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HOSPICE AND PALLIATIVE MEDICINE

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Submitted electronically to [NIHReform@mail.house.gov](mailto:NIHReform@mail.house.gov)

August 12, 2024

The Honorable Cathy McMorris Rodgers  
Chair,  
House Committee on Energy and Commerce  
2125 Rayburn House Office Building  
Washington, DC 20515

RE: Reforming the National Institutes of Health

Dear Chair Rodgers:

On behalf of the more than 5,200 members of the American Academy of Hospice and Palliative Medicine (AAHPM or Academy), we appreciate your interest in ensuring the National Institutes of Health (NIH) is best positioned to succeed in the 21<sup>st</sup> Century. AAHPM is the professional organization for physicians specializing in Hospice and Palliative Medicine. Our membership also includes nurses, social workers, spiritual care providers, pharmacists, and other health professionals deeply committed to improving quality of life for the expanding and diverse population of patients facing serious illness, as well as their families and caregivers. Together, we strive to advance the field and ensure that patients across all communities and geographies have access to high-quality, equitable palliative and hospice care.

We would like to thank you for the opportunity to provide the following feedback on the [\*\*Reforming the National Institutes of Health: Framework for Discussion\*\*](#).

## NIH Leadership Reform

### *Proposed Institutes: National Institute on Dementia*

Collapsing institutions with a strong scientific mission risks a loss of rigorous scientific proposals directly addressing specific value areas. For example, combining the National Institute of Nursing Research which supports nurse scientists with the National Institute on Minority Health and Health Disparities which addresses pervasive health disparities into the **National Institute of Health Sciences Research** could jeopardize the interdisciplinary research conducted by nurse scientists or research on health disparities which were highlighted during the COVID-19 public health emergency. Likewise, we appreciate the goal of a **National Institute for Disability Related Research** but worry that focusing an institute on disability will impact pediatric illness research conducted through the Eunice Kennedy Shriver National Institute of Child Health and Human Development as we are unsure whether pediatric research will be prioritized under such reforms.

We are especially concerned that the Framework proposes to change the National Institute on Aging (NIA) to the **National Institute on Dementia**. This change appears to significantly narrow the scope of the Institute, suggesting an exclusive focus on dementia and no longer appears inclusive of vital topics that aging adults face unrelated to dementia including frailty, caregiver research, falls, palliative care needs and delivery, polypharmacy, medical decision making.

When the NIA was established in 1974, it was intended to “improve the health and well-being of older adults through research.” We understand that the NIA is the lead federal agency for Alzheimer’s disease and related dementias research but note that the NIA is also “at the forefront of scientific discovery about the nature of health aging to extend the healthy, active years of life.”<sup>1</sup> Solely focusing the Institute on dementia appears to fail to support the many other aging issues that require coordination across institutes.

The U.S. Census Bureau projects that the population aged 65 and over will approximate 83.7 million by 2050, almost double that in 2012. As the population ages, the number of people living with serious, complex, and chronic illness will continue to grow. Many of the problems of our health care system – high costs, overutilization, lack of coordination, preventable transitions between health care institutions, and poor quality – become particularly evident during extended chronic and serious illness. We believe palliative care offers the solution and we strongly support the leadership of the NIA related to coordination of the trans-Institute palliative care research.

Palliative care is an interdisciplinary model of care aimed at preventing and treating the debilitating effects of serious and chronic illness – such as cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer’s, ALS, and MS – and involves the relief of pain and other symptoms that cause discomfort, such as shortness of breath and unrelenting nausea. Palliative care is patient- and family-centered – it focuses on matching treatment to achievable patient goals and supporting patients and their families/caregivers during and after treatment to maximize quality of life. In practice, this involves detailed and skilled communication with patients and families to elicit goals and preferences; expert assessment and management of physical, psychological, and other sources of suffering; and coordination of care across the multiple settings (e.g., hospital, post-acute care, ambulatory clinics, home) that patients can often traverse throughout the course of a serious

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<sup>1</sup> <https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-institute-aging-nia>

illness. Palliative care can be provided from the time of diagnosis and offered alongside life-prolonging and curative therapies for individuals living with serious, complex, and eventually terminal illness. Hospice care is palliative care tailored for individuals near the end of life.

AAHPM believes that palliative care providers and organizations, including hospices, are integral to meeting the “triple aim” of better care for individuals, improved health of populations, and lower growth in health care expenditures. Indeed, the National Priorities Partnership has highlighted palliative and end-of-life care as one of six national health priorities that have the potential to create lasting change across the U.S. health care system.

An expanding body of medical research has documented the benefits of high-quality palliative and hospice care for patients and families, for hospitals and payers, and for the health care system as a whole.<sup>i</sup> Palliative care is associated with enhanced quality of life for patients, higher rates of patient and family satisfaction with medical care, reduced hospital expenditures and lengths of stay, and other positive outcomes – including longer patient survival time. Furthermore, palliative care achieves these outcomes at a lower cost than usual care, by helping patients to better understand and address their needs, choose the most effective interventions, and avoid unnecessary/unwanted hospitalizations and interventions. Hospice care has also been associated with lower cost of care, better outcomes (such as relief of pain), and even longer life, despite its focus on comfort rather than treatment aimed at cure.

Still, too many patients with serious illness experience tremendous physical and psychosocial suffering and, unlike areas of medicine focused on curing or preventing disease, the evidence base for relieving suffering and improving quality of life for seriously ill patients and their caregivers is inadequate.<sup>ii,iii</sup> To ensure that the millions of Americans with serious illness and their families/caregivers receive the high-quality care that they need and deserve, more research is needed to better understand and address pain and other distressing symptoms related to serious illness, and to improve serious illness care delivery models, communication science, and caregiving science. We also know there are significant disparities in palliative and end-of-life care. New research holds the potential to reduce these disparities in the care of people living with serious illness and their families by integrating historically excluded patients and examining the role of social determinants of health — which for palliative care include loneliness, food access, poverty and financial toxicity, and insufficient or unsafe housing — in care delivery, quality, and outcomes.<sup>iv</sup>

**Research related to palliative care and serious illness crosses nearly every Institute, Center, and Office (ICO) at the NIH.** The Academy appreciates that Congress included an investment in palliative care research of \$12.5 million in the *Further Consolidated Appropriations, 2024* for the National Institute on Aging to implement a trans-Institute, multi-disease strategy to focus, expand, and intensify a national research program in palliative care. We are optimistic that the funding will help improve coordination and expand activities related to palliative care research across NIH. Further, we appreciate that the Senate FY 2025 Appropriations for Labor, Health and Human Services, Education, and Related Agencies provides \$12.5 million to continue this trans-Institute work.

**We urge you to retain NIA’s focus on vital topics that impact aging adults, such as palliative care research, and not suggest an exclusive focus on dementia.**

## Funding Reform

### *Restore Congress's Role in Directing Funding*

We appreciate the need for transparency in funding but stress the importance of ensuring adequate annual appropriations to support NIH's mission. Any reform of the Public Health Service (PHS) Evaluation Tap should be coupled with a plan to adequately fund NIH and ensure flexibility for emerging threats.

### *Reexamine Indirect Costs*

Indirect rates are federally negotiated by institutions (academic or otherwise) and are not at the discretion of an individual scientist. Offering preference to institutions with lower rates would potentially undermine the peer review process that ensures the most scientifically rigorous and impactful research is funded. Changes in this area could also have a greater impact on smaller research organizations.

Funding limits on independent research grants (i.e., R01 mechanism) have not increased in many years, effectively with inflation rates, this equates to a decrease. Indirect rates are tied to the total budget amounts and university and other academic and research institutions require this financial support for the infrastructure required to support the larger academic mission and infrastructure for scientists to conduct high impact research. Further decreasing of this support will have a significant negative impact on the institutional ability to serve their scientific missions.

### *Demand Transparency on Indirect Costs*

We believe it will be important to place the burden of reporting indirect costs on the recipient entities and not individual researchers.

## Grant Reform

### *Grant Recipients Must Remain Dynamic*

We understand the goal of ensuring a reasonable limit as to the amount of time one can feasibly devote to research projects. However, the recommendation does not provide enough detail to understand if the proposed cap of not "more than three ongoing concurrent NIH engagements" would apply when an individual is the principal investigator (PI) for three grants or if it would apply when an individual is a co-investigator. Since the overall responsibility differs in these roles, we strongly suggest that the cap apply to the PI role.

We are concerned that limiting funding to investigators who do not have significant NIH funding ignores the importance of a scientific peer review process and does not appropriately account for collaborative science and the benefit of team science.

### *Research Must Be Credible, Reliable, and Timely*

We support the need to continue to incentivize and build programs to support early career scientists. For the United States to continue to lead the world in scientific and medical breakthroughs and cutting-edge research, the scientific community needs to encourage the next generation of scientists to pursue academic research careers and retain these scientists in academic settings and not lose them to more lucrative careers in private industry. Palliative care research has experienced

a recent loss of staple early-career funding mechanisms and should benefit from increased opportunities for early-stage investigators.

*Establish Independent Review Entity for the Proposed National Institute on Infectious Diseases*

We believe it is important to ensure that scientific expertise is necessary to review proposals and provide ongoing oversight. We are concerned that making this a public, independent review committee could make the process more political without scientific foundation. A hybrid model, such as including an independent public community member with scientific background on a study section or review committee could address concerns.

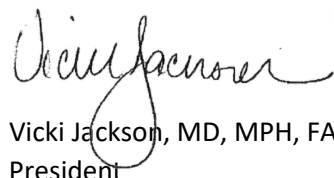
*Support Independent Community Review Oversight Boards*

We appreciate the goal of this recommendation and suggest that it could be strengthened by requiring that an Independent Community Review Oversight Board including individuals from the community where the research process and findings would potentially affect.

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Thank you for beginning the effort to reauthorize the NIH. We look forward to working with the Committee as it explores ways to strengthen the NIH and maintain the U.S. position as the global leader in basic science and biomedical research innovation. If you have any questions or need additional information, please reach out to Wendy Chill, Director, Health Policy and Government Relations at [wchill@aaahpm.org](mailto:wchill@aaahpm.org) or 847-375-6744.

Sincerely,



Vicki Jackson, MD, MPH, FAAHPM  
President

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<sup>i</sup> "The Evidence for High-Quality Palliative Care." American Academy of Hospice and Palliative Medicine. Accessed February 15, 2023. [https://aaahpm.org/uploads/advocacy/The\\_Evidence\\_for\\_High-Quality\\_Palliative\\_Care.pdf](https://aaahpm.org/uploads/advocacy/The_Evidence_for_High-Quality_Palliative_Care.pdf)

<sup>ii</sup> National Academies of Science Engineering and Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. The National Academies Press; 2015:1-612.

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

<sup>iv</sup> "Palliative Care In The Face Of Racism: A Call To Transform Clinical Practice, Research, Policy, And Leadership", *Health Affairs Forefront*, February 9, 2022. doi: 10.1377/forefront.20220207.574426