

Electronic Submission *via*:  
nintrstrategicplan@mail.nih.gov



December 13, 2021

To the National Institute of Nursing Research (NINR),

Thank you for the opportunity to provide feedback on the draft framework of the *NINR 2022-2026 Strategic Plan*. The Patient Quality of Life Coalition (PQLC) was formed to advance the interests of patients and families facing serious illness, including survivors. The Coalition includes more than 40 nongovernmental organizations dedicated to improving quality of care and quality of life for these adults and children. The Coalition is particularly focused on ensuring that clinicians and health care organizations have the needed knowledge base to ensure high-quality care for our most vulnerable patient population.

We deeply appreciate NINR's attention to and commitment to addressing health equity and social determinants of health and its aggressive plans to advance the science of nursing research. We are, however, concerned about the lack of inclusion and attention to research focused on persons with serious illness and their families in the new framework, an area of special vulnerability for under-resourced populations.

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 prevalent 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 strategy seems ill-advised 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) 2015<sup>1</sup> 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

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<sup>1</sup> National Academies of Science Engineering and Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press, 2015.

base to improve quality of life for seriously ill older adults, especially among people of color and the poor, is wholly inadequate.<sup>1,2</sup>

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 families. 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 plan, we cannot emphasize enough the importance of restoring research focused on patients with serious illness and their families, especially among diverse racial and ethnic populations, as a NINR Research Lens.

As you consider this request, we would note that in recent weeks we have written to 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. It is important that NINR maintain its leadership role in this area.

Until palliative care is integrated into the genome of biomedical research, NINR's continued investment in this area is critically needed. 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, unnecessary suffering that we see in the growing numbers of persons living with serious illness and their families will continue.

Thank you for your attention to this matter. For more information or to discuss further, please contact Jennifer Hoque, Associate Principal for Access to Care Policy, American Cancer Society Cancer Action Network at [Jennifer.Hoque@cancer.org](mailto:Jennifer.Hoque@cancer.org).

Sincerely,

American Academy of Hospice and Palliative Medicine  
American Cancer Society Cancer Action Network  
Association for Clinical Oncology  
Association of Pediatric Hematology/Oncology Nurses  
Cancer Support Community  
California State University Shiley Haynes Institute for Palliative Care  
Center to Advance Palliative Care  
Coalition for Compassionate Care of California  
Hospice and Palliative Nurses Association  
National Brain Tumor Society  
National Palliative Care Research Center  
Pediatric Palliative Care Coalition  
Physician Assistants in Hospice and Palliative Medicine

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<sup>2</sup> Brown E, Morrison RS, Gelfman LP. An Update: NIH Research Funding for Palliative Medicine, 2011-2015. *J Palliat Med* 2018;21(2):182-187. DOI: 10.1089/jpm.2017.0287

Francis S. Collins, M.D., Ph.D.,  
Director, National Institutes of Health  
9000 Rockville Pike  
Bethesda, Maryland 20892  
Sent via email: [collinsf@mail.nih.gov](mailto:collinsf@mail.nih.gov)



December 13, 2021

Dear Dr. Collins,

As you are aware, the National Institute of Nursing Research is in the process of creating a new strategic plan for 2022-2026 and have invited public commentary. We have submitted our recommendations to NINR and also wanted to ensure that you are aware of our concerns as well. The Patient Quality of Life Coalition (PQLC) was formed to advance the interests of patients and families facing serious illness, including survivors. The Coalition includes more than 40 nongovernmental organizations dedicated to improving quality of care and quality of life for these adults and children. The Coalition is particularly focused on ensuring that clinicians and health care organizations have the needed knowledge base to ensure high-quality care for our most vulnerable patient population.

We deeply appreciate NINR's attention to and commitment to addressing health equity and social determinants of health and its aggressive plans to advance the science of nursing research. We are, however, concerned about the lack of inclusion and attention to research focused on persons with serious illness and their families in the new framework, an area of special vulnerability for under-resourced populations.

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 prevalent 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 strategy seems ill-advised 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) 2015<sup>1</sup> report and two subsequent National Institutes of Health (NIH) workshops have reported extensive national data from multiple settings and disease categories showing a high prevalence of physical,

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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.<sup>1,2</sup>

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 families. When one examines research studies that have made the most significant impact on improving the care of those with serious illness, many of these have been NINR funded. We cannot emphasize enough the importance of restoring research focused on patients with serious illness and their families, especially among diverse racial and ethnic populations, as a NINR Research Lens.

In addition to encouraging NINR to restore palliative care as a key research priority, given the relevance of the needs of persons with serious illness and their families across multiple diseases, we request that you encourage the other NIH Institutes and Centers to follow NINR's leadership to ensure that palliative care is integrated into all relevant areas of research so that NINR is not the lone voice in this area.

Palliative care needs to be inserted into the genome of biomedical research and NIH investment in this area is critically needed. Without an expanded NIH focus in this area, we are deeply concerned that the research advances that we have seen will be lost and that the intolerable, unnecessary suffering that we see in the growing numbers of persons living with serious illness and their families will continue.

Thank you for your attention to this matter. For more information or to discuss further, please contact Jennifer Hoque, Associate Principal for Access to Care Policy, American Cancer Society Cancer Action Network at [Jennifer.Hoque@cancer.org](mailto:Jennifer.Hoque@cancer.org).

Sincerely,

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Medicine  
American Cancer Society Cancer Action  
Network  
Association for Clinical Oncology  
Association of Pediatric Hematology/Oncology  
Nurses  
Cancer Support Community  
California State University Shiley Haynes  
Institute for Palliative Care

Center to Advance Palliative Care  
Coalition for Compassionate Care of California  
Hospice and Palliative Nurses Association  
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