

Areas of Research Emphasis





Within the strategic objectives described above, our science offers a rich mix of topic areas that can be viewed in the context of diseases and disorders, phases of the lifespan, and population groups. Health promotion and disease prevention form the keystone of our science, reflecting current understanding of the most effective approaches to maintaining health. Improving quality of life is the ultimate goal of research in the fields of self-management, symptom management, and caregiving. Eliminating health disparities is essential if the entire population is to benefit from improved promotion and prevention strategies, as well as new interventions. Finally, research on the end of life – an important emerging field for which NINR has been designated the lead Institute at NIH – is a unique, and in many ways a cross-cutting, area of research and clinical science.



Promoting Health and Preventing Disease

The interplay of biology and behavior is especially apparent in health promotion and disease prevention. As our understanding of the role that lifestyle plays in disease increases, so does the need for predictors and strategies that target long-term behavior change. The development of interventions based on well-defined underlying mechanisms is critical to advancing health promotion and disease prevention.

Environmental and genetic factors, as well as emerging diseases, interact with behavior to create new challenges. Socioeconomic factors influencing health include housing, population density, and other factors related to geographic location. Many potential interventions must be studied, and perhaps modified, to take into account differences among urban, suburban, rural, and remote environments. NINR seeks to support research that will:

- ◆ Develop biomarkers to assess disease risk and response to treatment, identify susceptibility genes for at-risk individuals, and design interventions to moderate risk (e.g., neurohumoral markers for differential response to intervention).
- ◆ Develop or improve biobehavioral methods, measures, and intervention strategies to optimize health.
- ◆ Identify factors that influence decision-making that results in behavioral changes that promote health and prevent disease and disability.
- ◆ Identify and develop individual and family interventions designed to sustain health-promoting behaviors over time (e.g., prevention of obesity; prevention of HIV/AIDS transmission).
- ◆ Design intervention studies using community-based approaches to facilitate health promotion/risk reduction behaviors (e.g., families with special needs, such as parents or caregivers of persons with chronic illness or developmental disabilities).
- ◆ Investigate opportunities to identify and ameliorate the long-term consequences of prematurity, including near-term infants at risk for complications.

Improving Quality of Life

Prevention and treatment of disease are the principal goals of clinical research. Attainment of these goals is constrained by many factors, including the complexity of diseases and disorders for which the underlying mechanisms and pathways to intervention are not fully understood. Moreover, even successful treatment and survival of disease often leave patients facing many challenges in daily living. Our science offers many opportunities for research that will improve quality of life by enhancing the individual's role in managing disease, relieving symptoms of disease and disability, and improving outcomes.

Self-management

Our science brings a unique perspective to the interactions among healthy persons, patients and their families, and health practitioners. Self-management incorporates facets of both symptom management and the adoption of health-promoting behaviors. It is particularly important that persons at risk for disease, long-term survivors of disease, and persons with chronic disabilities succeed in modifying behavior in order to manage their own health. This focus on self-management research was in response to the desire of many people to take more responsibility for their own health, and to the increasing imperative of controlling the costs of health care.

As technology advances, new opportunities for the development of self-management strategies will emerge. In turn, improved tools for self-management will further stimulate the research agendas for technology development and research methods. NINR seeks to support research that will:

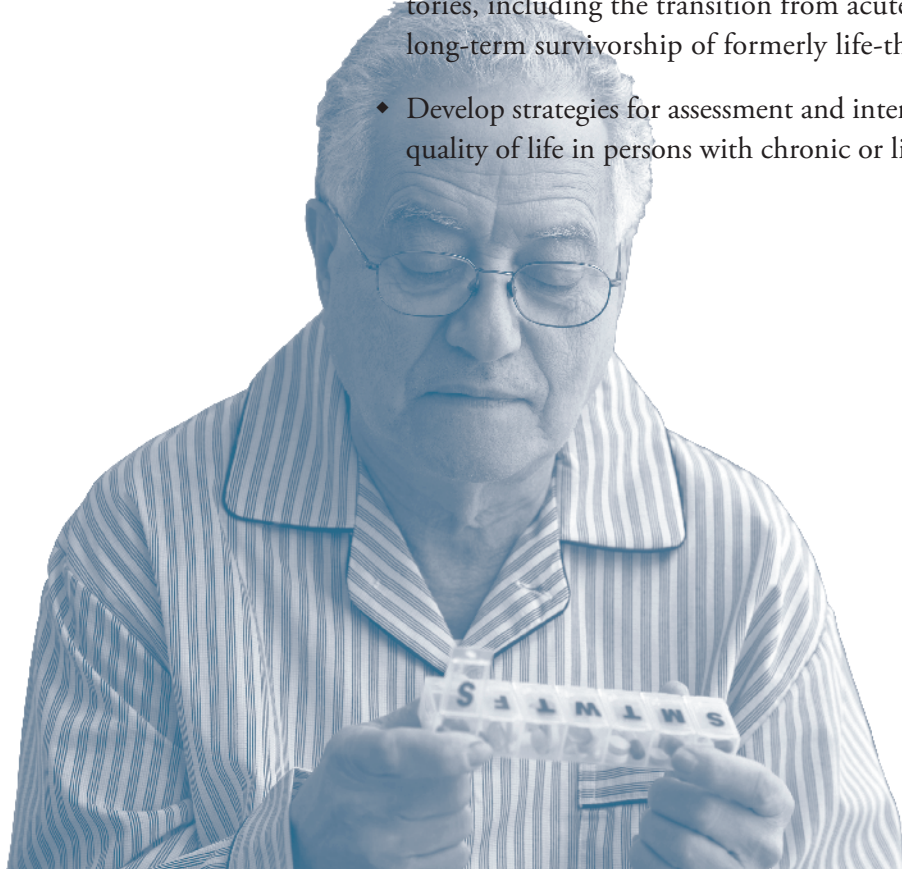
- ◆ Develop technologies to facilitate early self-identification and self-reporting of symptoms.
- ◆ Design self-management decision-making strategies that promote healthy lifestyle choices such as diet, exercise, and primary health care practices.
- ◆ Define the behaviors that support adherence to treatment for complex acute and chronic illnesses.
- ◆ Evaluate factors that impact independence and self-care in long-term care settings.
- ◆ Identify strategies for self-management and promotion of personal health among long-term survivors of disease and persons with chronic disabilities, including routine health monitoring and attention to co-morbid conditions.



Symptom Management

For the patient, a symptom may represent a minor annoyance, a disturbing portent, or a terrible burden. To the clinician or scientist, the same symptom may serve as a diagnostic aid, an indicator of disease severity, or an outcome that shows the success or failure of an intervention. Symptoms may appear or change at multiple points in the trajectory of illness and intervention, causing patients to seek relief or reassurance, or interrupting the course of treatment because of concerns about unpleasant or dangerous side effects. NINR seeks to support research that will:

- ◆ Delineate causative mechanisms underlying symptoms.
- ◆ Improve recognition of symptoms by patients, their caregivers, and health care providers.
- ◆ Develop interventions that improve patient response and adaptation to symptoms and symptom clusters in discrete and co-morbid conditions.
- ◆ Design strategies to improve management of symptoms over disease trajectories, including the transition from acute to chronic illness and periods of long-term survivorship of formerly life-threatening illnesses.
- ◆ Develop strategies for assessment and intervention to improve health-related quality of life in persons with chronic or life-threatening illnesses.



Caregiving

The Institute seeks to provide a scientific foundation for improving outcomes for care providers and recipients across diverse settings. Recent trends show that an increased number of our population lives to an advanced age, and children who in earlier times might have succumbed to premature birth, childhood illness or injury, now survive. Informal families and networks of peers augment or replace the traditional family as providers of informal care. Changes in the incidence and prevalence of acute and chronic illnesses combined with the proliferation of diverse health care settings (e.g., assisted living facilities, nursing homes, and home care provided by professionals or family members) are opening up new lines of research inquiry. NINR seeks to support research that will:

- ◆ Design interventions aimed at improving physiological and cognitive function in residents of long-term care facilities.
- ◆ Develop interventions to improve the quality of caregiving.
- ◆ Evaluate factors that impact the health and quality of life of informal caregivers and recipients.
- ◆ Identify factors that improve the transition from one care setting to another.
- ◆ Develop models for first responders in events such as natural disasters, environmental hazards, and other emergency situations.



Eliminating Health Disparities

NINR's commitment to eliminating health disparities dovetails with a period of growing national and international recognition of the impact of race, gender, socioeconomic status, ethnic origin, geography, and culture on the health of individuals and groups.

A greater understanding is needed of predisposing factors for many diseases and disorders. Socioeconomic factors, including living conditions, interact with biology and behavior to influence health outcomes. Culturally based practices can affect either risk or protective factors for many conditions. Inequities in access to treatment and differences in response to treatment present challenges to the well-being of individuals, families and communities.

NINR's focus on health promotion and disease prevention, and its consistent commitment to cultural sensitivity, position the Institute for leadership in NIH and Department of Health and Human Services (HHS) efforts to eliminate disparities in health and quality of life. NINR is a regular contributor to strategic planning related to health disparities at NIH and HHS. The success of NIH efforts to develop research infrastructure in minority-serving institutions has laid the groundwork for making research findings, tools, and methods more widely accessible.



Focusing on the integration of biology and behavior is critical to health disparities research. Gender differences, for example, reflect biological factors based on sex and the behavioral and cultural differences between the male and female in society. Research involving “underserved populations” may incorporate many variables – age, minority status, geographic location, economic status, disability and unrecognized co-morbid conditions, to name just a few. NINR will continue to develop and refine strategies to promote institutional and individual capacity for expanded research in this field. The Institute will support research that will:

- ◆ Elucidate mechanisms underlying disparities and design interventions to eliminate them, with particular attention to issues of geography (rural and remote settings), minority status, underserved populations, and persons whose chronic or temporary disabilities limit their access to care.
- ◆ Design culturally appropriate interventions to communicate risks and susceptibility to at-risk populations.
- ◆ Apply findings from biobehavioral, descriptive, and intervention studies to factors influencing health disparities among youth and adolescents.
- ◆ Identify strategies that will reduce the long-term adverse consequences of poor maternal and reproductive health in minorities and underserved populations.
- ◆ Evaluate and modify partnership and training programs to build capacity in minority-serving institutions and expand the pool of investigators from underrepresented groups.



Setting Directions for End-of-Life Research

The end of life has long been a focus of our science, given the importance of palliative care and respect for dying persons. Many factors have recently converged to increase public and professional interest in topics relevant to the end of life.

Advances in medicine and public health have altered the prospects for survival in every age group, but particularly in the very young and the very old. Many premature and low birth weight infants benefit from perinatal advances, while others face protracted courses of decline involving difficult decisions about appropriate interventions and quality of life. Cancer is no longer a death sentence for many children, but families whose children do not respond to treatment or are born with lethal genetic diseases often find themselves faced with choices no parent envisions having to make on behalf of a child. Almost everyone will confront similar decisions as their parents and other elders survive chronic and acute illnesses and live long enough to suffer from dementia, frailty, and organ failure. Only through research can one ensure that dying patients will receive adequate management of their symptoms of pain, fatigue, and depression, particularly if they are cognitively impaired or suffer from psychological impairments. Ironically, the medical and technological advances that extend life also set the stage for a prolonged process of dying, and generate new questions about the dying process itself.

The urgency of issues at the end of life has created important research opportunities. NIH has a broad interest in these research questions, given the number of diseases and conditions at the end of life. NINR has issued a number of research solicitations in response to the 1997 Institute of Medicine report, "Approaching Death: Improving Care at the End of Life." Because of NINR's emphasis on integrating biological and behavioral science in this area, the Institute has been designated the lead Institute for end-of-life research at NIH. This represents an important opportunity for nursing science to shape future directions in an emerging field and to lead the way in addressing some of the most critical questions in clinical care today.