategies included watching TV, lying down, describing their pain to their parents, wishing for it to go away, and going to bed. Most children reported a moderate to high effectiveness of pain management strategies, and all maintained above-average functional status. No differences were found between Latino and White children in their assessment of pain. These findings indicate that a variety of self-care strategies can help children with leukemia manage their disease-related pain.

End of Life: NINR has been at the forefront of advancing the science of end of life care, and is designated the lead Institute at the NIH for this area of research. NINR-supported research also addresses improving the quality of life of informal caregivers for patients at the end of life. Informal caregivers are family members or friends who provide care in the home. More than 24 million informal caregivers in the US provide hours of unpaid care, in addition to their other responsibilities for spouse, children, or work. Caregiving can and should be a positive experience, and NINR-funded research focused on reducing the negative effects associated with informal caregiving.

In Oregon, public initiatives emphasize the importance of advance directives to guide end-of-life care. NINR-supported nurse researchers surveyed over 1,100 family caregivers in Oregon who were involved in the care of a recent elderly decedent. Most of the decedents were over 75 years of age, 59% were female, and 83% were White. From caregiver reports, 78% of the decedents had a written advance directive, with Blacks and American Indians having the lowest rates. Strain among the caregivers was experienced in many ways, with 86% feeling emotionally drained, 65% feeling physically drained, 64% feeling confined, and 66% having sleep disturbances. Although almost all decedents had health insurance, caregivers reported a high level of financial burden from having to use family savings, alter job hours, or move to a new home, and from out-of-pocket expenses for medications, transportation, equipment, and paid assistants. Greater caregiver strain was associated with symptom distress, hospice enrollment, caregiver involvement, and financial burden. Given that most decedents had an advance directive, this high degree of strain was unexpected.

Sleep Research: NINR has supported a broad range of sleep research, including interventions for fatigue in breast cancer patients, sleep and pain and opioid use in other cancer patients, exercise and sleep in menopausal women, and sleep in children with chronic conditions such as juvenile rheumatoid arthritis.

One study investigated the relationship between sleep loss and inflammatory response. C-reactive protein (CRP) is an acute marker of the inflammatory response, and has been linked with the development of atherosclerosis. NINR researchers followed serial CRP levels of participants in two sleep deprivation experiments. In the first experiment, 10 healthy male volunteers, with an average age of 27 years, underwent an 88 hour period of total sleep deprivation. The volunteers were provided a balanced diet, but were not allowed caffeine, tobacco, or alcohol. In addition, they were not allowed to exercise. For these subjects, CRP levels increased steadily and significantly during the trial, and systolic blood pressure also increased. In the second experiment, 5 adult volunteers spent 10 days in partial sleep deprivation, allowed 4 hours of sleep each night. CRP levels for this group increased

significantly by the end of the study, and were significantly higher than a control group that slept 8 hours per night, while heart rate also increased. Experimental sleep deprivation led to elevated levels of CRP, and indicator of inflammation, which may contribute to the increased risk of cardiovascular disease morbidity noted with sleep disorders.

NIH Roadmap

September 30, 2004, marked the first anniversary of the Roadmap rollout at NIH. During this period NINR has taken a number of important steps to identify and integrate appropriate areas of science within the NIH Roadmap.

In January 2004, NINR convened the NINR Roadmap Implementation meeting, the first of its kind at NIH. At the meeting, interdisciplinary experts from around the nation explored how best to integrate NINR's research priorities and activities into this new Roadmap structure. Proposed areas for research emphasis included:

- With its focus on symptom management and health promotion, NINR is uniquely situated to catalyze interdisciplinary efforts in addressing the problems of patients with multiple chronic diseases;
- As the lead institute at NIH for end-of-life research, NINR can stimulate even more interdisciplinary research in this area;
- With its history of developing and using behavioral measures, NINR can further promote the development of improved quantitative measurements for behavioral research;
- With its emphasis on prevention, and the growing cadre of nurse investigators trained in the NINR *Summer Genetics Institute*, NINR could lead research in health promotion and disease prevention linked to genetics;
- Self-management, an important component of NINR research, is an opportune area for interdisciplinary research with chronic diseases, including chronic mental illness;
- The elderly should receive special emphasis, particularly with a focus on quality of life measures, chronic diseases, and co-morbidities.

NINR has been an active participant in a number of Roadmap activities. NINR staff participated in the initial reviews of the NIH Director's Pioneer Award and in writing RFAs for some interdisciplinary training initiatives. NINR staff have been active members of many Roadmap working groups, and have served on the steering/advisory committees for the clinical research networks project, the PROMIS project, and the P20 grants on interdisciplinary research. One of NINR's investigators was awarded a Roadmap P20 grant.

In March 2004, NINR convened the National Nursing Research Roundtable, a gathering of the leaders of a number of professional nursing organizations with major research agendas and missions, with the theme focused on the Roadmap. In October 2004, NINR co-sponsored the *State of the Science in Nursing Research* conference, attended by over 800 nurse investigators, which included presentation of many clinical and interdisciplinary research projects.

Re-engineering the Clinical Research Enterprise, and specifically interdisciplinary research within Research Teams of the Future, are integral themes from the *NINR Research Themes for the Future* that complements the NIH Roadmap elements.

Re-engineering the Clinical Research Enterprise: Most of NINR's funded research is clinical in nature, in that it focuses on patients, families, and communities. NINR-supported investigators use their unique clinical insights to bring research questions to the laboratory. NINR research questions focus on barriers that interfere with ability of people to attain and maintain health. NINR investigators also are uniquely positioned to translate research findings into standards of care, regulatory and certification requirements, and the clinical practice of many health providers in a variety of settings. NINR-supported research is often developed in partnership with the communities where new knowledge must be implemented to achieve the overarching goals of *Healthy People 2010*: to improve quality and years of healthy life and to reduce health disparities.

Moving quickly to make the NIH Roadmap come alive for NINR's scientific community, the Institute convened a number of groups to develop "NINR's Research Themes for the Future," which builds bridges between NINR's current and future initiatives and the NIH Roadmap initiatives.

Interdisciplinary Research Teams of the Future: NINR-supported science has a history of multi-disciplinary and interdisciplinary research. Research questions often are drawn from the interface of biologic and behavioral science. For example, in the Story of Discovery, the pathophysiology and gender differences of MI was integrated with clinical medicine and with insights drawn from behavioral science about the motivators of personal health behaviors.

The NINR Research Themes for the Future will guide the development of areas of research opportunity for NINR into the near future. These themes already have an underpinning of interdisciplinary research. For example, enhancing the use of technology in community-based care settings, incorporating communities into approaches to reduce health disparities, and promotion of health by changing lifestyle behaviors are all areas of science which require the contributions of many disciplines.

The NIH Roadmap initiatives encourage more interdisciplinary research of a level and type not seen before. NINR investigators now publish many of their research publications in interdisciplinary journals and in the journals of other specific disciplines, in addition to nursing journals. This demonstrates not only that many disciplines value NINR research, but also that this volume of multidisciplinary publications is a powerful predictor of successful interdisciplinary research and interdisciplinary practice.

Initiatives

NINR has compelling opportunities in FY 2006 to develop and expand research to increase the knowledge base of health professionals and improve the quality of life and advance the health status of patients and families.

Working group on improving cognitive function and quality of life (QOL) in central nervous system (CNS) disorders: Disorders of the CNS that disrupt cognitive function without causing global dementia, such as mild stroke, epilepsy, or multiple sclerosis, are both physically and mentally disabling. By affecting certain cognitive functions while leaving others intact, these disorders may result in impaired decision-making, disrupted psychosocial functioning, reduced productivity and employment, and reduced QOL. This working group meeting identified the need for research to describe the extent to which mild to moderate CNS deficits affect functional outcomes, and to develop and test interventions that address the subtle cognitive changes seen in many CNS disorders.

Increasing health promotion through studies on parenting capacities: Developmental problems and risky health behaviors among children and adolescents are more likely to occur in vulnerable families and in response to ineffective parenting practices. Meanwhile, a positive family environment where parents provide consistent supervision, communicate health and social values, and understand normal development helps to improve childhood outcomes. NINR will solicit research proposals that target the reduction of family risk factors, build upon protective factors, and promote healthy parenting characteristics and family dynamics.

Workshop on research in a multicultural society: The US is a multicultural society, and issues may arise when members of diverse groups interact in the context of health promotion and disease prevention. Many sectors of society lack access to health care services or information and are not benefiting from health care advances. Spirituality and social connectedness, cultural values, and traditional methods are gaining increasing importance in health care. This workshop will examine what we know about culturally sensitive research in a multicultural society and identify current gaps.

Biobehavioral methods to improve health outcomes: Maintaining positive health outcomes over time and across many populations requires an understanding of many biological, behavioral, and social factors. This initiative, derived from an NINR working group, is designed to foster biobehavioral research on the impact of biologic and behavioral factors on health outcomes, disease assessment and prevention, and quality of life. Research proposals on novel methods or emerging technologies is encouraged.

Providing end of life and palliative care in rural and frontier areas: Residents living in isolated rural or frontier areas typically have poor access to health care services, particularly for end-of-life care. This intervention will focus on understanding the scope of the problem and looking for ways to increase and improve end-of-life care through the use of technology, creating new ways to use existing networks and services, designing culturally appropriate interventions for palliative care, identifying possible alternative settings and methods for providing care, and supporting family caregivers.

The NIH Neuroscience Blueprint

Overview -- The Blueprint is a framework to enhance cooperation among fourteen NIH Institutes and Centers that support research on the nervous system. Over the past decade, driven by the science, the NIH neuroscience Institutes and Centers have increasingly joined forces

through initiatives and working groups focused on specific disorders. The Blueprint builds on this foundation, making collaboration a day-to-day part of how the NIH does business in neuroscience. By pooling resources and expertise, the Blueprint can take advantage of economies of scale, confront challenges too large for any single Institute, and develop research tools and infrastructure that will serve the entire neuroscience community.

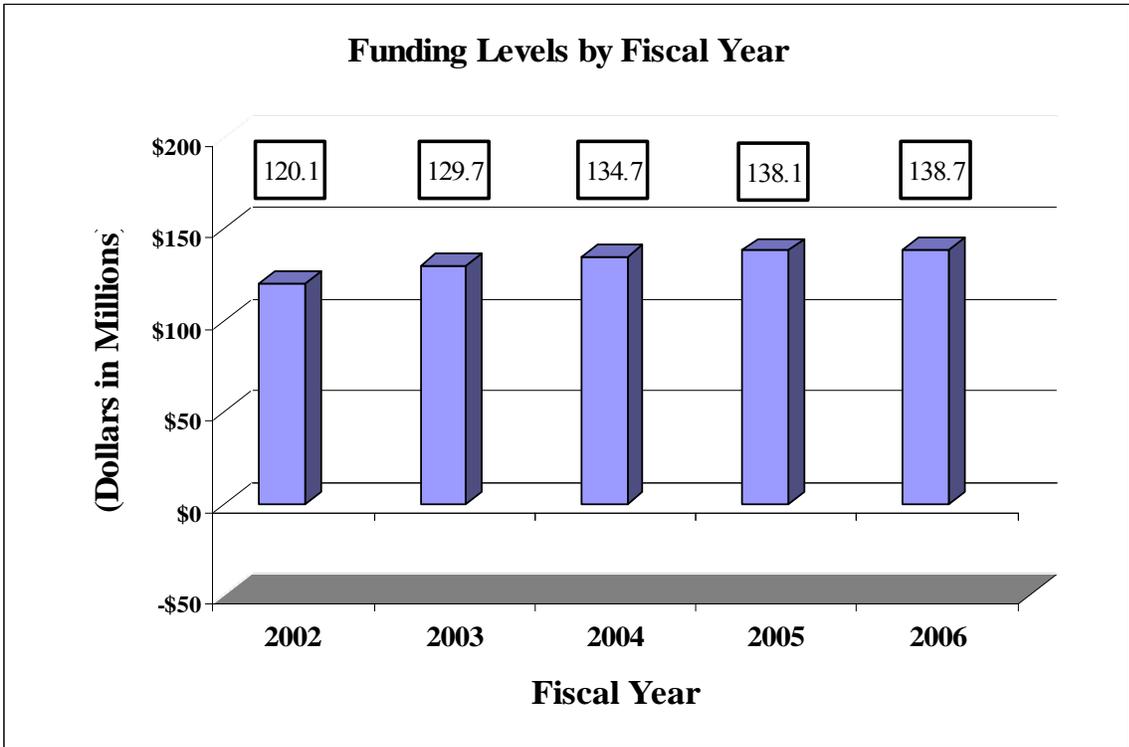
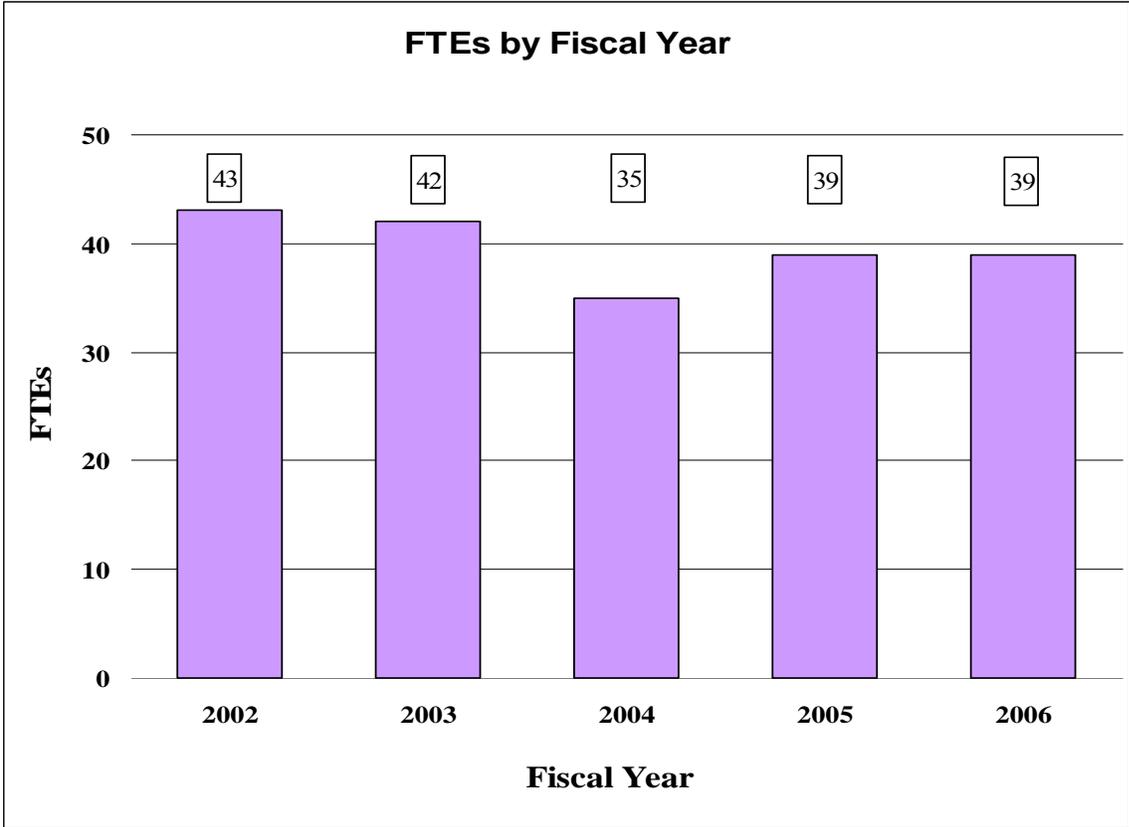
FY2005 -- For fiscal year 2005, the Blueprint participants are developing an initial set of initiatives focused on tools, resources, and training that can have a quick and substantial impact because each builds on existing programs. These initiatives, with the participation of all Blueprint Institutes, include an inventory of neuroscience tools funded by the NIH and other government agencies, enhancement of training in the neurobiology of disease for basic neuroscientists, and expansion of ongoing gene expression database efforts.

FY2006 -- Advances in the neurosciences and the emergence of powerful new technologies offer many opportunities for Blueprint activities that will enhance the effectiveness and efficiency of neuroscience research. Blueprint initiatives for fiscal year 2006 will include systematic development of genetically engineered mouse strains of critical importance to research on nervous system and its diseases and training in critical cross cutting areas such as neuroimaging and computational biology.

Budget Policy

The Fiscal Year 2006 budget request for the NINR is \$138,729,000, an increase of \$657,000 and .5 percent over the FY 2005 Appropriation. Also included in the FY 2006 request, is NINR's support for the trans-NIH Roadmap initiatives, estimated at 0.89% of the FY 2006 budget request. This Roadmap funding is distributed through the mechanisms of support, consistent with the anticipated funding for the Roadmap initiatives. A full description of this trans-NIH program may be found in the NIH Overview.

A five year history of FTEs and Funding Levels for NINR are shown in the graphs below.



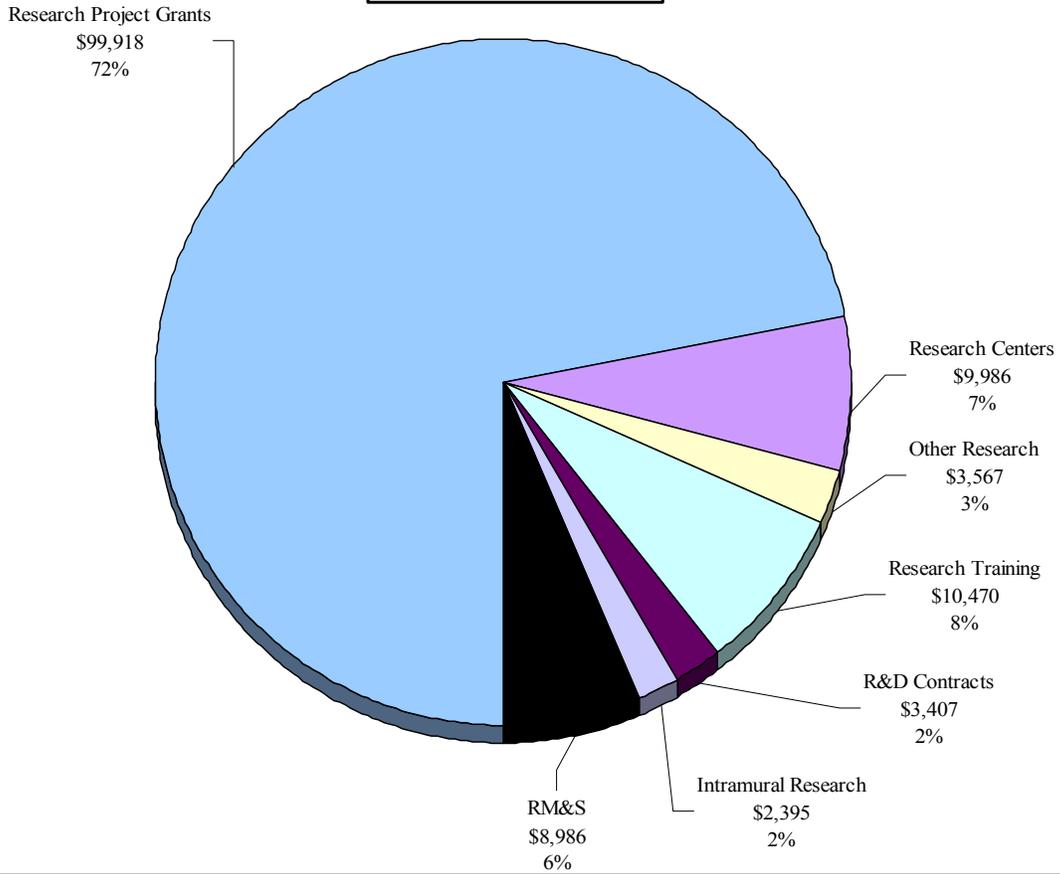
NIH's highest priority is the funding of medical research through research project grants (RPGs). Support for RPGs allows NIH to sustain the scientific momentum of investigator-initiated research while pursuing new research opportunities. We estimate that the average cost of competing RPGs will be \$262,800 in FY 2006. While no inflationary increases are provided for direct, recurring costs in non-competing RPG's, where the NINR has committed to a programmatic increase in an award, such increases will be provided.

Advancement in medical research is dependent on attracting, training, and retaining the best and the brightest individuals to pursue careers in biomedical and behavioral research. In the FY 2006 request, most stipend levels for individuals supported by the Ruth L. Kirschstein National Research Service Awards are maintained at the FY 2005 levels. To help prevent the potential attrition of our next generation of highly trained post-doctoral trainees, stipend levels for post-docs with 1-2 years of experience are increased by 4.0%. This will bring these stipends closer to the goal NIH established for post-doc stipends in March, 2000. In addition, individual post-doctoral fellows will receive an increase of \$500 in their institutional allowance for rising health benefit costs. The need for increased health benefits is particularly acute for these post-doctoral trainees, who, because of their age and stage of life are more likely to have family responsibilities. The increases in stipends and health insurance are financed within the FY 2006 request by reducing the number of Full-Time Training Positions. The NIH believes that it is important to properly support and adequately compensate those who are participating in these training programs so that the programs can continue to attract and retain the trainees most likely to pursue careers in biomedical, behavioral and clinical research.

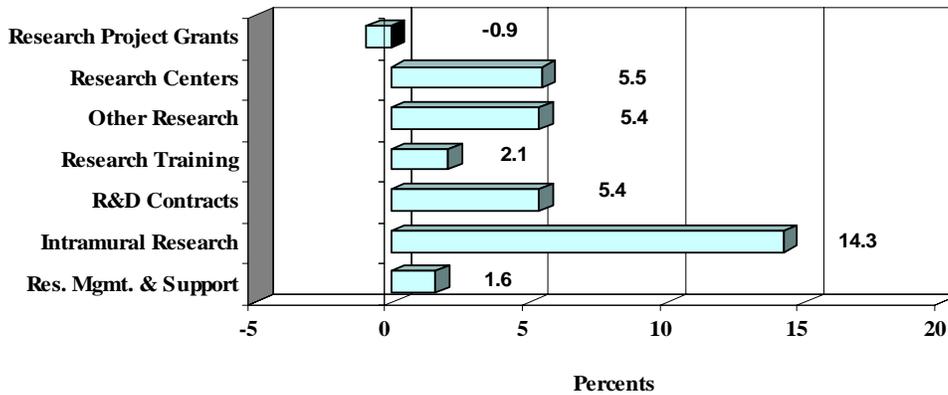
The FY 2006 request includes funding for 36 research centers, 35 other research grants, including 35 clinical career awards, and seven R&D contracts. Intramural Research will receive an increase of 14.3 percent as NINR expands its Intramural Research Program. Research Management and Support will receive an increase of 1.6 percent. NINR is participating in the NIH Neuroscience Blueprint. The FY 2006 request includes \$100,000 for a variety of Neuroscience Blueprint initiatives, including neuroscience cores, training initiatives, and the Neuromouse project.

The mechanism distribution by dollars and percent change are displayed below:

**FY 2006 Budget Mechanism
(Dollars in thousands)**



**FY 2006 Estimate
Percent Change from FY 2005 Mechanism**



NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Budget Mechanism - Total

MECHANISM	FY 2004 Actual		FY 2005 Appropriation		FY 2006 Estimate	
	No.	Amount	No.	Amount	No.	Amount
Research Grants:						
<u>Research Projects:</u>						
Noncompeting	196	\$71,895,000	187	\$69,371,000	184	\$71,180,000
Administrative supplements	(6)	810,000	(5)	250,000	(5)	250,000
<u>Competing:</u>						
Renewal	8	3,610,000	14	4,165,000	14	3,767,000
New	75	20,514,000	79	23,615,000	81	21,352,000
Supplements	1	114,000	1	113,000	1	109,000
Subtotal, competing	84	24,238,000	94	27,893,000	96	25,228,000
Subtotal, RPGs	280	96,943,000	281	97,514,000	280	96,658,000
SBIR/STTR	14	3,214,000	14	3,278,000	14	3,260,000
Subtotal, RPGs	294	100,157,000	295	100,792,000	294	99,918,000
<u>Research Centers:</u>						
Specialized/comprehensive	33	8,047,000	36	9,378,000	36	9,864,000
Clinical research	0	0	0	0	0	0
Biotechnology	0	56,000	0	88,000	0	122,000
Comparative medicine	0	0	0	0	0	0
Research Centers in Minority Institutions	0	0	0	0	0	0
Subtotal, Centers	33	8,103,000	36	9,466,000	36	9,986,000
<u>Other Research:</u>						
Research careers	32	2,980,000	35	3,039,000	35	3,165,000
Cancer education	0	0	0	0	0	0
Cooperative clinical research	0	0	0	0	0	0
Biomedical research support	0	0	0	0	0	0
Minority biomedical research support	0	3,000	0	3,000	0	4,000
Other	0	307,000	1	343,000	1	398,000
Subtotal, Other Research	32	3,290,000	36	3,385,000	36	3,567,000
Total Research Grants	359	111,550,000	367	113,643,000	366	113,471,000
<u>Research Training:</u>	<u>FTEs</u>		<u>FTEs</u>		<u>FTEs</u>	
Individual awards	92	2,858,000	88	2,082,000	88	2,082,000
Institutional awards	186	7,160,000	189	8,176,000	186	8,388,000
Total, Training	278	10,018,000	277	10,258,000	274	10,470,000
Research & development contracts (SBIR/STTR)	5 (0)	2,990,000 (6,000)	7 (0)	3,233,000 (0)	7 (6,000)	3,407,000 (6,000)
Intramural research	<u>FTEs</u> 3	1,646,000	<u>FTEs</u> 5	2,096,000	<u>FTEs</u> 5	2,395,000
Research management and support	32	8,497,000	34	8,842,000	34	8,986,000
Cancer prevention & control	0	0	0	0	0	0
Construction		0		0		0
Buildings and Facilities		0		0		0
Total, NINR	35	134,701,000	39	138,072,000	39	138,729,000
(RoadMap Support)		(463,000)		(873,000)		(1,241,000)
(Clinical Trials)		(1,630,000)		(1,671,000)		(1,679,000)

NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Budget Authority by Activity
(dollars in thousands)

ACTIVITY	FY 2004 Actual		FY 2005 Appropriation		FY 2006 Estimate		Change	
	FTEs	Amount	FTEs	Amount	FTEs	Amount	FTEs	Amount
<u>Extramural Research:</u>		\$124,558		\$127,134		\$127,348		\$214
Subtotal, Extramural research		124,558		127,134		127,348		214
Intramural research	3	1,646	5	2,096	5	2,395	0	299
Res. management & support	32	8,497	34	8,842	34	8,986	0	144
Cancer Control & Prevention	0	0	0	0	0	0	0	0
Total	35	134,701	39	138,072	39	138,729	0	657

NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Summary of Changes

FY 2005 Estimate		\$138,072,000	
FY 2006 Estimated Budget Authority		138,729,000	
Net change		657,000	
CHANGES	FY 2005 Appropriation		Change from Base
	FTEs	Budget Authority	FTEs Budget Authority
A. Built-in:			
1. Intramural research:			
a. Within grade increase		\$669,000	\$11,000
b. Annualization of January 2005 pay increase		669,000	6,000
c. January 2006 pay increase		669,000	12,000
d. One less day of pay		669,000	(3,000)
e. Payment for centrally furnished services		0	0
f. Increased cost of laboratory supplies, materials, and other expenses		1,418,000	27,000
Subtotal		53,000	
2. Research Management and Support:			
a. Within grade increase		3,486,000	59,000
b. Annualization of January 2005 pay increase		3,486,000	32,000
c. January 2006 pay increase		3,486,000	61,000
d. One less day of pay		3,486,000	(14,000)
e. Payment for centrally furnished services		1,677,000	13,000
f. Increased cost of laboratory supplies, materials, and other expenses		3,642,000	67,000
Subtotal		218,000	
Subtotal, Built-in		271,000	

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Summary of Changes--continued

CHANGES	2005 Current			
	Estimate Base		Change from Base	
	No.	Amount	No.	Amount
B. Program:				
1. Research project grants:				
a. Noncompeting	187	\$69,621,000	(3)	\$1,809,000
b. Competing	94	27,893,000	2	(2,665,000)
c. SBIR/STTR	14	3,278,000	0	(18,000)
Total	295	100,792,000	(1)	(874,000)
2. Research centers	36	9,466,000	0	520,000
3. Other research	36	3,385,000	0	182,000
4. Research training	277	10,258,000	(3)	212,000
5. Research and development contracts	7	3,233,000	7	174,000
Subtotal, extramural				214,000
6. Intramural research	<u>FTEs</u> 5	2,096,000	<u>FTEs</u> 0	246,000
7. Research management and support	34	8,842,000	0	(74,000)
8. Cancer control and prevention	0	0	0	0
9. Construction		0		0
10. Building and Facilities		0		0
Subtotal, program		138,072,000		386,000
Total changes	39		0	657,000

NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research
Budget Authority by Object

	FY 2005 Appropriation	FY 2006 Estimate	Increase or Decrease
Total compensable workyears:			
Full-time employment	39	39	0
Full-time equivalent of overtime & holiday hours	0	0	0
Average ES salary	\$0	\$0	\$0
Average GM/GS grade	11.9	11.9	0.0
Average GM/GS salary	\$77,167	\$79,212	\$2,045
Average salary, grade established by act of July 1, 1944 (42 U.S.C. 207)	\$0	\$0	\$0
Average salary of ungraded positions	113,231	116,232	3,001
OBJECT CLASSES	FY 2005 Appropriation	FY 2006 Estimate	Increase or Decrease
Personnel Compensation:			
11.1 Full-Time Permanent	\$2,925,000	\$3,043,000	\$118,000
11.3 Other than Full-Time Permanent	351,000	365,000	14,000
11.5 Other Personnel Compensation	25,000	26,000	1,000
11.7 Military Personnel	0	0	0
11.8 Special Personnel Services Payments	102,000	106,000	4,000
Total, Personnel Compensation	3,403,000	3,540,000	137,000
12.0 Personnel Benefits	752,000	779,000	27,000
12.1 Military Personnel Benefits	0	0	0
13.0 Benefits for Former Personnel	0	0	0
Subtotal, Pay Costs	4,155,000	4,319,000	164,000
21.0 Travel & Transportation of Persons	209,000	211,000	2,000
22.0 Transportation of Things	10,000	11,000	1,000
23.1 Rental Payments to GSA	0	0	0
23.2 Rental Payments to Others	63,000	65,000	2,000
23.3 Communications, Utilities & Miscellaneous Charges	45,000	47,000	2,000
24.0 Printing & Reproduction	69,000	70,000	1,000
25.1 Consulting Services	20,000	21,000	1,000
25.2 Other Services	1,328,000	1,391,000	63,000
25.3 Purchase of Goods & Services from Government Accounts	7,423,000	7,785,000	362,000
25.4 Operation & Maintenance of Facilities	25,000	26,000	1,000
25.5 Research & Development Contracts	31,000	31,000	0
25.6 Medical Care	40,000	40,000	0
25.7 Operation & Maintenance of Equipment	43,000	43,000	0
25.8 Subsistence & Support of Persons	0	0	0
25.0 Subtotal, Other Contractual Services	8,910,000	9,337,000	427,000
26.0 Supplies & Materials	175,000	177,000	2,000
31.0 Equipment	535,000	551,000	16,000
32.0 Land and Structures	0	0	0
33.0 Investments & Loans	0	0	0
41.0 Grants, Subsidies & Contributions	123,901,000	123,941,000	40,000
42.0 Insurance Claims & Indemnities	0	0	0
43.0 Interest & Dividends	0	0	0
44.0 Refunds	0	0	0
Subtotal, Non-Pay Costs	133,917,000	134,410,000	493,000
Total Budget Authority by Object	138,072,000	138,729,000	657,000

NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research

Salaries and Expenses

OBJECT CLASSES	FY 2005 Appropriation	FY 2006 Estimate	Increase or Decrease
Personnel Compensation:			
Full-Time Permanent (11.1)	\$2,925,000	\$3,043,000	\$118,000
Other Than Full-Time Permanent (11.3)	351,000	365,000	14,000
Other Personnel Compensation (11.5)	25,000	26,000	1,000
Military Personnel (11.7)	0	0	0
Special Personnel Services Payments (11.8)	102,000	106,000	4,000
Total Personnel Compensation (11.9)	3,403,000	3,540,000	137,000
Civilian Personnel Benefits (12.1)	752,000	779,000	27,000
Military Personnel Benefits (12.2)	0	0	0
Benefits to Former Personnel (13.0)	0	0	0
Subtotal, Pay Costs	4,155,000	4,319,000	164,000
Travel (21.0)	209,000	211,000	2,000
Transportation of Things (22.0)	10,000	11,000	1,000
Rental Payments to Others (23.2)	63,000	65,000	2,000
Communications, Utilities and Miscellaneous Charges (23.3)	45,000	47,000	2,000
Printing and Reproduction (24.0)	69,000	70,000	1,000
Other Contractual Services:			
Advisory and Assistance Services (25.1)	20,000	21,000	1,000
Other Services (25.2)	1,328,000	1,391,000	63,000
Purchases from Govt. Accounts (25.3)	4,595,000	4,957,000	362,000
Operation & Maintenance of Facilities (25.4)	25,000	26,000	1,000
Operation & Maintenance of Equipment (25.7)	43,000	43,000	0
Subsistence & Support of Persons (25.8)	0	0	0
Subtotal Other Contractual Services	6,011,000	6,438,000	427,000
Supplies and Materials (26.0)	175,000	177,000	2,000
Subtotal, Non-Pay Costs	6,582,000	7,019,000	437,000
Total, Administrative Costs	10,737,000	11,338,000	601,000

NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research

SIGNIFICANT ITEMS IN THE HOUSE APPROPRIATIONS COMMITTEE REPORT

FY 2005 House Appropriations Committee Report Language (H. Rpt. 108-636)

Item

Nurse management of chronic illness – The Committee is aware of the increasing role nurses play in patient education and management of chronic diseases like asthma and chronic obstructive pulmonary disease (COPD). The Committee encourages NINR to partner with other institutes to develop effective patient education and management models for nurses to use in the care and management of asthma and COPD. (p. 94)

Action taken or to be taken

NINR has supported research on the effectiveness of patient education and symptom management interventions for the care and management of chronic conditions by the patient or by the health care provider. These research projects focused on the development and validation of interventions that could be incorporated into clinical practice by health care providers, including nurses, if they are found to be feasible and to have a positive effect on patient outcomes. Examples are:

Cellular inflammation and airway size in asthma patients: In assessing and evaluating airways inflammation in asthma, neutrophil white blood counts have received less attention than eosinophil counts. However, neutrophil counts are associated with decreased airway size in asthma and may provide a better way of assessing the progress of airways inflammation in this disease.

Helping asthmatic children manage symptoms: Monitoring asthma symptoms helps in planning treatment strategies and facilitating assessment of environmental situations that make asthma worse. Children who used peak flow meters to assess breathing showed better improvement in asthma severity than those who merely kept a record of symptoms.

Upper Body Strength Training and COPD. This study examines effects of upper body (UB) strength training to enhance adherence to treatment. Aims are to compare short/long term effects after UB training on breathing difficulties during physical activities and abilities to perform exercise. Biobehavioral measures include x-ray absorptiometry to document changes in UB muscle mass and accelerometers to objectively measure frequency and duration of home exercises. The long term aim of the study is to decrease COPD exacerbations.

NINR will seek partnerships and collaborations with other ICs to promote research in this area. NINR held an invitational two day working group meeting with behavioral, biological, and immunological science experts representing the National Heart, Lung, and

Blood Institute (NHLBI), the National Institute for Biomedical Imaging and Bioengineering (NIBIB), the Office of Behavioral and Social Sciences Research (OBSSR), and others, to examine current knowledge of biobehavioral research in chronic diseases and to provide recommendations for further research. A research initiative for 2006 is being prepared that will encourage biobehavioral research in chronic diseases. NINR will seek co-sponsorship of the initiative from other institutes. One outcome of such research would be better information about the interaction between the disease process and psychological and behavioral factors. This in turn will help to inform patient education programs. For example, knowledge about the relationship between asthma pathology and symptoms experienced by patients will aid patient understanding of the self management role and its importance in disease management.

Item

Health disparities – The Committee commends NINR for its longstanding support of research to reduce health disparities among minorities. Along with research in promoting the health of minority men, NINR has focused past efforts on identifying risk factors and strategies to reduce the high rates of low birth-weight babies born to minority women. The Committee encourages NINR to expand these efforts to study other women’s health issues and to measure health indicators such as physiological, socioeconomic, emotional, environmental, cultural, and genetic factors. The seventeen recently-initiated Nursing Partnership Centers to Reduce Health Disparities are of special interest to the Committee. NINR’s goal of bringing together research-intensive schools of nursing and minority-serving schools of nursing into partnerships to promote health disparities research and expand the number of minority nurse researchers is commendable. The Committee looks forward to learning more about this creative approach. (p.95)

Action taken or to be taken

NINR continues to address research in women’s health issues. Two new initiatives broaden the scope of the disparities to be examined: Health Disparities Among Minority and Underserved Women and Enrolling Women and Minorities in HIV/AIDS Research Trials.

There are nine minority serving institutions who are participating with eight research intensive institutions in the “Nursing Partnership Centers on Health Disparities” initiative. The purpose of the initiative is to foster the development of nursing partnerships between researchers, faculty, and students at health disparity research programs. The Nursing Partnership Centers on Health Disparities at these institutions and other institutions with established health disparity research programs will expand the development of research infrastructure, and the research capacity of minority nurse investigators, at minority schools of nursing.

The investigators at these partnership research centers continue to work together successfully. The number of minority investigators engaged in the research, the number of research projects/planned projects, the number of different disease areas focused on in

the research, and the number of minority research subjects all continue to increase. Although research activities of the partnerships are early in their development, two completed pilots studies are reported here:

In a pilot study examining the use of traditional Chinese medicines (TCM) versus western medicine among Chinese-Americans with type 2 diabetes living in Hawaii was found that although 89% of subjects visited western medical clinics during acute illness, 56% of subjects used TCM in combination with western medicine, and only 7.5% of these informed their western medicine provider of using TCM. Subjects who used TCM reported using a wide variety of TCMS and well as other alternative and complementary treatments such as acupuncture and tai chi. TCMS were often perceived as having no side-effects. This pilot emphasizes the need for better communication between the health care provider and the patient in regard to the use of TCM and other alternative and complementary treatments, as well as the need for greater evidence-based treatments education for patients.

A pilot from another Center found good validity of the “Level of Service Inventory – Revised” (LSI-R), an assessment of recidivism risk in minority female offenders. These results support the use of evaluation to determine placement of female offenders under community supervision.

The Partnership Centers convened in October 2003 to identify challenges they have encountered in promoting health disparities researchers and research, as well as to identify new areas of opportunities. Markers of success reflecting positive research career development of minority investigators and health disparities research were identified and include: Advanced opportunities and strategies to enhance collaboration across centers and a web site to promote collaborations, exchange of ideas, and communication. Current efforts are focused on increasing the independence of the minority-serving institutions and fostering collaborations with other schools and departments in research efforts to benefit the underserved communities.

Item

End-of-life care – Dissatisfaction with care during the last stages of life has been widely reported by recent studies. The Committee applauds NINR’s plans to focus on children during the end-of-life, especially since the Institute of Medicine recently identified this population as being overlooked by research. (p.95)

Action taken or to be taken

NINR remains committed to stimulating and supporting research for children facing life threatening illnesses. A workshop was held entitled *Moving the Research Agenda forward for Children with Cancer* which discussed the trajectories of dying and models of care for patients, parents, siblings and healthcare providers at the end-of-life. Potential areas of research that were identified included end-of-life treatment decision-making; the

epidemiology of dying in children/adolescents; the experience of surviving the death of a child; outcomes of symptom interventions; and the cost of dying and the impact of cost factors on policy making.

These efforts led to a request for application entitled *Research to Improve Care for Dying Children and their Families*. Areas of research that are supported by this initiative include: *Good Parent Intervention at End of Life*, *Pediatric Advanced Illness Care Coordination*, and *Predicting Pediatric Risk of Death after Hospitalization*. Although these studies are in an early phase, they show a great deal of promise in increasing and improving scientific knowledge to guide the care of dying children and their families.

To continue this mission, the NINR issued the program announcement (PA) *Improving Care of Dying Children and their Families*. This PA seeks to encourage research that will improve the quality of life for children who are approaching the end-of-life, as well as the quality of the dying process, and bereavement following the death for the children's families, friends, and other care providers. Research is needed to identify and test approaches that health care providers can implement to improve the care of dying children in all settings, including children dying from a stigmatizing illness such as HIV/AIDS in areas with limited resources. NINR has taken the lead in promoting research in this area and has encouraged the participation of other institutes on this initiative.

NINR continues to fulfill its research mission for the future in end-of-life. NINR is convening, with the NIH Office of Medical Applications of Research (OMAR), a State-of-the-Science Conference on *Improving End-of-Life Care* in December of 2004. The conference addressed the following key questions: what defines the transition to end-of-life; what outcome variables are important indicators of the quality of the end-of-life experience for the dying person and for the surviving loved ones; what patient, family, and health care system factors are associated with improved or worsened outcomes; what processes and interventions are associated with improved or worsened outcomes; and what are future research directions for improving end-of-life care? An important session of this conference will explore the key factors affecting dying children and their families. An independent State-of-the-Science panel will explore and assess the scientific evidence regarding care at the end of life which will become part of an overall prepared state-of-the-science statement that is issued at the conclusion of the conference.

NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research

SIGNIFICANT ITEMS IN THE SENATE APPROPRIATIONS COMMITTEE REPORT

FY 2005 Senate Appropriations Committee Report Language (H. Rpt. 108-345)

Item

Minority Health and Disparities – The Committee commends NINR for its support of research to reduce disparities in the health of minority populations and is pleased that this will receive continued emphasis. It is important to reduce low birth-weight rates for minority women, which can be 50 percent higher than for white women. NINR's focus on early identification of risk factors and chronic diseases during pregnancy and on health promotion for pregnant minority women will be important to lower the unacceptably high number of low birth-weight babies in the country. NINR is also urged to continue its successful research in promoting the health of minority men who have a reduced life expectancy compared to women. Research of effective health promotion strategies such as smoking cessation, nutrition, physical activity, and increased management of stress are critical to improving and extending the life cycle of minority men. (p. 143)

Action taken or to be taken

NINR is committed to reducing health disparities across the nation as attested by the relatively large number of funded studies focusing on minority health/health disparities. NINR funded investigators are conducting a variety of studies related to the leading causes of morbidity, mortality, and disability among diverse populations of racial and ethnic racial minorities across the lifespan. Significant areas of research focus on several of the leading health indicators namely physical activity, overweight/obesity, tobacco use, substance abuse, responsible sexual behavior, mental health promotion, injury and violence. Additionally, NINR funded investigators examine the influence of psychosocial and cultural variables that influence health seeking behaviors and health outcomes of racial and ethnic minority populations. Recently published NINR supported studies include a community based health care model for American Indian families that used storytelling as the vehicle to convey health messages on thirteen reservations. These messages were designed to help motivate tribal members to adopt health promoting behaviors. Among currently ongoing studies is one on cardiovascular health in children and youth. This large, longitudinal project follows children through puberty to study risk factors for cardiovascular disease, and the contributions of obesity, physical activity and lipid profiles to this risk.

NINR also provides leadership by convening workgroups around complex health disparity issues that require collaborative interdisciplinary biobehavioral approaches. A specific example is the workgroup *Optimizing Pregnancy Outcomes in Minority Populations* convened on March 3-4, 2003 in Bethesda, Maryland. This workgroup brought together researchers in the fields of nursing, epidemiology, psychology, and clinical and basic sciences in a collaborative, multi-disciplinary approach to address this issue and formulate future research strategies. Topics presented and discussed ranged from the psychosocial and biological influences on pregnancy in minority populations, stress and neuroendocrine mechanisms in prematurity and low birth weight outcomes, to behavioral influences and maternal health, and environmental exposures. In addition, new methodological approaches were discussed as well as the need for better identification of physiological pathways and biochemical markers for disparities in pregnancy outcomes. The recommendations from this workgroup formed the basis for PA 04-027 *Reducing Preterm and Low Birth Weight in Minority Families*.

In addition to the above PA, NINR is currently soliciting research applications related to the following Health Disparities Program Announcements:

- Health Disparities among minority and underserved women
- Health Promotion Among Racial and Ethnic Males
- Community Partnered Interventions To Reduce Health Disparities

NINR also serves as a cosponsor on the following NIH wide initiatives addressing Health Disparities:

- Race/Ethnic Disparities in the Incidence of Diabetes Complications
- The Role of Gene-Environmental Interactions Underlying the Health Disparity of Premature Birth

NINR supports research core centers that provide infrastructure for studies that will lead to evidence-based practice guidelines that will affect health outcomes. Targeted study groups include chronic illness, vulnerable populations, and geriatric populations.

Item

Nurse-managed Health Centers – The Committee urges the NINR to increase funding for nurse-managed health centers and advanced practice nurses in research and demonstration projects. (p. 144)

Action taken or to be taken

The NINR supports comprehensive research training and career development programs (fellowships, career development awards and infrastructure support through Centers) to prepare individuals to conduct nursing research in interdisciplinary settings. This is part of the broader NINR mission to support clinical and basic research to establish a scientific basis for the care of individuals across the life span - from management of patients during illness and recovery to the reduction of risks for disease and disability, the promotion of healthy lifestyles, promoting quality of life in those with chronic illness, and care for individuals at the end-of-life. NINR supports research on the effectiveness

of advanced practice nurses and their impact upon patient health outcomes. Numerous studies, supported by NINR, have shown that advanced nurse practitioners provide more or equivalently effective care compared to physicians. These studies are often supported through collaborations with AHRQ and focus on patient outcomes rather than practice issues. Examples follow:

Nursing's Impact on Quality of Life Outcomes in Ovarian Cancer: Women who develop ovarian cancer usually present with advanced disease at diagnosis and these women are at high risk for prolonged physical problems and sustained psychological distress over their illness trajectory. A randomized clinical study is testing the effects of an intervention on quality of life (QOL) outcomes (anxiety, depression, uncertainty, overall QOL). The intervention is administered by an oncology advanced practice nurse working in consultation with a psychiatric consultation-liaison nurse. This study has implications for psychological distress and physical health recovery after breast cancer diagnosis and may also have implications for follow-up care in other serious illnesses.

Effects of Telemonitoring of Heart Failure Patients and Caregivers: This pilot study will evaluate whether electronic home monitoring (EHM) by an advanced practice nurse is more effective than usual home care in enhancing patient outcomes and decreasing hospital costs. Results will determine whether post-hospital discharge monitoring and support through EHM reduces the proportion of readmissions and emergency department visits and increases the time between discharge and readmission for older adults with heart failure.

Self Care Interventions for Black Women with Type 2 Diabetes Mellitus (DM): Black women experience one of the highest rates of type 2 DM and suffer disproportionately from diabetes related complications. Diabetes is now the second leading cause of death among Black women. The purpose of this study is to evaluate the effect of a tested, culturally sensitive intervention of diabetes education, coping skills training, and diabetes care designed to improve diabetes metabolic control in Black women with type 2 DM. Advanced practice nurses will provide the culturally sensitive education program.

Future NINR initiatives include research that evaluates the feasibility and effectiveness of interventions for translation into practice settings that include nurse-managed interventions in collaboration with clients to promote self-care by the patient. This approach promotes independence and adherence to therapeutic regimens. NINR will build on recommendations from a group of experts convened to explore the science base that currently exists related to self management of chronic illnesses and related symptoms.

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Authorizing Legislation						
	PHS Act/ Other Citation	U.S. Code Citation	2005 Amount Authorized	FY 2005 Appropriation	2006 Amount Authorized	2006 Budget Estimate
Research and Investigation	Section 301	42§241	Indefinite	\$127,814,000	Indefinite	\$128,259,000
National Institute of Nursing Research	Section 41B	42§285b	Indefinite		Indefinite	
National Research Service Awards	Section 487(d)	42§288	<u>a/</u>	10,258,000		10,470,000
Total, Budget Authority				138,072,000		138,729,000

a/ Amounts authorized by Section 301 and Title IV of the Public Health Act.

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Appropriations History

Fiscal Year	Budget Estimate to Congress	House Allowance	Senate Allowance	Appropriation <u>1/</u>
1997	51,951,000	45,231,000	53,936,000	59,743,000
1998	55,692,000	56,950,000	59,443,000	48,043,000
1999	62,229,000 <u>2/</u>	68,198,000	69,834,000	69,834,000
Rescission				(46,000)
2000	65,335,000	76,204,000	90,000,000	90,000,000
Rescission				(478,000)
2001	84,714,000	102,312,000	106,848,000	104,370,000
Rescission				(20,000)
2002	117,686,000	116,773,000	125,659,000	120,451,000
Rescission				(23,000)
2003	129,768,000	131,438,000	131,438,000	131,438,000
Rescission				(854,000)
2004	134,579,000	134,579,000	135,579,000	135,555,000
Rescission				(831,000)
2005	139,198,000	139,198,000	140,200,000	139,198,000
Rescission				(1,126,000)
2006	138,729,000			

1/ Reflects enacted supplementals, rescissions, and reappropriations.

2/ Reflects a decrease of \$187,000 for the budget amendment for bioterrorism.

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Detail of Full-Time Equivalent Employment (FTEs)

OFFICE/DIVISION	FY 2004 Actual	FY 2005 Appropriation	FY 2006 Estimate
Office of the Director (includes FTEs from the Office of Science Policy and Public Liaison and the Office of Administration Management)	17	17	17
Associate Director for Scientific Programs and Division on Extramural Activities	15	17	17
Division of Intramural Research	3	5	5
Total	35	39	39
FTEs supported by funds from Cooperative Research and Development Agreements	(0)	(0)	(0)
FISCAL YEAR	Average GM/GS Grade		
2002	12.4		
2003	11.8		
2004	11.8		
2005	11.9		
2006	11.9		

**NATIONAL INSTITUTES OF HEALTH
National Institute of Nursing Research**

Detail of Positions

GRADE	FY 2004 Actual	FY 2005 Appropriation	FY 2006 Estimate
Total - ES Positions	1	0	0
Total - ES Salary	\$143,498	\$0	\$0
GM/GS-15	1	1	1
GM/GS-14	10	11	11
GM/GS-13	4	5	5
GS-12	5	5	5
GS-11	1	1	1
GS-10	2	2	2
GS-9	3	3	3
GS-8	2	2	2
GS-7	2	2	2
GS-6	0	0	0
GS-5	0	0	0
GS-4	0	0	0
GS-3	0	0	0
GS-2	0	0	0
GS-1	0	0	0
Subtotal	30	32	32
Grades established by Act of July 1, 1944 (42 U.S.C. 207):			
Assistant Surgeon General Director Grade			
Senior Grade	0	0	0
Full Grade			
Senior Assistant Grade			
Assistant Grade			
Subtotal	0	0	0
Ungraded	16	17	17
Total permanent positions	31	32	32
Total positions, end of year	48	50	50
Total full-time equivalent (FTE) employment, end of year	35	39	39
Average ES salary	\$143,498	\$0	\$0
Average GM/GS grade	11.8	11.9	11.9
Average GM/GS salary	\$74,285	\$77,167	\$79,212