



AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE

BOARD OF DIRECTORS

EXECUTIVE COMMITTEE

Vicki Jackson, MD MPH FAAHPM
PRESIDENT

Arif Kamal,
MD MBA MHS FASCO FAAHPM
PRESIDENT-ELECT

Elise Carey, MD FACP FAAHPM
TREASURER

Kimberly Curseen, MD FAAHPM
SECRETARY

Holly Yang,
MD MSHPEd HMDC FACP FAAHPM
PAST PRESIDENT

Joseph D. Rotella,
MD MBA HMDC FAAHPM
**CHIEF MEDICAL OFFICER,
EX-OFFICIO BOARD MEMBER**

DIRECTORS AT LARGE

Michael Barnett,
MD MS FAAP FAAHPM

Rachelle Bernacki, MD MS FAAHPM

Gary Buckholz, MD HMDC FAAHPM

Sandra Gomez, MD FAAHPM

Christopher A. Jones,
MD MBA HMDC FAAHPM

Dio Kavalieratos, PhD FAAHPM

Stacie Levine, MD FAAHPM

Mary Lynn McPherson,
PharmD PhD BCPS FAAHPM

Laura J. Morrison, MD FACP FAAHPM

Lindsay Ragsdale, MD FAAP FAAHPM

Alvin L. Reaves, III, MD FACP FAAHPM

Phillip Rodgers, MD FAAHPM

Bethany Cox Snider,
MD HMDC FAAHPM

Alison Wiesenthal, MD FACP FAAHPM

CHIEF EXECUTIVE OFFICER

Wendy-Jo Toyama, MBA FASAE CAE

Submitted electronically to cures.rfi@mail.house.gov

August 2, 2024

The Honorable Larry Bucshon, M.D.
2313 Rayburn House
Washington, DC 20515

The Honorable Diana DeGette
2111 Rayburn House
Washington, DC 20515

RE: 21st Century Cures Act/Cures 2.0 Request for Information

Dear Representatives Bucshon and DeGette:

On behalf of the more than 5,200 members of the American Academy of Hospice and Palliative Medicine (AAHPM or Academy), we appreciate your longstanding leadership to advance medical research and health care delivery in the United States. 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 feedback on the next steps for the 21st Century Cures initiative. Our key recommendations are in response to the second question posed by your RFI, ***“What elements might be missing that are essential for further progress?”***

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 can serve as an important part of the solution.

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 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. The importance of palliative care becomes particularly apparent when considering the number of individuals who report experiencing symptoms of Long COVID. **While the 21st Century Cures Act and Cures 2.0 have spurred advancements to address Long COVID via the National COVID-19 Preparedness Plan and the establishment of the Office of Long COVID Research and Practice, access to palliative care remains critical for individuals suffering a variety of Long COVID symptoms that can have a significant impact on their quality of life.**

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.¹ 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.^{ii,iii} 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.^{iv}

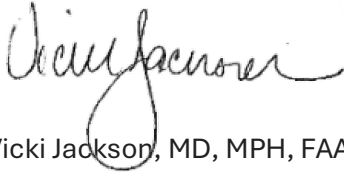
Research related to palliative care and serious illness crosses nearly every Institute, Center, and Office (ICO) at the National Institutes of Health (NIH), but also poses challenges because it does not fit neatly within a single ICO. The Academy appreciates that Congress included an investment in palliative 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.

AAHPM believes that absence of palliative care research as a focus of the Cancer Moonshot initiative detracts from the 21st Century Cures’ aim to shape a health care landscape that is innovative, responsive, and patient-focused. The Cancer Moonshot initiative was initially funded through the 21st Century Cures Act with a focus on areas of cancer research that are most likely to benefit patients as a result of new investment. The Cancer Moonshot was reignited in 2022 with the goal of reducing the death rate from cancer by at least 50% over the next 25 years and improving the experience of people and their families living with and surviving cancer.

To date, much of the Cancer Moonshot’s progress has been made in the areas of cancer prevention and detection. More work, however, is needed to improve the quality of life for those living with and surviving cancer including the interventions that address whole-person needs and help maintain functional status, which is especially critical to tolerating cancer-directed therapies. This gap has been highlighted by the Cancer Moonshot’s Blue Ribbon Panel, which called for the acceleration of research to help improve symptom management for cancer patients and survivors. **Any future legislation should clearly articulate palliative care as integral to the Cancer Moonshot initiative.**

Thank you for your efforts to build upon the 21st Century Cures Act and ensure that patients can access life-changing treatments. If you have any questions or need additional information, please reach out to Wendy Chill, Director, Health Policy and Government Relations at wchill@aahpm.org or 847-375-6744.

Sincerely,

A handwritten signature in black ink, appearing to read "Vicki Jackson". The signature is fluid and cursive, with the first name "Vicki" being more prominent than the last name "Jackson".

Vicki Jackson, MD, MPH, FAAHPM
President

ⁱ "The Evidence for High-Quality Palliative Care." American Academy of Hospice and Palliative Medicine. Accessed February 15, 2023. https://aahpm.org/uploads/advocacy/The_Evidence_for_High-Quality_Palliative_Care.pdf

ⁱⁱ 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.

ⁱⁱⁱ 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

^{iv} "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