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American Academy of Hospice
and Palliative Medicine
(AAHPM)

Association of
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(APC)

The Catholic Health Association
of the United States
(CHA)

Center to Advance
Palliative Care
(CAPC)

HealthCare
Chaplaincy Network™
(HCCN)

Hospice and Palliative
Nurses Association
(HPNA)

National Association for Home
Care & Hospice
(NAHC)

National Hospice and
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(NHPCO)

National Palliative
Care Research Center
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Physician Assistants in Hospice
and Palliative Medicine
(PAHPM)

Social Work Hospice &
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(SWHPN)

Society of Pain & Palliative
Care Pharmacists
(SPPCP)

Shannon N. Zenk, PhD, MPH, RN, FAAN
Director
National Institute of Nursing Research (NINR)

Via
ninrstrategicplan@mail.nih.gov

Dec 13, 2021

Dear NINR Director Zenk:

Thank you for the opportunity to provide feedback on the draft framework of the *NINR 2022-2026 Strategic Plan*. The National Coalition for Hospice and Palliative Care is dedicated to advancing the equitable access, delivery and quality of hospice and palliative care for all. We improve the care of people with serious or life limiting illnesses across the lifespan by convening the field, advocating for equitable policies and improved health outcomes, establishing best practices and sharing resources. The thirteen national organizations that form the Coalition represent more than 10,000 nurses and scientists, 5,200 physicians and scientists, 1,000 physician assistants, 5,000 chaplains, 8,000 social workers, interdisciplinary researchers and pharmacists, along with over 1,800 palliative care programs caring for millions of patients and families each year across the United States. We bring a broad, multidisciplinary perspective on the needs of patients with serious illness, and we believe that patients and caregivers, (regardless of race, gender, gender identity, sexual orientation, age, religion, ethnicity, socioeconomic status or ability) are always the intended beneficiaries of our work.

We deeply appreciate the National Institute of Nursing Research (NINR's) attention and commitment to addressing health equity and social determinants of health and its aggressive plans to advance the science of nursing research. However, we are concerned that this proposed Framework and recommended "Research Lenses" lack the inclusion and attention to research focused on persons with serious illness and their caregivers, an area of special vulnerability for underserved populations. We note in the May 18th Report, *Transdisciplinary Approaches to Palliative and End-of-Life Care* as Objective 3.4 was included which makes the complete absence of this area in the new framework

additionally puzzling. NINR has been a national leader in advancing palliative care research and, as a result, tremendous progress has been made in this area. Nevertheless, the evidence base to ensure high-quality care for this high-need/high-cost population is inadequate, especially as it pertains to people of color and the poor.

As in every other aspect of health care in the United States, inequitable access to quality care during serious and life-threatening illness is especially true for Black, indigenous, and people of color in the United States. During life's greatest challenge – a serious illness affecting function and quality of life – racial and ethnic disparities in access to care are of highest moral and ethical importance, particularly when that care is focused on relief of suffering, support for family caregivers, and delivering services matched to what patients say they need. Removing this specific focus on palliative care research from NINR's future strategic framework and plan seems premature and has the potential not only to halt recent advances in this area of science, but also to fail to close gaps in care during serious illness for those most at risk.

While medical advances have transformed previously fatal conditions such as cancer and heart disease into illnesses that older adults can live with for many years, they have not been accompanied by corresponding improvements in function and quality of life. The National Academy of Medicine (NAM) 2015¹ report and two subsequent National Institutes of Health (NIH) workshops co-sponsored by NINR have reported extensive national data from multiple settings and disease categories showing a high prevalence of physical, psychosocial, and financial suffering associated with serious illness in older adults; mismatches between patients' goals for care and treatments received; and a health care system that fails to deliver appropriate care to persons with serious illness and their caregivers. Suffering is not an inevitability when living with serious illness; it can be addressed. Yet, the evidence base to improve quality of life for seriously ill older adults, especially among people of color and the poor, is wholly inadequate. ^{1,2}

Over the past decade, the National Institute of Nursing Research has not only led the effort to close this knowledge gap but also catalyzed significant investment in needed palliative care research through partnership with other NIH Institutes and Centers and by private sector philanthropy. The NINR-funded [Palliative Care Research Cooperative Group](#) is but one example of how NINR has transformed care for persons with serious illness and their caregivers. When one examines research studies that have made the most significant impact on improving the care of those with serious illness, the great majority of these have been NINR funded. As you move forward with finalizing your new strategic framework and plan, we cannot emphasize enough the importance of restoring research focused on individuals with serious illness and their caregivers, as an NINR Research Lens, especially among diverse racial and ethnic populations.

As you consider this request, we have also shared these comments and concerns with NIH Director Dr. Francis Collins to encourage him to direct the other NIH Institutes and Centers to follow NINR's leadership to ensure that palliative care is integrated into all areas of research across NIH. However, it is important that NINR maintain its leadership role in this area and that your stated goal, and that of NIH, to prioritize stakeholder engagement be upheld.

Without NINR's continued focus in this area, we are deeply concerned that the research advances that we have seen will be lost and that the intolerable suffering that we see in the growing numbers of persons living with serious illness and their caregivers will continue.

Our comments were developed in collaboration with the Patient Quality of Life Coalition of which we are an active member. We strongly encourage you to consider additional stakeholder engagement before finalizing this framework and plan. The National Coalition for Hospice and Palliative Care requests the opportunity to have a dialogue with you and your team as you work to finalize this plan. Please contact Amy Melnick, Executive Director, National Coalition of Hospice and Palliative Care, at 202.306.3590 or amym@nationalcoalitionhpc.org if we can move forward with scheduling a time to bring leaders from our Coalition organizations together and meet with you and your team to discuss the potential long term impact of these changes. Thank you for your consideration.

List of Endorsing Organizations

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