National Institute of Nursing Research

THE NINR STRATEGIC PLAN:

ADVANCING SCIENCE, IMPROVING LIVES

A Vision for Nursing Science

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Prologue from the NINR Director

The release of this new Strategic Plan for the National Institute of Nursing Research occurs as we commemorate 30 years of nursing science at the National Institutes of Health. It was three decades ago when the vision of nurse scientists across the United States was finally realized with the establishment by the U.S. Congress of a National Center for Nursing Research at the NIH. The creation of the Center was a clear recognition by policymakers of the essential role of nursing science in the health research enterprise. And, it was a hard-fought victory for those who had long advocated for such a step to be taken, already knowing what would soon be evident to the scientific community at large: that nurse scientists had been, and would increasingly be, major players in addressing the health challenges of those and future times.

Fast forward to the present day, when the health challenges faced by our Nation may be different but are no less significant: an aging and increasingly diverse population; people living longer but with multiple chronic conditions; and the persistent and troubling fact that many people with advanced illness spend their last days, months, or years often with poorly managed symptoms in settings that do not reflect their needs or preferences. However, as has always been the case, where some see challenges, the field of nursing science, and we at NINR, see a tremendous opportunity to continue to have a significant impact on the health and quality of life of those across the U.S. and the world beyond.

Given the strongly clinical focus of nursing science, the research supported by NINR will continue to play an indispensable role in addressing the health challenges of today and tomorrow. Nursing science provides the evidence base to support the practice of the largest health care profession, as well as to improve wellness and quality of life for all individuals. Given the rise in the incidence of long-term chronic conditions, it is critically important that improving the quality of life for those with chronic illness remains a primary focus of nursing research. Individuals, regardless of their health status, age, gender, or racial and ethnic minority status, should be able to experience a high quality of life, minimally burdened by adverse symptoms, with the ability to successfully

manage their own health. Perhaps more importantly, individuals, families, clinicians, and communities should be equipped with evidence-based strategies for maintaining wellness and preventing illness from occurring in the first place.

We also recognize that today is a time of extraordinary opportunity in the health research enterprise as a whole. We are entering an era of precision medicine, in which we will be able to tailor treatments to individuals based on their genes, environment, and lifestyle. The field of data science will change the way that scientists collect, store, and analyze large datasets, which could revolutionize the way in which we conduct clinical research and clinical trials, and in which we explore the genetics of illness and adverse symptoms. The scientists supported by NINR are emerging as leaders in both of these areas, contributing their expertise to the multidisciplinary teams that will unlock the potential of precision medicine and data science, leading to the next generation of advances in the health sciences.

In developing this Strategic Plan, we have focused on the areas of science in which the needs are greatest, and for which we believe NINR-supported science can have the largest impact. The Plan reflects not only the long-standing focus areas of nursing science, but also areas in which nurse scientists can use their expertise in clinical research and their understanding of the relationship between behavior and biology to further expand the reach and impact of nursing science in the larger community. The Plan is organized around four scientific themes: symptom science, wellness, self-management of chronic conditions, and the science of end-of-life and palliative care. It acknowledges the many ways in which new innovations and technologies can contribute to advancing nursing science across these four areas. Finally, it describes and reaffirms NINR's longstanding and continuing commitment to developing the next generation of nurse scientists: those individuals and team members who will carry the field of nursing science into the next thirty years and beyond.

The NINR Strategic Plan was developed using a careful and deliberate planning process that involved the input of interdisciplinary scientists, clinicians, advocates, and other experts across the Nation, as well as members of the public. It incorporates the feedback that we received during the recent NINR Innovative Questions initiative, in which members of the scientific community and the general public were encouraged to provide NINR with their ideas for new research questions that could rapidly lead to improvements in health and quality of life over the next ten years. We also recognize that science is ever-changing, and that we need to be ready to change course when a new challenge or opportunity presents itself. Therefore, it is essential that this Plan be seen not as a static, but a living document, one which we can adapt as the need arises.

I want to acknowledge and thank all of those who contributed to the development of this Strategic Plan in various ways over the past several years. Your input and expertise were essential in developing this vision for the future of nursing science. I am excited about the future. Nursing science has accomplished much over the past thirty years, and by working together, the achievements of the next three decades will be even more remarkable, leading to better health and better lives for individuals, families, and communities across the U.S. and around the world.

Dr. Patricia A. Grady

Dr. Patricia A. Grady
September 2016

An Introduction to the Strategic Plan

NINR MISSION

The mission of the National Institute of Nursing Research (NINR) is to promote and improve the health and quality of life of individuals, families, and communities.

To achieve this mission, NINR supports and conducts clinical and basic research and research training on health and illness, research that spans and integrates the behavioral and biological sciences, and that develops the scientific basis for clinical practice. From premature infants in neonatal intensive care units, to adolescents living with diabetes, to elderly cancer survivors coping with pain, nursing research develops the science to help people strengthen the quality of their lives. Nursing science transcends the boundaries of disease and research disciplines to better understand the experiences of individuals and families living with illness and to develop personalized approaches that maximize health and well-being for individuals at all stages of life, across diverse populations and settings.

NINR's scientific programs encompass topics such as:

- Exploring the mechanisms underlying symptoms of illness and developing personalized treatments that address these mechanisms through symptom science research;
- Enhancing wellness by understanding the physical, behavioral, cultural, and environmental influences on health status and developing culturally tailored interventions to prevent illness and promote health;
- Helping individuals with chronic conditions better understand and manage these conditions by engaging individuals as active participants in managing their own health;
- Providing caregivers with better tools for fulfilling their caregiving responsibilities and maintaining their own quality of life;
- Developing palliative care strategies to help individuals and families manage the symptoms of life-limiting conditions and plan for end-of-life decisions;
- Using innovative technologies to develop novel interventions that deliver personalized care and real-time health information to patients, families, and health care providers; and,
- Promoting the development of an innovative, multidisciplinary, and diverse nursing science workforce through a variety of training programs and mechanisms.

DEVELOPMENT OF THE NINR STRATEGIC PLAN

Following the publication of the Institute's 2011 Strategic Plan, NINR sought to implement programs of research in each of the topics identified by that framework. Building on that Strategic Plan, past scientific accomplishments, and current research priorities, four areas of scientific focus emerged:

- *Symptom Science: Promoting Personalized Health Strategies*
- *Wellness: Promoting Health and Preventing Disease*
- *Self-Management: Improving Quality of Life for Individuals with Chronic Illness*
- *End-of-Life and Palliative Care: The Science of Compassion*

In addition, NINR identified two cross-cutting areas vital to the advancement of nursing science. These two areas were seen as essential to advancing all of the Institute's research portfolios, and NINR emphasizes these areas in all of its programs and activities.

- *Promoting Innovation: Technology to Improve Health*
- *21st Century Nurse Scientists: Innovative Strategies for Research Careers*

These scientific focus areas and cross-cutting topics provided the blueprint for developing this Strategic Plan, and are described in more detail in the following pages.

In carrying out its mission, NINR is committed to enhancing scientific stewardship — to encourage new thinking and creativity in nursing science that will allow the exploration of the questions essential to producing results-oriented research. NINR will continue this commitment to enhancing scientific stewardship in order to identify new scientific opportunities in which NINR can have a significant impact on the health of the American people.

FUTURE RESEARCH DIRECTIONS:

THE INNOVATIVE QUESTIONS INITIATIVE

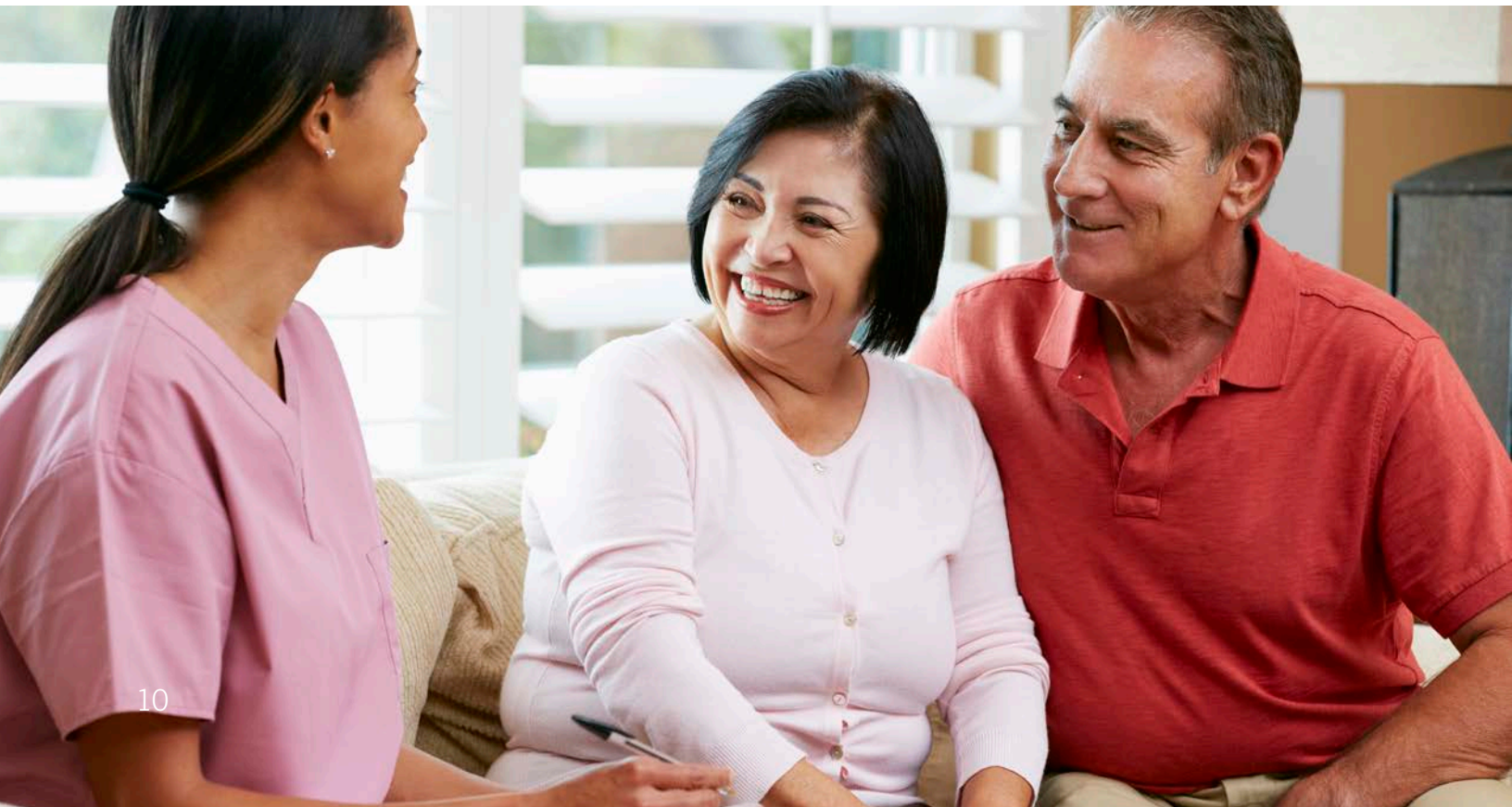
To develop future research directions within each of its focus areas, NINR engaged its stakeholders in a dialogue to identify novel scientific questions. Through this initiative, Innovative Questions (IQ), NINR sought ideas to encourage new thinking and creativity in nursing science, explore unanswered questions, promote results-oriented research, and guide the science over the next five to ten years. The IQ initiative consisted of two components: a series of workshops and a public website. The IQ workshops brought together leading interprofessional scientists to identify and refine innovative research questions through a consensus-building discussion format. On NINR's IQ website, members of the scientific community, professional organizations, and the general public were given the opportunity to submit research questions directly to NINR, and to comment on questions submitted by others. The innovative questions that emerged from the IQ initiative have been made available on the NINR website to serve as a resource for the nursing science community. These questions can be used by anyone, from experienced investigators to trainees, in considering future directions for their own programs of research. The questions also provide the larger scientific community with a better understanding of the potential and importance of nursing science.

The innovative questions also played a major role in informing the future research directions presented in this Strategic Plan. Within each of the focus areas described in this Plan, the innovative questions, along with other considerations such as emerging research areas, portfolio balance, and trans-NIH research priorities, were used to develop a series of specific research priorities that will guide NINR-supported science over the next several years. These priorities represent areas of research in which it is anticipated that NINR support can have the most impact on improving health and quality of life in the next 10–20 years. It is important to remember, however, that this Plan is intended to be a flexible, living document. As new science and new opportunities emerge, and as new health challenges arise, NINR will regularly seek to reassess and adapt its research strategies to meet these needs and opportunities.

SYMPTOM SCIENCE:

PROMOTING PERSONALIZED HEALTH STRATEGIES

For the past three decades, NINR has supported research on new and better ways to manage adverse symptoms and improve quality of life. Nursing science develops and applies new knowledge in biology and behavior, including in genomics and biomarkers, to improve our understanding of symptoms, such as pain, fatigue, and sleep disturbance, as well as impaired cognition and disordered mood, which can occur with numerous acute and chronic illnesses and conditions. In promoting symptom and symptom management science, NINR supports research focused on understanding the biological and behavioral aspects of symptoms, with the goal of developing and testing new interventions to reduce the disabling effects of symptoms and improving patient health outcomes and quality of life. As the U.S. population lives longer with chronic conditions and related adverse symptoms, a concerted and transformative approach to symptom science research will be needed to address the resulting increased health burden and enable people to live well over their entire lives.



The many symptoms associated with a single illness, or, in many cases, occurring with co-morbid illnesses or conditions, often severely compromise the quality of life of individuals suffering from these conditions. New strategies are greatly needed for effectively managing the symptoms of co-morbid conditions and improving patient quality of life. Many individuals are also affected by multiple symptoms at the same time. The physiological basis for these co-occurring symptoms, or symptom clusters, and the best strategies for managing them, remain important areas of investigation. Nursing science, with its foundational link to the lived experiences of individuals, provides a unique scientific perspective into both the clinical and biologic features of symptoms and the negative effects of conditions and treatments. This expertise, in conjunction with interprofessional collaboration, is critical to continued scientific progress towards innovation in symptom science.

NINR supports research at universities, hospitals, and other institutions across the Nation on a broad range of topics related to symptom science. In addition, NINR houses an intramural research program on the NIH campus in Bethesda, Maryland dedicated to improving the understanding of the underlying biological mechanisms of a range of symptoms, their effect on patients, and the biological and behavioral bases for how patients respond to interventions. NINR is committed to supporting collaborative, innovative, and interprofessional symptom science research that will generate meaningful and practical clinical applications.

PROFILES OF SYMPTOM SCIENCE

NINR supports research to develop improved, personalized strategies to prevent or manage the adverse symptoms of illness across diverse populations and settings, and throughout the lifespan. From the bench to the bedside, and from the clinic to the home, NINR-supported symptom science research is developing evidence-based symptom management strategies built on a fundamental understanding of the biology of symptoms.

- **Traumatic brain injury in military personnel linked to a biomarker of neuro-degeneration, measured with a novel and sensitive detection method** – A protein linked to short-term complications after traumatic brain injury (TBI), may also be responsible for long-term complications that can result from TBI. Using a novel and ultra-sensitive technology, researchers in NINR's Division of Intramural Research were able to measure levels of a protein, tau, in the blood months and years after military personnel had experienced TBI. They found that these elevated tau levels are associated with chronic neurological symptoms, including post-concussive disorder (PCD) and chronic traumatic encephalopathy (CTE), independent of other factors such as depression and post-traumatic stress disorder (PTSD). This finding provides an insight into the underlying biology of TBI, and could someday lead to new strategies for mitigating TBI's debilitating symptoms.[1]

- **Two specific symptom clusters in heart failure patients identified using big data approaches in an international study** – To better characterize the many adverse symptoms of heart failure across populations, scientists compared data describing the symptoms of 720 heart failure patients across China, Taiwan, the Netherlands, Sweden, and the U.S. They identified two groups of associated symptoms, or symptom clusters, which were consistent across all patients: 1) a physical capacity symptom cluster that included dyspnea, difficulty in walking or climbing, and fatigue, and 2) an emotional/cognitive symptom cluster that included worrying, feeling depressed, and cognitive problems. These findings, which indicate that symptoms of heart failure are consistent across cultures, are important information for improving symptom recognition and acting early to avoid adverse outcomes.[2]

- **COMT polymorphism: a putative genetic biomarker for predicting individual differences in sleep physiology** – Understanding the biologic and genetic underpinnings of sleep, and the effects of poor sleep on health has long been a focus of NINR's research programs in symptom science. In one example, scientists studied individuals with an alteration in a protein called *catechol-O-methyltransferase*, or *COMT*, a protein involved in metabolizing neurotransmitters such as dopamine. This alteration is caused by a genetic mutation

[1]Olivera A, Lejbman N, Jeromin A, French LM, Kim H, Cashion A, Mysleweic V, Diaz-Arrastia R, Gill J. Peripheral total tau in military personnel who sustain traumatic brain injuries during deployment. JAMA Neurol. 2015 Oct 1;72(10): 1109-16.

[2]Moser DK, Lee KS, Wu JR, Mudd-Martin G, Jaarsma T, Huang TY, Fan XZ, Strömberg A, Lennie TA, Riegel B. Identification of symptom clusters among patients with heart failure: an international observational study. Int J Nurs Stud. 2014 Oct;51(10):1366-72.

in the COMT gene. In healthy individuals subjected to partial sleep deprivation, those with the mutation exhibited different changes in their sleep physiology, including greater declines in brain waves potentially associated with the drive to sleep. This mutation in the COMT gene could therefore serve as a biomarker to predict individual differences in sleep physiology and further our understanding of the effects of sleep deprivation.[3]

NIH SYMPTOM SCIENCE MODEL AND NINR SYMPTOM SCIENCE CENTER

NINR developed the NIH Symptom Science Model (NIH-SSM) to guide biobehavioral research in symptom science. The model begins with the identification of a symptom or complex group of symptoms, which is then characterized into a phenotype with biological and clinical data, followed by the application of genomic and other discovery methodologies to illuminate biomarker targets for therapeutic and clinical interventions. NINR is using the NIH-SSM in the NINR intramural research program to organize and implement biobehavioral, symptom-management, and tissue-injury research. The model is also used as a framework for training and career development opportunities including on-campus trainings and research fellowships.[4]

NINR is also developing a trans-NIH, NINR-led, Symptom Science Center to implement the NIH-SSM in promoting biomarker discoveries that can be translated into clinical practice to eliminate or reduce symptom burden, and engage patients and families in care. As a trans-NIH resource, the Symptom Science Center will provide a hub where collaborative teams of interdisciplinary intramural, and subsequently extramural, investigators can address symptom research challenges such as those posed by multiple chronic illnesses. The Center will expand the expertise of symptom science in the NIH intramural community, mentor early stage clinicians and scientists, and promote discovery that integrates subjective and biologic data to inform personalized approaches to symptom management.

[3]Goel N, Banks S, Lin L, Mignot E, Dinges DF. Catechol-O-methyltransferase Val158Met polymorphism associates with individual differences in sleep physiologic responses to chronic sleep loss. PLoS One. 2011 6(12):e29283.

[4]Cashion AK and Grady PA. The National Institutes of Health/National Institute of Nursing Research intramural research program and the development of the National Institutes of Health Symptom Science Model. Nurs Outlook. 2015 Jul-Aug;63(4):484-7.

Future Directions: *Promoting Personalized Health Strategies*

Advancing symptom science research will remain a high-priority focus for NINR. This focus has renewed urgency as more Americans experience multi-morbid conditions accompanied by the adverse, often co-occurring symptoms that significantly impact their quality of life. There is a critical need to understand the biological and behavioral dynamics of symptoms that can change the trajectory of chronic conditions. The expanding capacity and proven value of "omics" science, including the areas of proteomics and microbiomics to name just a few, provide momentum for developing personalized health strategies for symptom management. Of particular relevance to nursing science is the integration of biomarkers with phenotypic indicators. An example of this is a study to explore the relationship between biomarkers and the management of fatigue in patients undergoing treatment for prostate cancer, an important area of research given that fatigue during cancer treatment is the most distressing symptom reported by patients. Other studies include efforts to understand the relationship between inflammation and symptom distress in patients with digestive disorders, and to explore the feasibility of using genomics and proteomics to predict risks for PTSD following traumatic brain injury. This integration of biomarkers and phenotypic indicators can lead to better knowledge of the underlying biological mechanisms of symptoms such as fatigue, dyspnea, impaired cognition, pain, and disordered mood, and to improved assessment and management of these symptoms among diverse populations and settings. It is important to understand the added value of these indicators beyond standard clinical parameters in assessing physical and psychological symptoms and determining the effectiveness of interventions to better manage these symptoms.

In continuing to advance symptom science, NINR will support basic, clinical, and biobehavioral research to promote personalized health strategies for symptom management. Areas of focus will include, but are not limited to, supporting research to:

- Develop, test, and disseminate novel, scalable symptom management interventions, including non-pharmacological interventions, in real-world clinical settings to improve health outcomes and quality of life.
- Determine common biobehavioral, mechanistic pathways that change a symptom trajectory from acute to chronic.
- Determine key interceding points in symptom management that can alter (improve or adversely affect) the trajectory of chronic conditions.
- Demonstrate how biomarkers can be used to: better understand symptom expression and variability; advance biobehavioral interventions to manage symptoms; develop personalized symptom management and prevention strategies to complement conventional treatment; and better assess and manage physical and psychological symptoms in persons with chronic conditions.

WELLNESS:

PROMOTING HEALTH AND PREVENTING ILLNESS

The most effective way to overcome the effects of illness is to prevent illness from occurring in the first place. For more than 30 years, NINR has supported research to promote long-term health, including healthy behaviors, and to prevent illness and comorbidities across health conditions, settings, and the lifespan. Research supported in this area focuses on the physical, social, behavioral, and environmental causes of illness, determinants of health, and assessment of behaviors that lead to healthy lifestyle choices. The ultimate goal of this research is the development of evidence-based, personalized interventions to promote wellness among individuals and across populations and settings. Important to these efforts is using genomics and other omics fields to obtain an improved understanding of the genotypic and phenotypic indicators that can help predict those at risk for developing or acquiring certain illnesses and chronic conditions. Past efforts in this area have targeted such areas as: preventing HIV transmission in a variety of settings, including inner cities in the U.S. as well as in nations in Africa; preventing obesity through interventions to promote healthy eating and exercise; and exploring new strategies for promoting health and quality of life among informal caregivers of individuals with Alzheimer's disease and other dementias.

In promoting wellness, NINR is committed to supporting research to achieve the goal of the best possible health for people across the lifespan and in diverse populations. An important component of this is building the science to understand and prevent chronic illness, improve quality of life, reduce burden for patients and informal caregivers across the spectrum of diseases or conditions, and eliminate health disparities. To achieve this goal, NINR will continue to support research aimed at the development of innovative approaches to advance health and wellness for individuals, families, and communities. Examples of research in this area could include efforts to develop and test behavioral interventions to: prevent obesity by promoting physical activity, improve parenting skills for new parents of premature infants, promote cognitive function and neurological health, reduce the risk of acquiring HIV, and promote preventive health screenings among underserved populations. NINR-supported scientific findings in the area of wellness can inform the health-promotion and disease-prevention activities of other agencies across

the federal government, strengthening the scientific foundation for their ongoing efforts to improve health outcomes and health services, and reduce the burden of illness on patients and families.

Across all science areas, NINR emphasizes the important contributions of scientific program partnerships with underrepresented and minority communities. Of particular importance to the science of wellness is research addressing sex and gender differences, health disparities, social determinants of health, and environmental influences. By working in close research partnerships with communities, nurse scientists are well positioned to develop culturally congruent, feasible, and sustainable interventions to promote healthy behaviors and prevent chronic conditions across the lifespan.

PROFILES IN WELLNESS

NINR advances wellness through supporting science investigating the key biological, behavioral, and social factors that promote long-term health and healthy behaviors and prevent the development of disease across health conditions, settings, and the lifespan. Wellness research emphasizes understanding the multiple causes of illnesses, assessing the social and physical behaviors that lead to healthy lifestyle choices, and designing personalized, evidence-based health promotion interventions that are culturally appropriate.

- **Higher nurse staffing levels and increased nurse education reduces preventable hospital deaths** – In the largest study of its kind to-date, scientists conducted a detailed analysis of patient outcomes associated with nurse staffing and education. Using data from nearly 500,000 patients who underwent common surgeries in 300 hospitals in nine European countries, and from surveys of over 25,000 nurses, the study found that an increase in nurses' workload by one patient increased the likelihood of in-hospital death within 30 days of admission by 7 percent. The study also determined that for every 10-percent increase in nurses on staff with bachelor's degrees, the likelihood of patient death decreased by 7 percent. The study underscores the potential risks to patients of cuts in nurse staffing levels and suggests that an increased emphasis on bachelor's-level education for nurses could reduce hospital deaths.[5]

- **A healthy lifestyle intervention increases physical activity, reduces overweight, and improves psychosocial outcomes in high school students** – A teacher-delivered intervention program (COPE-Healthy Lifestyles TEEN [Thinking, Emotions, Exercise, and Nutrition]) promoting healthy lifestyles improved health behaviors, body mass index, social skills, severe depression, and academic performance in high school adolescents. Routine integration of such programs into health education curricula in high school settings may be an effective way to prevent high-risk teen populations from becoming overweight or obese, and could lead to improved physical health, psychosocial outcomes, and academic performance. This was one of the first studies to report multiple immediate improvements that were sustained over time using a teacher-delivered, cognitive-behavioral skills-building intervention program incorporated into a high school health education class.[6]

[5]Aiken LH, Sloane DM, Van den Heede K, et al. Nurse staffing and education and hospital mortality in nine European countries: a retrospective observational study. Lancet. 2014 May 24;383(9931):1824-30.

[6]Melnyk BM, Jacobson D, Kelly S, Belyea M, Shaibi G, Small L, O'Haver J, Marsiglia FF. Promoting healthy lifestyles in high school adolescents: a randomized controlled trial. Am J Prev Med. 2013 Oct;45(4):407-15.

- **Modified electrocardiogram monitoring in the prehospital setting can predict health outcomes for patients with symptoms of acute coronary syndrome** – Because time is of the essence, it is recommended that paramedics acquire electrocardiograms (ECGs) on patients with symptoms of acute coronary syndrome (ACS) during transport to the hospital. A team of scientists developed a modified ECG technique that could quickly be administered by a paramedic with the results automatically transmitted to the hospital via cell phone. In a randomized trial conducted in a rural area, this strategy increased the percentage of patients with ACS receiving a pre-hospital ECG and decreased the time between the first 911 call and the hospital receiving the first ECG, compared to standard care. This allowed hospital personnel additional time to prepare for the incoming patient, potentially leading to faster treatment and improved patient outcomes.[7]

[7]Drew BJ, Sommargren CE, Schindler DM, Benedict K, Zegre-Hemsey J, Glancy JP. A simple strategy improves prehospital electrocardiogram utilization and hospital treatment for patients with acute coronary syndrome (from the ST SMART Study). Am J Cardiol. 2011 Feb 1;107(3):347-52.

Future Directions: *Promoting Health and Preventing Illness*

Research supporting the science of wellness is an integral piece of the foundation of NINR's mission and will remain a priority into the future. In addition, this focus on health promotion and disease prevention is consistent with efforts across NIH and the entire federal government, which have recognized that improved efforts at prevention are critical to reducing the burden of illness in this and future generations. Having promoted such research efforts throughout its history, NINR will continue supporting research on the promotion of health and prevention of illness across the lifespan and diverse communities with a particular focus on:

- Employing research that integrates the latest scientific advances in areas such as precision medicine, mobile health (m-health), and omics science, and takes advantage of innovations in data science in order to develop interventions to promote health and wellness that are leading-edge, effective, and translatable to clinical practice.
- Determining the complex relationships between physical activity, nutrition, and environment, and the prevention, development, and trajectory of communicable and non-communicable illnesses and acute trauma — with a particular emphasis on sex and gender differences and health disparities.
- Supporting nurse-led multidisciplinary, collaborative initiatives focused on employing innovative and sustainable strategies to prevent chronic conditions across the lifespan and in underrepresented minority populations.
- Determining, developing, and/or improving the personal and social pathways that can be translated into health promotion and illness prevention across the lifespan.
- Employing research approaches such as community-based participatory research and participatory action research to determine the most feasible and effective biobehavioral interventions to reduce or eliminate health disparities.

SELF-MANAGEMENT:

IMPROVING QUALITY OF LIFE FOR INDIVIDUALS WITH CHRONIC CONDITIONS

Chronic diseases are the leading causes of death and disability in the U.S. Nearly 50 percent of U.S. adults are living with one or more chronic illnesses, and over 85 percent of health care costs in the U.S. are at least partially attributable to chronic disease. Symptoms of chronic conditions impair quality of life, and have negative impacts for caregivers and communities. Strategies for improving quality of life in the presence of chronic conditions are critically needed. NINR supports research on patient-focused self-management programs to engage individuals and families as active participants in maintaining and improving quality of life while living with a chronic condition or multiple chronic conditions. Self-management research encompasses health strategies that allow an individual and their health care provider to adapt treatments to individual circumstances by accounting for social, cultural, economic, and emotional factors that can influence their health and quality of life.

NINR maintains a strong interest in supporting research to improve self-management strategies for individuals with multiple chronic conditions. For example, NINR-supported scientists are examining the use of innovative and practical technologies to improve treatment and medication adherence in persons with more than one chronic health condition. Researchers are also examining the integration of interactive electronic health records for clinicians and patients to improve safe and effective use of medications for individuals with multiple chronic conditions who must manage complex medication regimens.

PROFILES OF SELF-MANAGEMENT

NINR emphasizes self-management of chronic conditions through the support of research to improve: management of multiple and complex symptoms in co-morbid conditions; chronic condition self-management in children and adolescents; and approaches for patients and family caregivers to manage multiple chronic health conditions in the home setting. By supporting research to develop patient-focused self-management strategies, NINR seeks to improve the quality of health care and quality of life for individuals, families, and communities.

- **A mobile device "app" that uses a novel detection algorithm improves symptom monitoring in adolescents and may improve asthma self-management** – Accurately monitoring symptoms of asthma is important for proper self-management of the condition. However, this can be a challenge for those with asthma, particularly adolescents. An interdisciplinary team of researchers developed and tested an automated device for asthma monitoring (ADAM), applying technology to help assess asthma symptoms objectively and accurately. The device uses an iPod, an external microphone, and an app that monitors symptoms including coughing and wheezing. The device was found to be a valid asthma monitoring tool, and was well received by users. These results indicate that ADAM can improve self-management of asthma in adolescents.[8]

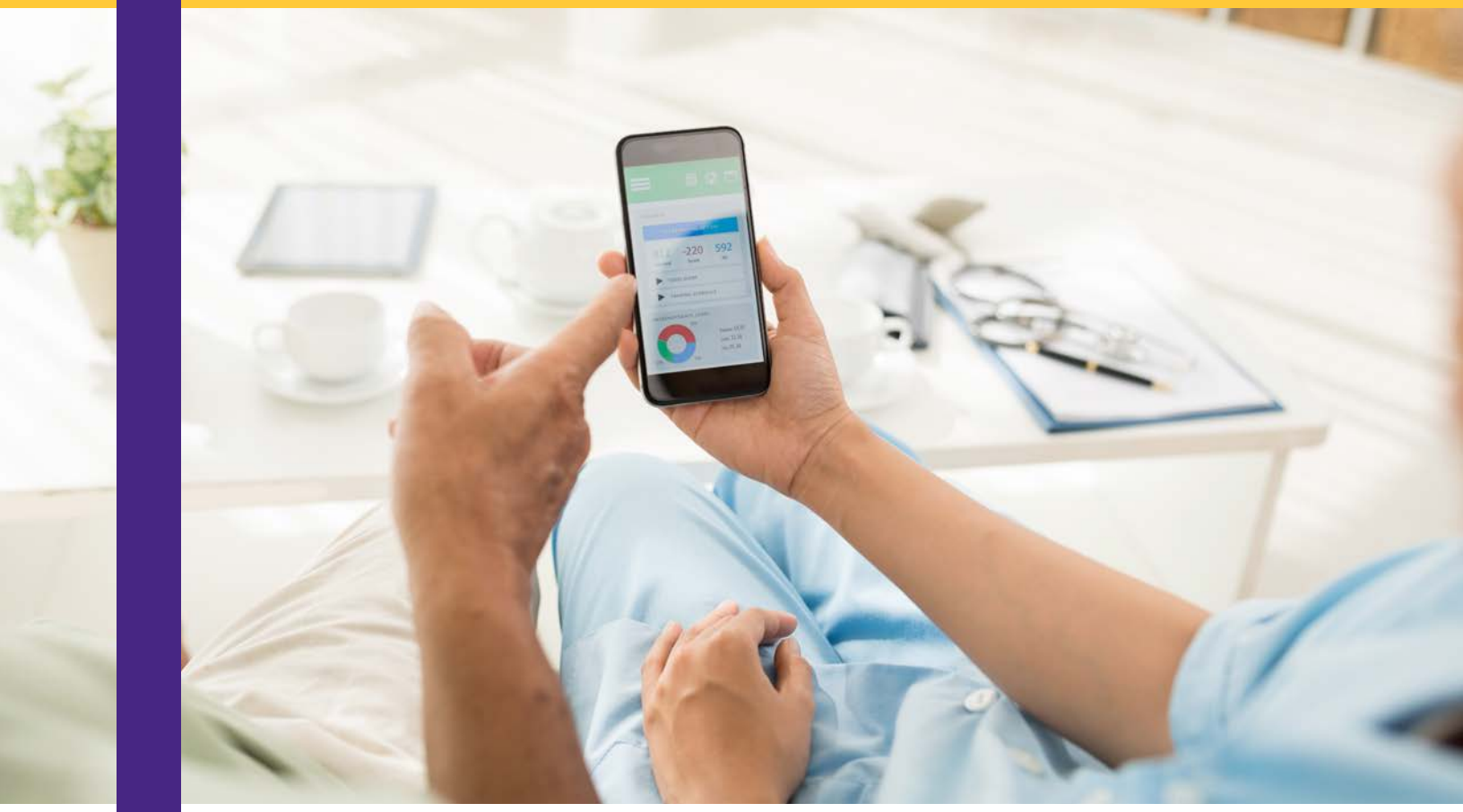
- **Nurse care coordination and medication self-management improve clinical outcomes in frail older adults with multiple chronic conditions** – Frail older adults who received nurse care coordination and a medication management pillbox had significantly better outcomes than did those who received no intervention. A more sophisticated medication dispensing system did not result in better outcomes than the pillbox. The clinical outcomes included quality of life, functional status, depressive symptoms, and cognitive functioning. The findings demonstrate the value of this nurse-led intervention in frail older adults with multiple chronic conditions.[9]

- **School- and community-based asthma intervention for students** – Effective asthma self-care behaviors are an important component of a successful asthma management plan for children and adolescents. To expand asthma self-care education beyond health offices and clinics, a team of nurse specialists and teachers developed a school- and community-based asthma health education and counseling program for elementary school students

[8]Rhee H, Miner S, Sterling M, Halterman JS, Fairbanks E. The development of an automated device for asthma monitoring for adolescents: methodologic approach and user acceptability. JMIR mHealth uHealth. 2014 June 19; 2(2): e27.

[9]Marek KD, Stetzer F, Ryan PA, Bub LD, Adams SJ, Schlidt A, Lancaster R, O'Brien AM. Nurse care coordination and technology effects on health status of frail older adults via enhanced self-management of medication. Nurs Res. 2013 Jul-Aug;62(4):269-78.

and their family caregivers. In an NINR-supported randomized clinical trial, the students who received the new program demonstrated increased improvement in episode management and risk reduction/prevention behaviors, compared with students who received a control program. These findings demonstrate that integrating an asthma education program into the regular school curriculum holds promise for improving asthma management among elementary school students.[10]



[10]Kintner EK, Cook G, Marti CN, Allen A, Stoddard D, Harmon P, Gomes M, Meeder L, Van Egeren LA. Effectiveness of a school- and community-based academic asthma health education program on use of effective asthma self-care behaviors in older school-aged students. J Spec Pediatr Nurs. 2015 Jan;20(1):62-75.

Future Directions: *Improving the Quality of Life for Individuals with Chronic Conditions*

The science of self-management involves strategies to help individuals, in conjunction with their formal and informal caregivers, families, health care professionals, and communities, better understand, monitor, and manage their chronic conditions, including multiple chronic conditions. NINR's commitment to the science of self-management focuses on enhancing healthy behaviors and adherence to treatment, promoting functional status across conditions, improving health outcomes, maintaining quality of life, and limiting disabilities by using pragmatic approaches to assess outcomes. NINR will also continue supporting research to guide individuals from diverse, multicultural backgrounds and their families in personalizing self-management skills and tools. Finally, NINR will support multiple efforts to integrate advanced technologies, including mobile health (mHealth) strategies, into self-management interventions. These technologies can, for example, facilitate more timely and effective patient-provider communication, provide real-time feedback on patient status and progress to clinicians, and incorporate treatment reminders to improve adherence, all of which may promote patient independence and improve health outcomes. Research in this area will seek to:

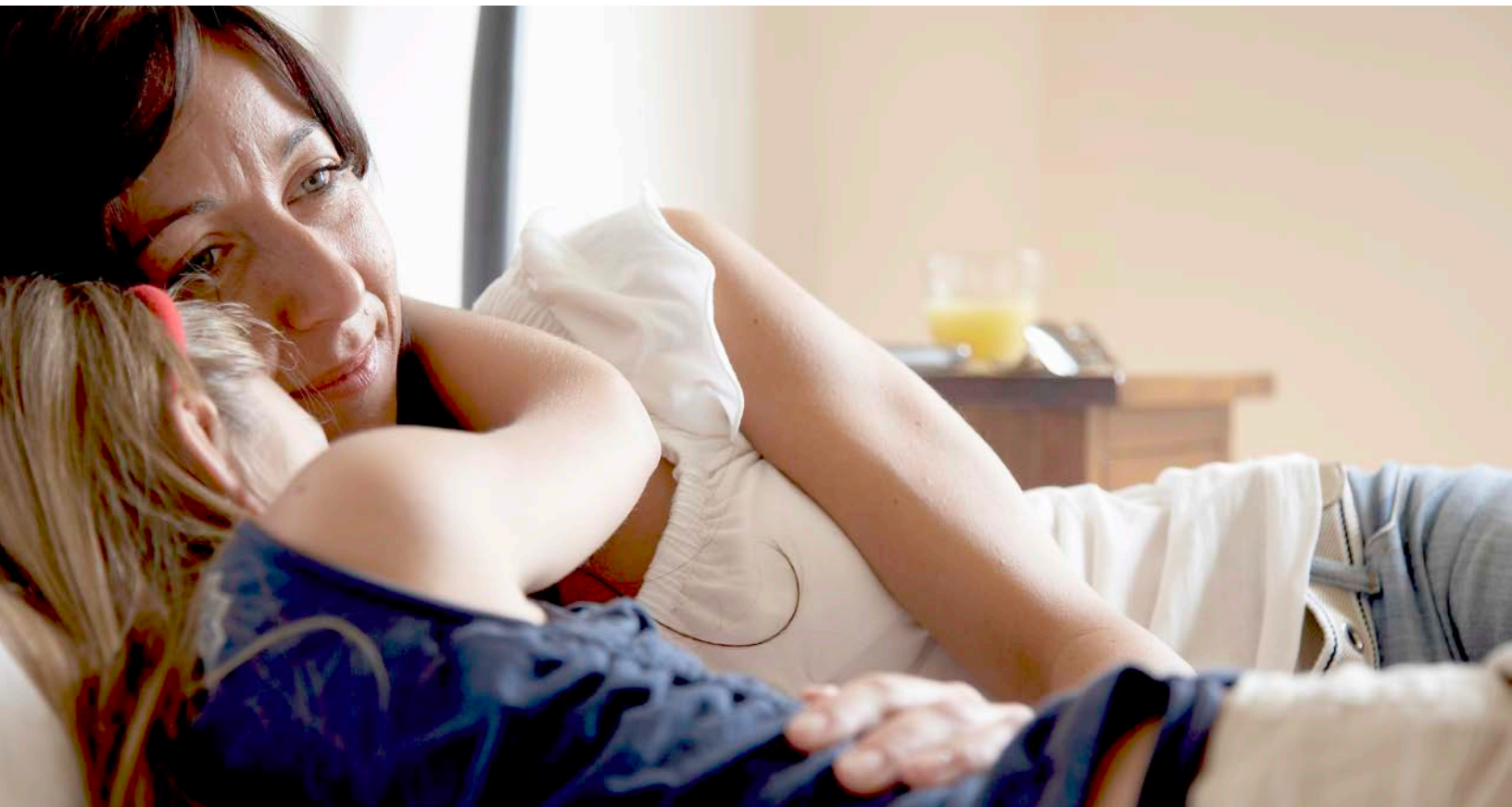
- Identify the basic mechanisms that influence successful self-management, in multiple conditions and settings, including the examination of mediators and moderators of self-management that impact adherence to treatment and sustainability or that impact interventions.
- Examine effects of multicomponent interventions integrating environmental factors, caregivers, and other health care professionals (e.g., occupational therapy, physical therapy, informatics) to promote daily functional health and wellbeing, while reducing adverse physical, functional, emotional, and behavioral outcomes.
- Incorporate personalized decision making, health, disability, and social factors/determinants in interventions to activate access to resources to maintain health and quality of life.
- Develop and incorporate innovative technologies, devices, and biobehavioral interventions to assist in monitoring and promoting health and improving access to health care in those with chronic conditions.
- Apply data science approaches to validate existing self-management measures, including available cohorts of existing data, to predict self-management intervention outcomes across multiple chronic conditions and in large samples.

END-OF-LIFE AND PALLIATIVE CARE:

THE SCIENCE OF COMPASSION

As the lead NIH Institute for end-of-life research, NINR supports science to assist individuals, families, and health care professionals in managing the symptoms of advanced, serious illness and planning for end-of-life decisions. NINR also recognizes that high-quality, evidence-based palliative care is a critical component of maintaining quality of life at any stage of illness, not limited to the end of life. Activities in this area address issues such as: relieving symptoms and suffering; enhancing communication between patients, families, and clinicians; and understanding decision-making surrounding care of advanced illness at the end of life.

NINR established its Office of End-of-Life and Palliative Care Research (OEPCR) to coordinate and support ongoing and future efforts in improving advanced care for serious illness. OEPCR is leading efforts to stimulate end-of-life and palliative care initiatives,



facilitate interprofessional science and collaboration, and identify opportunities for science to inform health care practice. Research supported under NINR's end-of-life and palliative care program seeks to inform high-quality care for individuals and their caregivers, improve management of pain and other symptoms, and facilitate decision-making at all stages of illness, including at the end of life.

End-of-life and palliative care science encompasses research to increase understanding of the unique challenges, barriers, and personal experiences faced by individuals of all ages with advanced illness, from infants and children to the elderly. It also focuses on the experiences of their families and other informal caregivers in navigating the often difficult circumstances of their loved one's advanced illness. Research priorities in end-of-life and palliative care science focus on high-quality research that advances new knowledge to assist individuals, their families, and their health care providers. This research explores strategies to manage the complex experiences of advanced symptoms and mitigate the effects of advanced illness on the health and well-being of the individual as well as informal caregivers. In order to optimize decision making, other areas of interest include studies of interventions to promote engagement in ongoing, personalized conversations about end-of-life care preferences and values.

PROFILES OF END-OF-LIFE AND PALLIATIVE CARE

End-of-life and palliative care science develops strategies to prevent and manage the symptoms of advanced illness. It includes management of pain and other symptoms and emotional, social, spiritual, and informed decision-making support. Interventions address supportive, palliative, and hospice needs across a continuum of services in coordination with individuals, families, and their health care teams. Examples of NINR end-of-life and palliative care research activities include:

- **Palliative Care Research Cooperative (PCRC)** – NINR supported the extension and expansion of a palliative care research cooperative, bringing together multidisciplinary investigators from over 60 institutions across the nation to focus on building the science of end-of-life and palliative care. The cooperative's mission is to develop scientifically based methods that lead to meaningful evidence for improving quality of life of individuals with advanced and/or potentially life-limiting illnesses and their caregivers, including family members and other care providers. Through these combined efforts, NINR will continue to build the science of end-of-life and palliative care to address the challenges and complex issues faced by individuals and families across the Nation.

- **Discontinuing statin therapy for patients with life-limiting illnesses is found to be safe and beneficial** – In a multicenter trial, researchers in the NINR-supported PCRC examined the safety of discontinuing statin therapy in patients with advanced, life-limiting illness. They found no significant differences in mortality between patients who had discontinued statin therapy and those who had not. These patients who discontinued statins also reported improved quality of life, and health care costs were reduced. These findings provide important evidence needed to inform decision making about statin therapy at the end of life, and highlight the need for providers to have meaningful discussions with patients about treatment options and maximizing their quality of life, key concepts in palliative care.[11]

- **Changing patient outcomes and the practice of hospice care** – An NINR-supported study used an analysis of a national database to evaluate U.S. hospice demographics. These data led to the first cross-sectional study of hospice utilization using a CMS database. Findings from this study underscored the complexity of the hospice patient population and the resource requirements of hospices serving patients with higher comorbidity burden. Researchers demonstrated that while hospices reported implementing individuals' preferences for palliative and hospice care, comprehensive implementation of preferred practices was rare and difficult for small, free-standing hospices to achieve.

[11]Kutner JS, Blatchford PJ, Taylor DH, Ritchie CS, Bull JH, Fairclough DL, Hanson LC, LeBlanc TW, Samsa GP, Wolf S, Aziz NM, Currow DC, Ferrell B, Wagner-Johnston N, Zafar SY, Cleary JF, Dev S, Goode PS, Kamal AH, Kassner C, Kvale EA, McCallum JG, Ogunseitan AB, Pantilat SZ, Portenoy RK, Prince-Paul M, Sloan JA, Swetz KM, Von Gunten CF, Abernethy AP. Safety and benefit of discontinuing statin therapy in the setting of advanced, life-limiting illness. a randomized clinical trial. 2015. JAMA Intern Med. May; 175(5): 691-700.

Publication of these data[12] generated wide-spread commentaries in sources such as the New York Times and JAMA Internal Medicine. Public attention was drawn to data showing that one-fifth of Medicare-certified hospices active in 1999 had closed or withdrawn from the program by 2009, and four out of five Medicare-certified hospices that entered the marketplace between 2000 and 2009 were for-profit.

In addition to supporting end-of-life and palliative care research, NINR recognizes the importance of communicating science by taking information learned from research and disseminating it to patients, families, and health care providers via the Institute's website and publications.

To that end, NINR has engaged in outreach initiatives, based on the latest science, to provide information and support to the scientific community, clinicians, and the public regarding palliative and end-of-life care.

- **Summit on the Science of End-of-Life and Palliative Care:** In 2011, NINR convened a national summit on "The Science of Compassion: Future Directions in End-of-Life and Palliative Care." This three-day, trans-NIH scientific summit focused on examining the current state of end-of-life and palliative care science, and envisioning and discussing future directions in research to improve quality of life for those with advanced illness. The nearly 1,000 attendees included scientists, palliative and end-of-life care health professionals, educators, policy analysts, members of professional organizations, and members of the public. The event consisted of: a town hall discussion on the ethics of science at the end of life; three plenary sessions examining various aspects of palliative and end-of-life care science; a special session focused on parents and clinicians as partners in research; ten breakout scientific sessions; and a poster session. Topics for discussion included: complex and co-morbidities; communication and advance care planning; pediatric and perinatal issues; research methodologies; the use of new technologies; and pain and symptom management, among many others. The summit featured research from junior and senior scholars in the field and provided mentoring opportunities, reflecting NINR's continued commitment to developing future nurse scientists. Events like this summit serve to invigorate and guide the research community's efforts towards real progress in improving quality of life for those with advanced illness.[13]

- **Palliative Care: Conversations Matter® Campaign:** NINR designed an evidence-based campaign to raise awareness of pediatric palliative care and to facilitate conversations about palliative care among health care providers, children living with a serious illness, and their families. To develop the campaign, NINR invited parents and palliative care clinicians, scientists, and

[12]Aldridge Carlson, MD, Barry CL, et al. (2012). Health Affairs, 31(12):2690-2698; Kelley AS, Deb P, W, et al. (2013). Health Affairs, 32 (3):552-561.

[13]For more information, and videos of the event: **http://www.ninr.nih.gov/researchandfunding/scienceofcompassion**

professionals to give their input and expertise on what they felt was needed in the field. The first phase of the campaign focused on health care providers and offered evidence-based materials, such as video vignettes and customizable patient education sheets, to help providers discuss palliative care with pediatric patients and their families. The campaign's second phase focused on providing resources, such as brochures, for patients and families to increase awareness and empower families to begin a dialogue with health care providers. The Institute hopes that Palliative Care: Conversations Matter® will increase the use of palliative care for children and teens living with serious illnesses.[14]

- **End-of-Life Module for NIHSeniorHealth.gov:** NIHSeniorHealth.gov, a joint effort of the National Institute on Aging and the National Library of Medicine, provides research-based, online health information for older adults that is presented in clear, large print, easy-to-read segments, as well as in open-captioned videos that offer simple navigation. NINR's End-of-Life module on NIHSeniorHealth.gov contains specific information for older Americans and their caregivers facing a myriad of questions regarding death and dying, as well as information on palliative and end-of-life care. The module addresses topics such as pain and other symptoms, places and planning for end-of-life care, support for caregivers, and coping with grief.[15]

[14]For more information: **http://www.ninr.nih.gov/conversationsmatter**

[15]For more information: **http://nihseniorhealth.gov/endoflife/preparingfortheendoflife/01.html**

Future Directions: *The Science of Compassion*

NINR is committed to supporting innovative end-of-life and palliative care investigations to explore novel approaches for evidence-based interventions, as well as studies to ascertain the physical and psychosocial correlates of serious advanced illness. Other priorities include studies focusing on developing new strategies for aligning care with diverse individual and family-centered goals and preferences throughout the trajectory of advanced illness and into the bereavement period. By addressing the sensitive topic of end-of-life, NINR seeks to provide an evidence base for practical and useful information about the most common issues faced by individuals with a life-limiting condition or serious illness and their caregivers. NINR will continue to support research focused on topics unique to the end of life and palliative care, including:

- Developing strategies to optimize integrated and coordinated care transitions, differential interventions, and treatments to improve patient-centered outcomes of hospice and palliative care across diverse care settings, populations, and cultural contexts.
- Determining the theoretical and causal mechanisms that underlie multidimensional and complex issues and choices in end-of-life and palliative care.
- Developing the most effective ways to screen, assess, monitor, and treat the met and unmet end-of-life and palliative care needs of individuals with serious advanced illness and their families.
- Developing, testing, and implementing personalized, culturally congruent, and evidence-based palliative and hospice interventions or treatments that best address the needs of underserved, disadvantaged, and diverse populations across the care continuum.
- Discovering the unique palliative characteristics of multidimensional advanced symptoms with the goal of developing personalized targeted interventions to alleviate or manage symptoms.

SUPPORTING INNOVATION AND 21ST CENTURY NURSING SCIENCE WORKFORCE

NINR views innovation and support for the 21st Century nurse scientist workforce as vital to the advancement of nursing science and health care, and as focus areas that cut across the Institute's research portfolio. In implementing research programs within the four main areas of scientific focus, NINR also emphasizes the promotion of Innovative Technologies and supporting 21st Century Nurse Scientists.

PROMOTING INNOVATION:

TECHNOLOGY TO IMPROVE HEALTH

Innovative technologies play a critical role in advancing health care, and nursing science can foster the development of novel, culturally sensitive interventions that deliver tailored care and real-time health information to patients, families, clinicians, and communities. The frontier of technology holds great promise for rapid advances in data science, genomic and molecular research, as well as devices and software to improve health across the health sciences. NINR continues to support research programs that are developing and refining technologies to improve symptom risk assessment and identify potential interventions. NINR is further committed to supporting the development of innovative health technologies to reach diverse and underserved populations and promote health, prevent illness, and improve health-related quality of life across the lifespan.

PROFILES IN INNOVATION

NINR-supported research to develop novel technologies is expanding the influence of nursing science and bringing important innovations to clinical practice. Examples of NINR-supported science advances in technology include:

- **Intelligent sensors embedded in the home detect changes in health status and can promote healthy independent living** – A nurse-led, interdisciplinary team of scientists conducted research on the development of a sensor system for use in apartments in a senior living community. A number of sensors are placed around a resident's apartment and are connected to a computer that develops a model for the normal daily patterns of each resident. Changes in behaviors or patterns of daily life, such as restlessness in bed, time spent in bed, general activities, and time away from the apartment are noted. If behaviors are detected that differ from the resident's usual pattern, an alert is sent to the nurse care coordinator and clinicians for review. These behavioral changes can signal changes in health earlier than the appearance of clinical signs, and this knowledge can help to promote independent living for older adults.[16]

- **Unpowered ankle exoskeleton harnesses the body's energy to make walking more efficient** – Researchers designed a lightweight ankle exoskeleton that harnesses the power of a person's own muscles to make walking more efficient. This device requires no external power, instead using a spring system to reduce the load placed on the calf muscles and make walking easier. The researchers tested the devices on nine healthy adults, who wore them on both legs while walking on a treadmill. These experiments revealed that wearing the exoskeleton reduced the energy cost of walking by 7.2 percent, which is equivalent to the effect of taking off a 10-pound backpack. Although the exoskeleton was only a prototype, it holds promise as a way to make walking easier for people recovering from an injury or dealing with normal aging issues.[17]

- **Decrease in readmissions after implementing EHR-based decision support tool** – Hospital readmissions are a common and costly problem, and new tools are needed to help clinicians identify patients in need of post-acute care. A team of researchers created an evidence-based decision support tool that integrates with hospital electronic health record (EHR) systems to help identify high-risk patients when they are admitted to the hospital, so their care can be tailored to prevent readmissions. With support from NINR, the research team installed the tool in a three-hospital academic health system and compared readmission outcomes before and after implementation. They found a 33-percent relative reduction in 30-day readmissions and a 37-percent relative reduction in 60-day readmissions after implementation, suggesting that this evidence-based decision support tool can help connect patients to the care they need for better outcomes after discharge.[18]

[16]Rantz MJ, Scott SD, Miller SJ, Skubic M, Phillips L, Alexander G, Koopman RJ, Musterman K, Back J. Evaluation of health alerts from an early illness warning system in independent living. Comput Inform Nurs. 2013 Jun;31(6):274-80.

[17]Collins SH, Wiggin MB, Sawicki GS. Reducing the energy cost of human walking using an unpowered exoskeleton. Nature. 2015 Jun 11;522(7555):212-5.

[18]Bowles KH, Chittams J, Heil E, Topaz M, Rickard K, Bhasker M, Tanzer M, Behta M, Hanlon AL. Successful electronic implementation of discharge referral decision support has a positive impact on 30- and 60-day readmissions. Res Nurs Health. 2015 Apr;38(2):102-14.

Future Directions: *Technology to Improve Health*

The accelerating availability and accessibility of innovative technologies provide nursing science with an ideal opportunity to reach diverse and underserved populations, improving health and preventing illness across the lifespan. Over the next five years and beyond, NINR will continue building on the exponential growth and accessibility of multiple technological platforms, supporting research into multiple strategies to reach underserved and high-need populations. In this endeavor, NINR will prioritize research to:

- Identify the essential components of successful, evidence-based, innovative interventions that are easily tailored to diverse population groups across health care settings.
- Support interprofessional research and develop system infrastructures by building partnerships with technical developers (e.g., engineers and designers) and communities to design and test new technologies in various settings.
- Develop technologies to maximize the use of innovative methodologies that capture community voice and cultural context in the promotion of positive health behaviors and management of chronic conditions across conditions, communities, and ages.
- Explore a wide range of technological formats (e.g., video/audio, data collection tools, smart devices) that can be used to improve the cultural congruence of health interventions and support real-time clinical decisions to improve health.

21ST CENTURY NURSE SCIENTISTS:

INNOVATIVE STRATEGIES FOR RESEARCH CAREERS

The development of a strong cadre of nurse scientists has been a primary goal of NINR since its establishment. To continue to support advancements in science and improvements in health, it is essential that the scientific workforce of the future be innovative, multidisciplinary, and diverse. NINR supports a wide range of activities, in both its extramural and intramural programs, to ensure excellence in the next generation of nurse scientists. In addressing the goal of preparing a diverse and talented research workforce, NINR supports a variety of training opportunities for scientists and trainees at all career levels, particularly those at an early career stage who are so critical to sustaining the future of innovative research and high quality health care. NINR devotes significant support to individual and institutional pre- and postdoctoral research fellowships, as well as career development awards, and sponsors numerous "research intensives" for nurse scientists at all career levels.

PROFILES OF PROGRAMS SUPPORTING 21ST CENTURY NURSE SCIENTISTS

Maintaining a strong commitment to training the next generation of nurse scientists will continue NINR's contribution to helping nursing science meet existing and impending health care challenges. Some examples of NINR's support for the development of the 21st Century Nurse Scientist workforce include[19]:

- **National Research Service Awards (NRSA):** NINR supports awards to enable scientists to be trained to conduct independent nursing research and to collaborate in interdisciplinary research through individual and institutional predoctoral, postdoctoral, and senior fellowships.

- **Career Development Awards (Ks):** With an emphasis on early-career investigators, NINR uses career development awards to provide support and protected time for an intensive, supervised career development experience leading to research independence.

- **NINR Summer Genetics Institute:** Incorporating genetics methodology into research on symptom management has been a priority for the Institute for many years, given NINR's ongoing strategic focus of expanding biobehavioral research. Since 2000, the NINR Division of Intramural Research has sponsored the NINR Summer Genetics Institute (SGI). This intensive summer training program provides graduate students and faculty with a foundation in molecular genetics to enhance their research and clinical practice. SGI graduates number more than 200, and are successfully building programs of research in genetics related to nursing, disseminating findings through publications, and integrating genetics content in nursing school curricula across the country.

- **Symptom Methodologies Boot Camps:** In 2010, NINR began offering one-week intensive summer training workshops in symptoms methodologies. These "Symptom Methodologies Boot Camps" cover topics relevant to symptoms such as pain, fatigue, and sleep, and cover issues such as data science methods, measurement, treatments, genetics, and omics, with the goal of increasing the research capability of graduate students and faculty.

- **NINR Graduate Partnerships Program (GPP):** A doctoral fellowship program that coordinates training and funding for nursing students who are motivated to undertake careers in basic or clinical research, the GPP offers the academic environment of a university and the breadth and depth of research at the NIH. NINR GPP fellows focus their dissertation research primarily in pathophysiological mechanisms related to symptoms and symptom management, health promotion, disease prevention, tissue injury, and genetics.

[19]For more information on NINR training opportunities: **http://www.ninr.nih.gov/training**

Future Directions: *Promoting Innovative Strategies for Research Careers*

NINR will maintain its foundational commitment to supporting a diverse, innovative, and multidisciplinary workforce, with the goal of developing the next generation of investigators and enhancing overall research capacity in strategically important areas of research. These efforts will continue to include awards to encourage earlier entry into research careers, to expand the interprofessional/interdisciplinary backgrounds of new investigators, and to enhance the abilities of mid-career investigators. There is a critical need for the nurse scientists of tomorrow to develop skillsets to lead scientific investigations in all areas of NINR's mission, including continuing efforts to:

- Identify novel and modifiable biologic and behavioral contributors to the physiology of symptom risk, severity, duration, and response to treatment.
- Improve the understanding of key biologic, environmental, cultural, and other measures that influence wellness among individuals and families across diverse populations and settings.
- Develop innovative research methods and technologies to address the chronic illness trajectory, especially among individuals who experience disparate health outcomes.
- Identify and develop interventions to assist individuals, families, and health care professionals in managing the symptoms of life-limiting conditions and planning for end-of-life decisions.

NINR will support and expand training strategies to secure the foundation for excellence in nursing science into the future. In addition, NINR reaffirms its commitment to a more diverse nurse scientist workforce and nursing faculty and will continue its support of critical NIH efforts to enhance the diversity of the research workforce.

ENHANCING NINR'S STEWARDSHIP OF NURSING SCIENCE

Throughout its 30 year history, NINR has served as the primary federal resource for the support of nursing science. In that capacity, NINR plays a major role in guiding the agenda for the field of nursing science in the U.S. This role as a steward of nursing science guides the work of NINR on an ongoing basis, and the Institute constantly strives to find new and better ways to set research priorities, manage science, and engage the nursing science community in shaping the future of this field of research. NINR conducts comprehensive, ongoing planning and analyses activities for developing new research initiatives and managing a balanced research portfolio. These data and results-driven processes are used by NINR to help determine the areas of science in which the Institute will solicit research applications, and to ensure that NINR-supported research, both solicited and investigator-initiated, is appropriately balanced across NINR focus areas.

The planning process results in scientific initiatives, approved by NINR's Advisory Council, that seek to target NINR support to areas in which nursing science can have a major impact on health outcomes and quality of life. All new initiatives will be consistent with the strategic priorities described in this Strategic Plan. However, the Strategic Plan is intended to be a flexible, living document. As new science and new opportunities emerge, and as new health challenges arise, NINR will regularly seek to reassess and adapt its research strategies to meet these needs and opportunities.

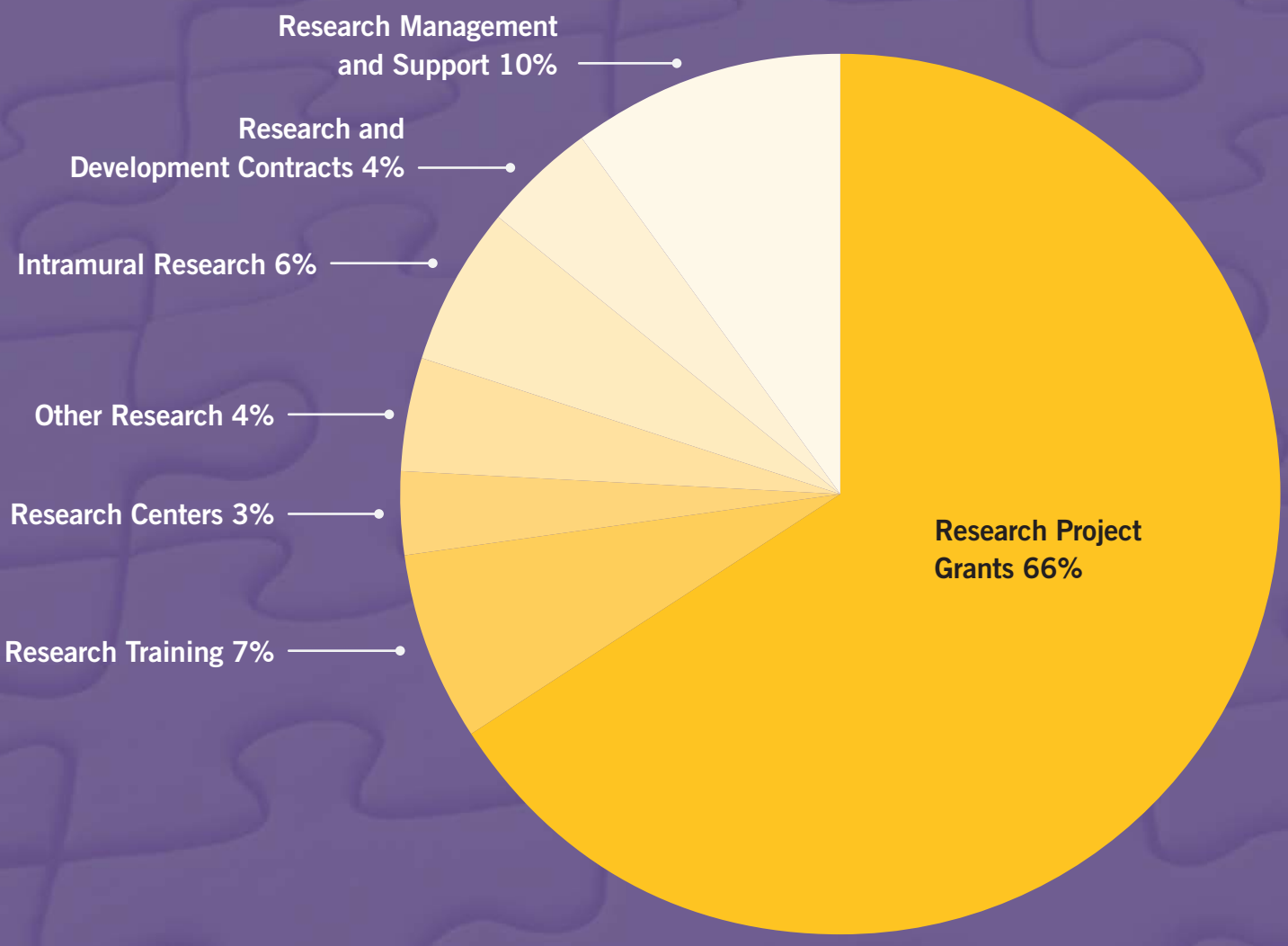
NINR also maintains a strong commitment to engagement with and outreach to the scientific community and the public, facilitating the dissemination, implementation, and translation of NINR-supported science into practice. The IQ initiative is one example of how the Institute has worked with its stakeholders to gather input on future research directions. Through multiple communication vehicles, including the comprehensive NINR website, NINR keeps its stakeholders informed of Institute research and training opportunities, new advances in NINR-supported science, and other news and information regarding Institute activities.

APPENDICES

APPENDIX A: NINR BUDGET

NINR's budget is specified by annual appropriations laws. The initial budget of NINR, as a Center, was $16 million. Today, NINR's annual appropriation is over $146 million, the large majority of which supports research at universities, hospitals, and other organizations across the United States. NINR's funding is distributed approximately as shown:

Estimated FY 2017 Budget Mechanisms



Source: FY 2017 NINR Congressional Justification.

APPENDIX B: STRATEGIC PLANNING PROCESS

The primary purpose of this Strategic Plan is to present a blueprint for NINR's support of nursing science for the next five years and beyond. The Plan describes the Institute's vision for nursing science and lists research objectives organized across four broad areas of scientific focus. The Plan is intended to convey the areas of science in which NINR will focus its efforts in order to maximize the Institute's resources and the impact of those resources on improving health and quality of life.

In developing this Plan, NINR conducted a systematic process to determine the areas of health in which there are the greatest needs, and in which NINR-supported research could have the greatest impact. In doing so, NINR sought input from a broad range of sources, including the scientific community and the general public.

The formal development of the Plan began in 2013 with the Innovative Questions (IQ) initiative. The IQ initiative, described in detail below, solicited input on future research directions from scientists, clinicians, and the general public, through scientific workshops and a public website. The initiative resulted in a series of research questions that were approved by a committee of NINR senior staff and were posted on the NINR website as a resource to the scientific community.

Using the areas of scientific focus that emerged from the implementation of NINR's previous Strategic Plan as a framework, NINR staff began drafting a new Strategic Plan in 2015. This draft included research objectives that were based largely on the questions obtained through the IQ initiative. An update on the new Plan was provided to the National Advisory Council for Nursing Research (NACNR) at its September 2015 meeting, and members of the NACNR were provided with a draft of the Plan for their review and comments prior to their January 2016 meeting. In February 2016, a draft of the Plan was posted on the NINR website for public comment. Representatives of advocacy groups, professional societies, faculty, staff, and students from schools of nursing,

clinicians, and scientists provided helpful comments and perspectives, many of which were incorporated into the Plan. The Plan was published in print and on the NINR website in September 2016.

This Strategic Plan is intended to be a living document, which can be reassessed and evaluated on an ongoing basis. As needs arise and new opportunities emerge, NINR research priorities will be reviewed and adjusted where appropriate. As this Strategic Plan is implemented over the next several years, the objectives described in the Plan provide a guide for analyses of current portfolios and the development of future initiatives. New initiatives will be assessed in terms of relevance to the Plan, scientific innovation, public health need, and resources required. Periodic reviews of the Institute's research activities, as well as emerging scientific opportunities and health care needs, will continue to inform NINR planning activities during the life of this Plan. Emerging health challenges, Congressional directives, NIH and HHS priorities, and opportunities for trans-NIH, trans-HHS, and other collaborations will also play a role in setting future NINR research priorities.

INNOVATIVE QUESTIONS WORKSHOPS 2013-2014

In November 2013, NINR launched the Innovative Questions (IQ) initiative. Inspired by similar successful efforts at NIH and other organizations, the goal of the IQ initiative was to initiate a dialogue with NINR stakeholders to identify novel scientific questions. NINR sought thoughts and ideas that would encourage new thinking and creativity in nursing science, explore unanswered questions, promote results-oriented research, and guide the science over the next 5 to 10 years. The IQ initiative consisted of two components, a series of workshops, and a public website. The IQ Workshops brought together leading scientists and interdisciplinary experts to identify and refine innovative research questions through a consensus-building, discussion format. These workshops were held in Bethesda, Maryland in 2013 and 2014. The questions that emerged from the discussion at each of the workshops and from the input provided through the public website are shown on the following pages, along with a list of the participants in each workshop. We are grateful to everyone who participated in the IQ initiative for their time and input, and we appreciate the assistance provided by the NINR staff and contractors during the process.

SYMPTOM SCIENCE: PROMOTING PERSONALIZED HEALTH STRATEGIES

November 2013

New advances in genomics and other fields have allowed nurse scientists to better understand the symptoms of chronic illness, such as pain, fatigue, and disordered sleep. NINR supports research to develop improved, personalized strategies to treat and prevent the adverse symptoms of acute and chronic illness across diverse populations and settings. On November 8, 2013, NINR convened a workshop of experts in the field of symptom science. These experts were asked to propose and discuss a series of research questions that could point the way forward for nursing science in symptoms research and inform future NINR efforts in this area.

Innovative Questions in Symptom Science

- What are the biological and behavioral dynamics of symptoms (e.g., dyspnea, fatigue, impaired sleep/insomnia, pain, depression) that can change the trajectory of chronic illnesses, and how can the dynamics be optimized and maintained to prevent symptom relapse?
- What innovative care delivery models (e.g., interdisciplinary, family-based), research methods (e.g., community engaged research, pragmatic trials), and technologies (e.g., eHealth) can be leveraged to improve symptom management and change the chronic illness trajectory especially among individuals who experience disparate health outcomes?
- How do lifestyle factors, environmental conditions, symptom clusters, and symptom treatments impact quality of life and symptom management in different chronic conditions?
- How do symptom precursors (e.g., biomarkers or conditions such as obesity) contribute to the physiology of symptom risk, severity, duration, and response to treatment?
- What are the 'omic,' phenotypic, and state-dependent indicators related to the mechanism, assessment, and management of high-impact symptoms (e.g., pain,

fatigue, dyspnea) and what is the added value of these indicators beyond clinical parameters in explaining physical and psychological symptoms in both patients and their informal caregivers?

- What are the common mechanistic pathways (e.g., stimulus to perception, perception to report) that can distinguish underlying symptom cluster trajectories that are amenable to intervention at various points along those pathways?
- What are the personalized markers (e.g., biomarkers and clinical factors) that can be used to stratify subgroups of patients with different patterns among symptoms to determine the symptom management strategies most effective in improving quality of life?
- What innovative methodologies (e.g., modeling) can be used to analyze symptom management algorithms to identify the interventions most likely to be successful in clinical or pragmatic trials?
- How can we create a standardized, feasible, valid, and relevant data and technology infrastructure to routinely collect and aggregate symptom data from patient health records, but also from other types of assessments (biological, physiological, performance) to inform clinical care and research?
- What are the biological indicators that can help determine the presence and severity of subjective symptoms in individuals who cannot self-report (e.g., small children, individuals with cognitive decline) to help improve clinical assessment and management? Is there a role for fMRI?
- What state-of-the-art research designs/methods (e.g., mixed methods, SMART, MOST) should investigators use to test personalized symptom management strategies to include scalable interventions?

MEETING ROSTER

Workshop Chair

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WELLNESS: PROMOTING HEALTH AND PREVENTING ILLNESS

January 2014

The most effective way to overcome the effects of illness is to prevent it from occurring in the first place. In focusing on wellness, nursing science seeks to promote health and prevent illness across health conditions, settings, the lifespan, and in minority and underserved populations. NINR supports research to understand the physical, behavioral, and environmental causes of illness; assess behaviors that lead to healthy lifestyle choices; and develop evidence-based interventions to promote wellness. On January 15, 2014, NINR convened a workshop of experts in the field of wellness. These experts were asked to propose and discuss a series of research questions that could point the way forward for nursing science in wellness research and inform future NINR efforts in this area.

Innovative Questions in Wellness

- What study designs (e.g., pragmatic, adaptive, social network analysis, comparative effectiveness) and analytical techniques (e.g., propensity modeling, data visualization) can be used to implement cost-effective, sustainable wellness interventions across communities and populations?
- What factors moderate and mediate the effects of lifestyle interventions designed to promote healthy behaviors among family members (e.g., intergenerational) while considering the environmental context (e.g., social, structural, and demographic)?
- What are the most accessible, effective, and affordable technologies (e.g., multimedia, mobile) to deliver personalized interventions that improve wellness outcomes across populations and settings (e.g., patient monitoring, shared decision making, skill building, communication, care transitions) that are minimally obtrusive, secure, and promote comfort for end users?

- What are the variables (e.g., biological, behavioral, economic, cultural, genetic, environmental) that interact to influence family member wellness and what interventions are most effective in promoting health outcomes?
- What interventions (individual or group) can care providers deliver that are effective in developing health promoting and risk reducing behaviors in early childhood and how can individual characteristics be matched to interventions that provide benefit over the lifespan?
- What are the etiological pathways (e.g., biological, psychological, environmental, genetic) and how can these pathways be used to prevent chronic illnesses with known risk factors (e.g., obesity, health literacy) in childhood and across the lifespan?
- What innovative methods (e.g., trajectory science, longitudinal case studies, agent based, and computation science) and data sources (e.g., electronic health records, existing longitudinal studies) can be used to explore characteristics (e.g., physiological, biological, behavioral) and their interrelationships that are associated with maintenance of healthy behaviors over time?
- How can we capitalize on natural experiments, community-based efforts and community/academic partnerships to promote healthy behaviors, decrease risk, and promote wellness?

WELLNESS: PROMOTING HEALTH AND PREVENTING ILLNESS

January 2014

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SELF-MANAGEMENT: IMPROVING QUALITY OF LIFE FOR INDIVIDUALS WITH CHRONIC ILLNESS

March 2014

The science of self-management examines strategies to help individuals with chronic conditions and their caregivers better understand and manage their illness and improve their health behaviors. NINR-supported research helps individuals from diverse backgrounds and their families live with chronic illness by developing effective approaches to self-management that can improve quality of life while reducing the burden for caregivers and the health care system. On March 25, 2014, NINR convened a workshop of experts in the field of self-management. These experts were asked to propose and discuss a series of research questions that could point the way forward for nursing science in self-management research and inform future NINR efforts in this area.

Innovative Questions in Self-Management

- What clinical scenarios using point-of-care/self-monitoring diagnostic devices could significantly improve self-management?
- What are the brain-behavior links in the self-management of acute and chronic illnesses in the context of moderating variables such as environment and family factors?
- What interventions are efficacious and effective for self-management of symptoms across chronic conditions?
- How do we make self-management interventions sustainable across the lifespan for individuals who face changing health conditions?
- What factors facilitate translation of effective self-management interventions?
- What modifiable epigenetic factors are influenced by self-management interventions, and how may they shape biological (e.g., inflammatory and oxidative stress pathways) and behavioral outcomes in patients with chronic conditions and related symptoms?

- Within rural environments, what factors (social, cultural, and political) hinder or support the self-management behaviors of individuals, families, and communities, and how can technology and community participatory interventions be used to eliminate chronic disease-related health disparities?
- What is the influence of networks (e.g., kinship, social, etc.) on self-management at the family and community level, and what technologies can best optimize self-management and disease prevention across the lifespan?
- What interventions are needed to address variations in cognitive function/decision making to improve self-management behaviors, clinical outcomes, and quality of life?

MEETING ROSTER

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END-OF-LIFE AND PALLIATIVE CARE: THE SCIENCE OF COMPASSION

May 2014

As the lead NIH Institute for end-of-life research, NINR supports science to assist individuals, families, and health care professionals in managing the symptoms of life-limiting conditions and planning for end-of-life decisions. NINR also recognizes that high-quality, evidence-based palliative care is a critical component of maintaining quality of life at any stage of illness, not just at the end of life. On May 7, 2014, NINR convened a workshop of experts in the field of end-of-life and palliative care. These experts were asked to propose and discuss a series of research questions that could point the way forward for nursing science in end-of-life and palliative care research and inform future NINR efforts in this area.

Innovative Questions in End-of-Life and Palliative Care

- How do we overcome barriers in underserved, hard-to-reach populations in order to implement culturally congruent, patient- and caregiver-centered palliative care strategies?
- What palliative care interventions/strategies best align with patient and caregiver goals?
- How do type, intensity, complexity, and fluctuation of symptom burden impact individual and family goals for care?
- What are the best models for community-based palliative care?
- What are the strategies for assessing caregiver preparedness and self-care abilities for palliative care early in the illness trajectory?

- For symptom management at end of life, what are the best minimally invasive methods to monitor functional status, physiological status, and patient reported outcomes?
- What electronic data collection methods can be used by health care providers to monitor, evaluate, and improve palliative/end-of-life care?
- What are the best ways to measure patient reported outcomes using standardized, widely used instruments or common data elements?
- What are the most effective ways to motivate and engage individuals, caregivers, and families in conversations about end-of-life goals and values that inform decision making?
- How do we operationalize and individualize palliative care and which models best meet the supportive and end-of-life care needs of patients and families?
- What factors in palliative care impact the process of bereavement?

MEETING ROSTER

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PROMOTING INNOVATION: TECHNOLOGY TO IMPROVE HEALTH

June 2014

Innovative technologies play a critical role in advancing health care, and nursing science can provide the foundation for developing novel, culturally sensitive interventions that deliver personalized care and real-time health information to patients, families, clinicians, and communities. On June 2, 2014, NINR convened a workshop of experts in the field of technology. These experts were asked to propose and discuss a series of research questions that could point the way forward for nursing science in technology research and inform future NINR efforts in this area.

Innovative Questions in Technology

- How can technologies be used to analyze intervention components (i.e., determine what works for which populations under what conditions) and increase treatment fidelity?
- What are the fundamental approaches, metrics, and system infrastructures needed to design technologies that are acceptable to diverse populations and integrate the ideas of clinicians and technical developers (e.g., engineers and designers)?
- How can emerging technologies be used to explain and predict patient trajectories, inform interventions, and support real-time clinical decision making?
- What are the mechanisms by which innovative technologies (such as robots, avatars, and games) can be used to facilitate behavior change and decrease the burden of illness?
- What are the essential principles, characteristics, or features of existing and yet-to-emerge technologies that facilitate effective long-term management of chronic illness, reduce health disparities, and improve health outcomes?

- In what ways can patient and community voices and the cultural context inform the design/selection/deployment of technologies to improve health outcomes?
- How can information technology be used to promote health behavior change and reduce disease risk by engaging different individuals (e.g., extended family, lay coaches, teachers) to reinforce health care provider messages?
- How can mHealth technologies that provide personalized physiological feedback (e.g., seizure management, heart rhythm) be integrated with clinical systems to promote positive health outcomes?
- How can technologies be used to slow the progression of chronic illnesses/ conditions across the lifespan?

MEETING ROSTER

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APPENDIX C: NATIONAL ADVISORY COUNCIL FOR NURSING RESEARCH

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APPENDIX D: A HISTORY OF NINR

30 YEARS OF ADVANCING SCIENCE, IMPROVING LIVES

1950s

Federal support begins for nursing research at the National Institutes of Health (NIH) in 1955. The Nursing Research Study Section is established. The chairman is the world-famous medical inventor and heart surgeon Michael DeBakey, who is credited with first articulating the need for a national nursing research institute.

1960s

The Federal nursing research function is moved to the Division of Nursing within what is now the Health Resources and Services Administration. Support is provided for training of nurse investigators, and for nursing research projects and pre- and postdoctoral fellowship programs.

1970s

The American Nurses Association Commission on Nursing Research recommends recognition of nursing research in the mainstream of biomedical and behavioral science.

1980s

Two reports are instrumental in the placement of nursing research at NIH. In 1983, an Institute of Medicine report calls for a Federal nursing research entity in the mainstream of science. A 1984 Task Force report requested by the NIH Director finds that nursing research activities within NIH are relevant to the NIH mission and can be expanded administratively.

November 20, 1985

P.L. 99-158, the Health Research Extension Act of 1985, creates the National Center for Nursing Research (NCNR) at the NIH.

April 16, 1986

Department of Health and Human Services Secretary Otis S. Bowen creates the administrative structure of NCNR.

April 1986 – June 1987

Dr. Doris Merritt, Special Assistant to NIH Director serves as Acting Director of NCNR. The initial budget is $16 million. The National Advisory Council first meets in February 1987.

June 1987 – March 1994

Dr. Ada Sue Hinshaw serves as the first Director of NCNR.

1992

Dr. David Olds establishes that visits by home nurses significantly lower mothers' high blood pressure during pregnancy and result in better timing of subsequent pregnancies. Abuse and neglect of their children are also reduced.

June 10, 1993

NCNR achieves Institute status at NIH, becoming the National Institute of Nursing Research (NINR) after the NIH Revitalization Act of 1993 is signed into law.

June 14, 1993

DHHS Secretary Donna Shalala implements the NIH Revitalization Act transforming NCNR into an Institute, NINR.

July 1994 – April 1995

Dr. Suzanne Hurd serves as Acting Director of the NINR.

1994

Dr. Loretta Sweet Jemmott, through various funding sources including NINR, tests several gender appropriate, culturally sensitive interventions on hard to reach, vulnerable populations and significantly reduces sexual risk behaviors for HIV. The Centers for Disease Control and Prevention selects three of the interventions for use as model curricula in their Division of Adolescent and School Health. The model, "Be Proud! Be Responsible!" is distributed nationwide.

April 3, 1995

Dr. Patricia A. Grady is appointed Director of the NINR.

November 1997

NINR is designated as the lead NIH Institute to coordinate collaborative research at NIH and other Federal agencies on end-of-life and palliative care, a new area of science.

1998

Dr. Joanne Harrell, building on research that shows risk for cardiovascular disease can begin at an early age, demonstrates that a specially designed classroom educational program for elementary school children can significantly lower their cholesterol levels in just eight weeks.

Dr. Nancy Bergstrom, in a multi-site study, tests the Braden scale for risk of pressure sores and finds its predictive capability accurate. The scale is now used widely in nursing homes and hospitals.

1999

Dr. Mary Naylor demonstrates that transitional care from hospital to home, consisting of discharge planning at the hospital and follow-up interventions in the residence, can improve significantly the health of older adult patients who are hospitalized with common medical and surgical problems. The interventions are conducted by multidisciplinary teams that include advanced practice nurses. Per patient days in the hospital, hospital readmissions, and costs to the health care system are all reduced substantially.

Dr. Jon Levine establishes that gender plays a key role in pain relief, with women obtaining satisfactory relief from kappa-opioid drugs, such as Stadol or Nubain, while men receive little benefit. Kappa-opioids have fewer side effects than more typically used morphine-like opioids.

2000

The Summer Genetics Institute (SGI) is established by NINR and is based at the National Institutes of Health. The SGI is a two-month, full-time summer research training program targeted at faculty, graduate students, and advanced practice nurses. It features classroom and laboratory components that are designed to provide a foundation in molecular genetics for use in clinical practice and the research laboratory. Students receive doctoral-level graduate credits.

Dr. Margaret Grey reports that providing training in coping skills, such as social problem solving, communication, and conflict management, for young people with type-1 diabetes mellitus has long-lasting positive effects. Their ability to control their disorder and quality of life is improved significantly. Ongoing research addresses behavioral interventions with parents and younger children to promote the child's metabolic control and their overall well-being.

2002

Dr. Linda Aiken's ongoing research consistently shows that hospital working conditions and adequacy of nurse staffing per patient can affect patients' recovery. In hospitals where nurses have lower patient workloads, patients have substantially lower mortality rates.

2003

Dr. Martha Hill finds that interventions conducted at the community level by a multidisciplinary health care team reduces high blood pressure in inner city young African-American males who are typically underserved by the health care system. This research illustrates that culturally sensitive, successful interventions can be conducted for vulnerable populations and can help reduce health care disparities.

2005 – 2006

NINR celebrates 20 years at NIH and plays a key role in the NIH Roadmap Initiative, launched by the NIH Director to address opportunities and gaps in research that will accelerate the progress of science.

2007

Dr. J. Randall Curtis and collaborators report that an intervention to improve communication between clinicians in intensive care units and family members of a dying patient significantly reduces feelings of stress, anxiety, and depression in the family members. The intervention, which consisted of a set of guidelines for conducting family conferences, reduced symptoms related to post-traumatic stress disorder in family members up to three months after the death of their loved one.

2009

Dr. Pamela Mitchell reports that a behavioral intervention called Living Well with Stroke (LWWS) reduced the incidence of depression in stroke survivors. Post-stroke depression, which occurs in as many as one-third of stroke survivors, can lead to poorer response to rehabilitation and increased use of health care services. LWWS, which consists of counseling and physical activity sessions, significantly reduced depression scores both immediately after treatment and at a one-year follow-up.

2010

U.S. Senate resolution, S. Res. 642, congratulated NINR on a quarter century of achievement in science and public service. The resolution was introduced by Senator Daniel Inouye (Hawaii) and cosponsored by Senator Susan Collins (Maine).

2010 – 2011

NINR commemorates the 25th anniversary of nursing science at the NIH. Special events included scientific symposia, a joint conference co-sponsored with the NIH Clinical Center on symptom science, and the release of a history book examining NINR's first 25 years.

2011

NINR convened a national summit on "The Science of Compassion: Future Directions in End-of-Life and Palliative Care." This three-day, trans-NIH scientific summit focused on examining the current state of end-of-life and palliative care science, and envisioning and discussing future directions in research to improve quality of life for those with advanced illness. The nearly 1,000 attendees included scientists, palliative and end-of-life care health professionals, educators, policy analysts, members of professional organizations, and members of the public.

2013

Dr. Bernadette Melnyk reports that a teacher-delivered intervention program promoting healthy lifestyles improved health behaviors, social skills, severe depression, and academic performance in high school adolescents. Routine integration of a programs such as this into health education curricula in high school settings may be an effective way to prevent high-risk teen populations from becoming overweight or obese, and

could lead to improved physical health, psychosocial skills, and academic outcomes, according to the study.

2013 – 2014

To identify future research directions within each of its focus areas, NINR engaged its stakeholders in a dialogue to identify novel scientific questions. Through this initiative, Innovative Questions (IQ), NINR sought ideas to encourage new thinking and creativity in nursing science, explore unanswered questions, promote results-oriented research, and guide the science over the next five to ten years. The IQ initiative consisted of two components: a series of workshops and a public website.

2014

NINR designed an evidence-based campaign, Palliative Care: Conversations Matter®, to raise awareness of pediatric palliative care and to facilitate conversations about palliative care among health care providers, children living with a serious illness, and their families. The first phase of the campaign focused on health care providers, while the second phase was focused on providing resources, such as brochures, for patients and families to increase awareness and empower families to begin a dialogue with health care providers.

2015

NINR intramural scientist Dr. Jessica Gill reports that the tau protein, previously linked to acute symptoms immediately following a traumatic brain injury (TBI), may also be responsible for long-term complications that can result from TBI. The findings suggest that long after the primary brain injury, tau accumulations may contribute to chronic neurological symptoms that can significantly affect quality of life for those who have experienced TBI.

2015 – 2016

NINR commemorates the 30th anniversary of nursing science at the NIH with a series of scientific symposia and lectures that serve to highlight the critical role that NINR-supported research plays in the health research enterprise. The Institute looks forward to the next 30 years of continuing its work to improve the health and quality of life of individuals in the U.S. and around the world.

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