

State of the Science of Serious Illness Research: Past, Current and Future

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November 3, 2023



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**Mount
Sinai**

Why are we all here?

To relieve suffering and improve quality of life for persons and families living with serious illness

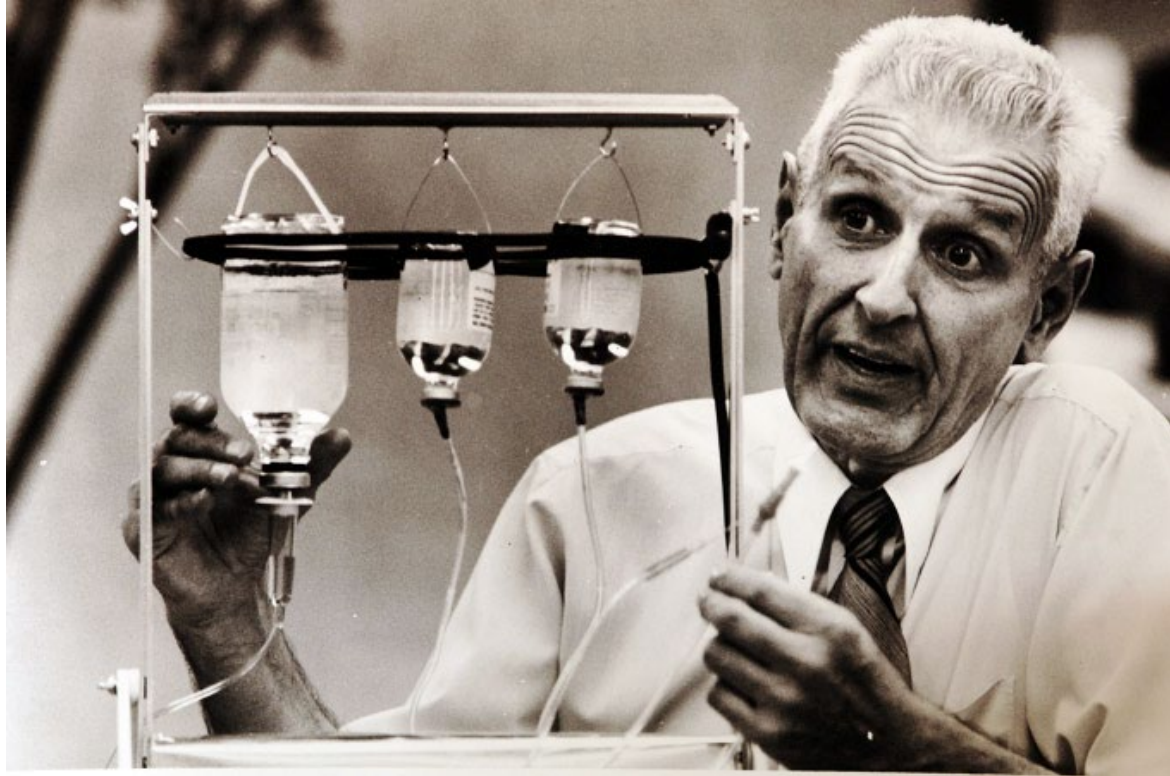
Serious Illness...

“A health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers.”

Palliative Care...

“Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.”

The "New" Beginning: 1990



ARTICLE | November 22, 1995

A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)

JAMA The Journal of the
American Medical Association

1995

64 NIH grants awarded

\$9,023,749 in total costs

0.069% of Total NIH Funding

1995

719 US hospitals report “End-of-Life Care Services”: 15% of all hospitals

1997: Five Palliative Medicine Fellowship Programs



Mount Sinai Hospital

Northwestern Memorial Hospital

Cleveland Clinic

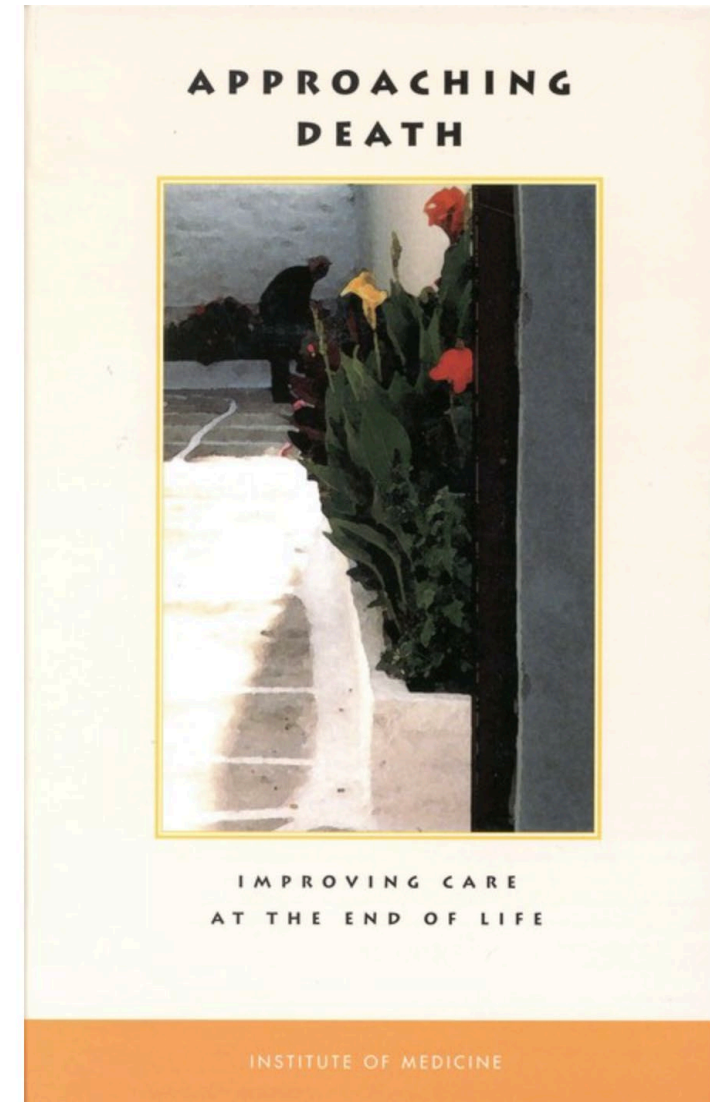
Massachusetts General Hospital

Memorial Sloan Kettering Cancer Center



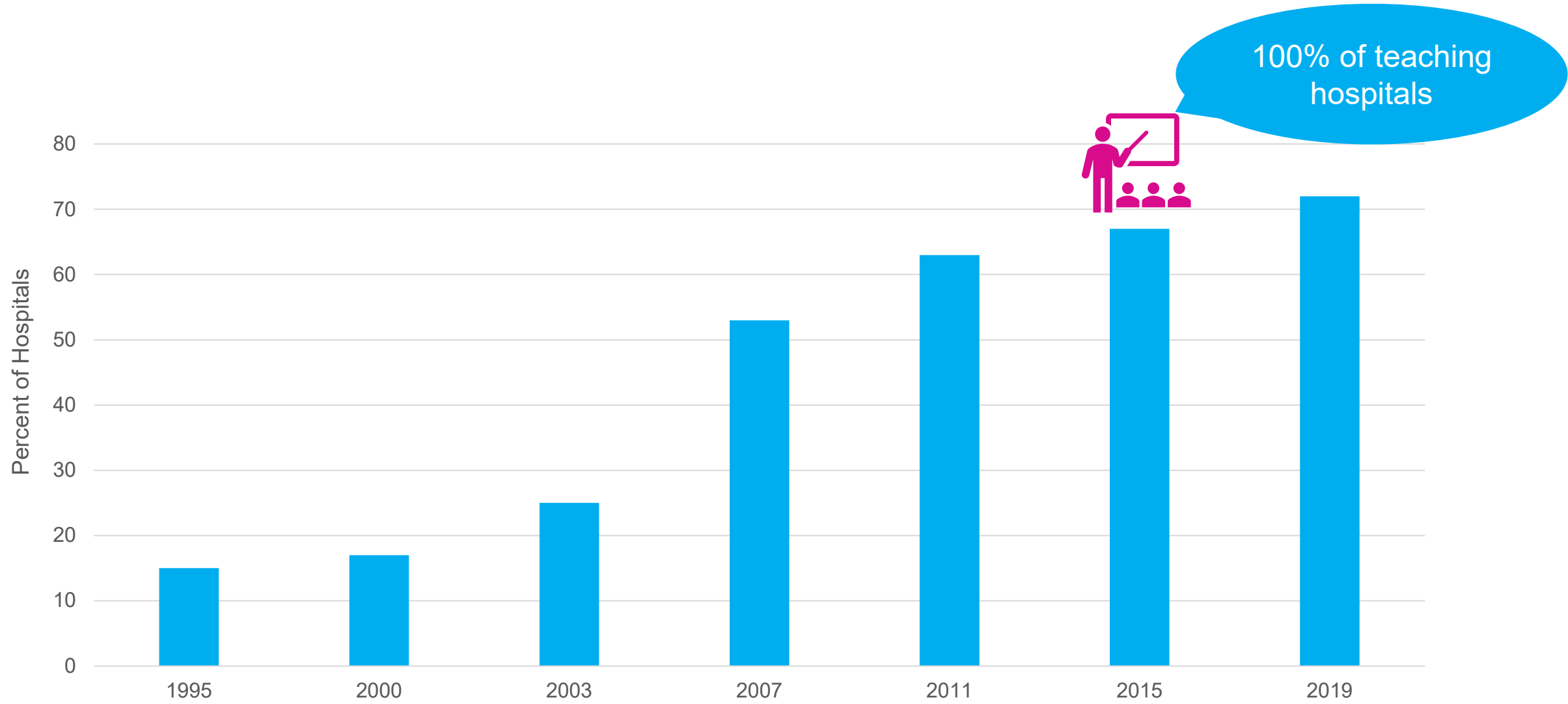
1997

- Too many people with serious illness suffer needlessly
 - Most with serious illness experience inadequately treated symptoms; fragmented care; poor communication with their clinicians; and strains on family caregiver and support systems
- Legal, organizational, and economic obstacles obstruct reliably excellent palliative care
- Education and training of health care professionals fail to provide the necessary knowledge and skills required to care for the seriously ill
- **The knowledge base is inadequate to support evidence-based palliative care clinical practice**



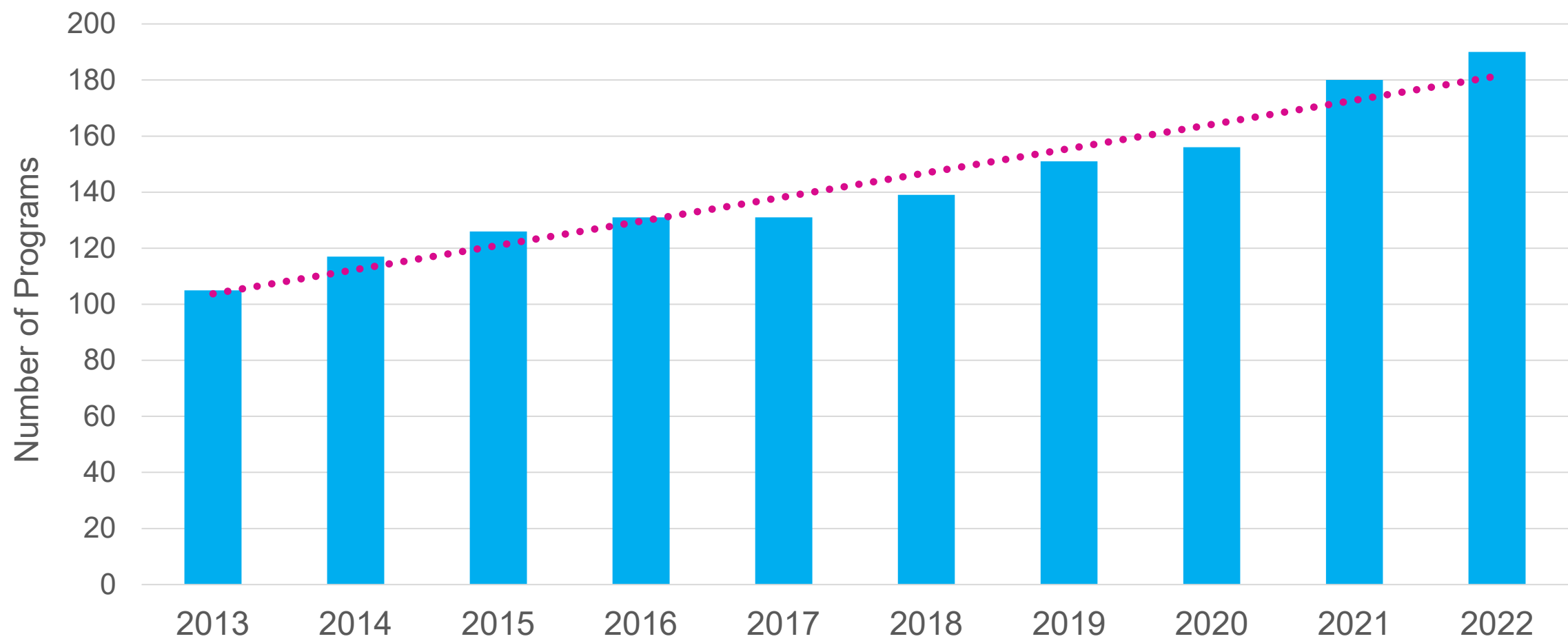
Twenty Five Years Later...

US Hospitals (50+ beds) With Palliative Care Programs



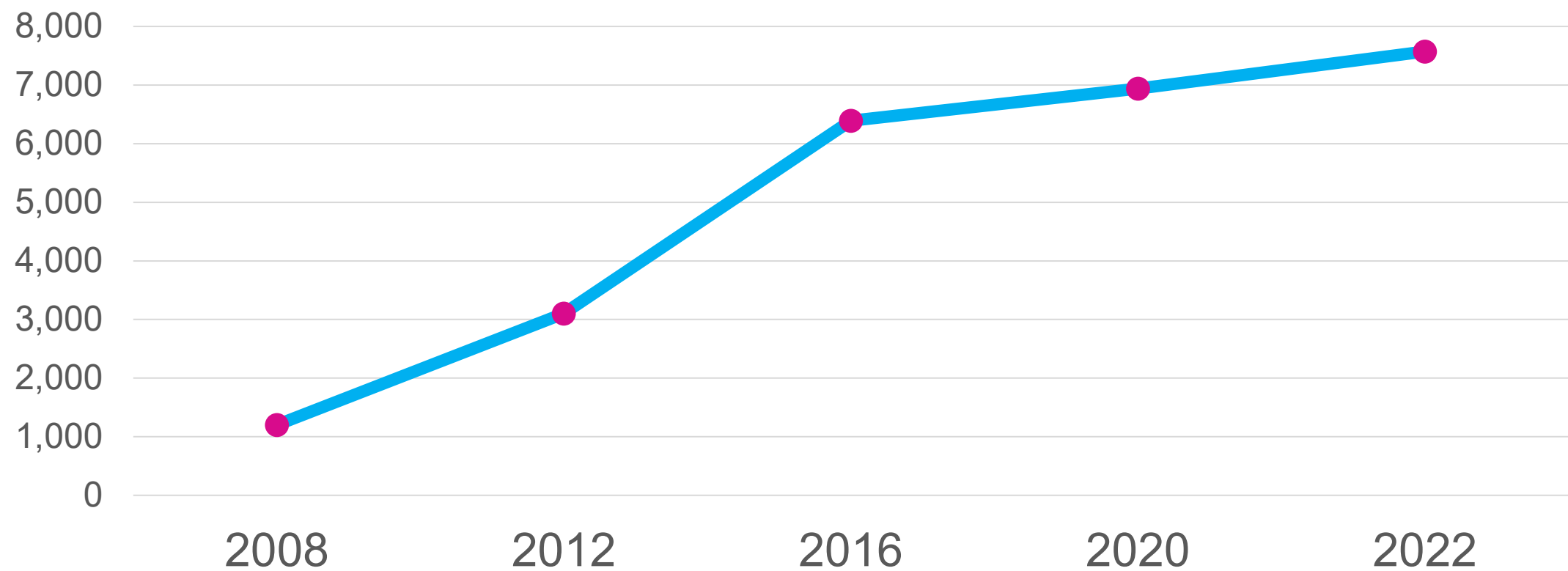
Source: CAPC and NPCRC

Palliative Medicine Fellowship Programs



Source: AAHPM and National Residency Match Program

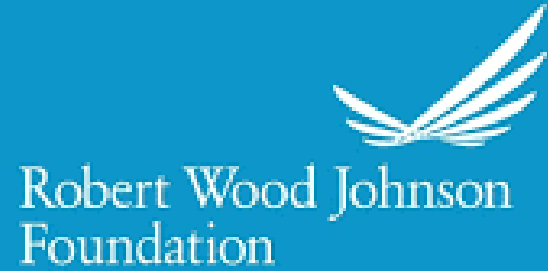
Board Certified Palliative Medicine Physicians



Source: ABMS

This Did Not Occur by Accident...

MONEY



PROJECT ON DEATH IN AMERICA

> \$250
million

And...

- Altman Foundation
- Archstone Foundation
- Atlantic Philanthropies
- California Healthcare Foundation
- Cambia Foundation
- Cameron and Hayden Lord Foundation
- Emily Davie and Joseph S. Kornfeld Foundation
- Gary and Mary West Foundation
- Gordon and Betty Moore Foundation
- Hearst Foundations
- Pat and Jay Baker Foundation
- The American Cancer Society
- The Brookdale Foundation Group
- The Commonwealth Fund
- The Fan Fox and Leslie R. Samuels Foundation
- The Greenwall Foundation
- The New York Community Trust
- The John A. Hartford Foundation
- The SCAN Foundation
- The Y.C. Ho/Helen and Michael Chiang Foundation
- U.S. Cancer Pain Relief Taskforce
- And many other individual donors and local foundations...

LEADERSHIP

STRATEGY







Top-Down

Create a supportive environment
via media, advocacy accreditation,
policy, regulation, payers, public
awareness

Bottom-Up

Promote and develop serious illness
evidence base, enhance the
workforce (clinicians, scientists,
educators) increase # and quality of
palliative care programs via research
& technical assistance

Guiding Principles

Create a unified scientific community

Align with the prevailing scientific culture and infrastructure and plan for integration

Focus on what is scalable and has low unit costs

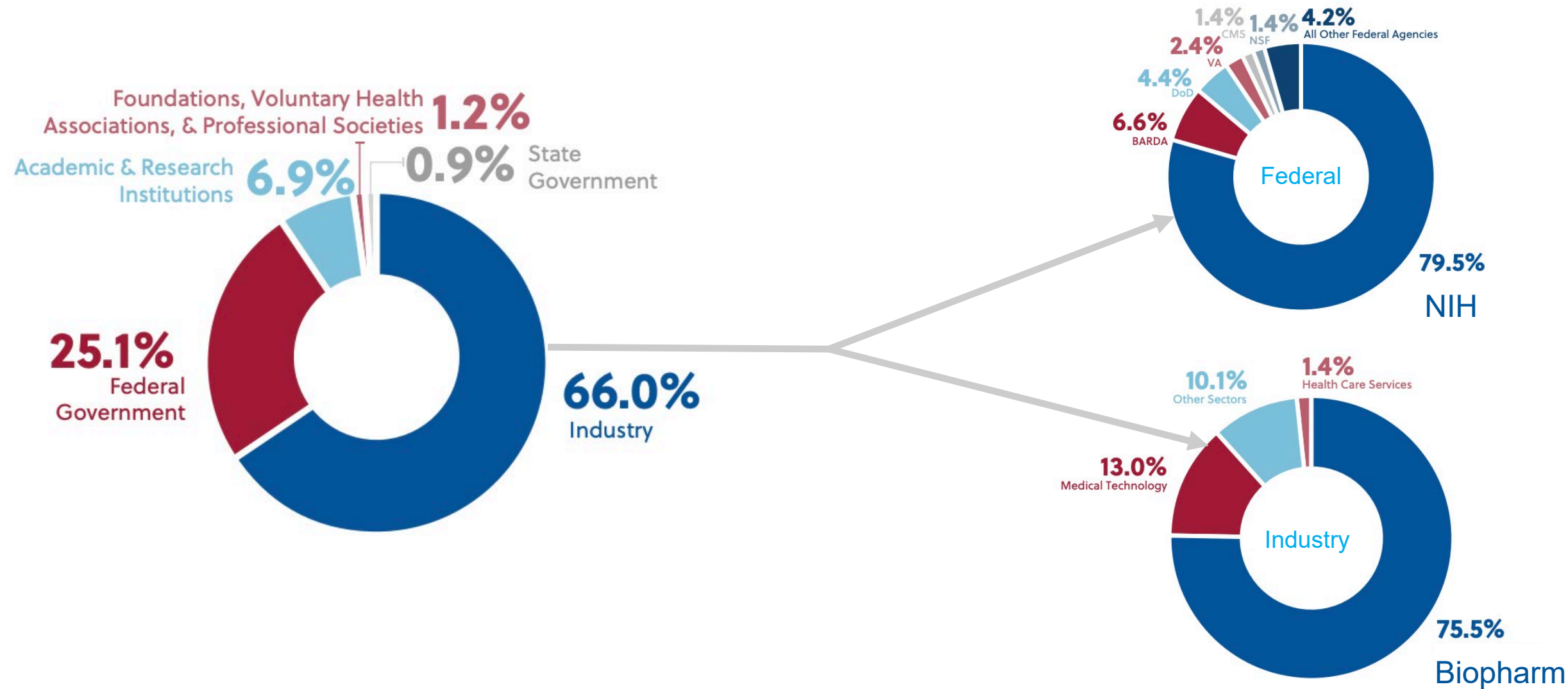
- Reduce opportunity costs

- Don't reinvent the wheel

Create long-term sustainability

- Philanthropic dollars are scarce and limited

Biomedical Research Funding in the United States



1997



2004

NIH State of the Science Conference

Planning Committee

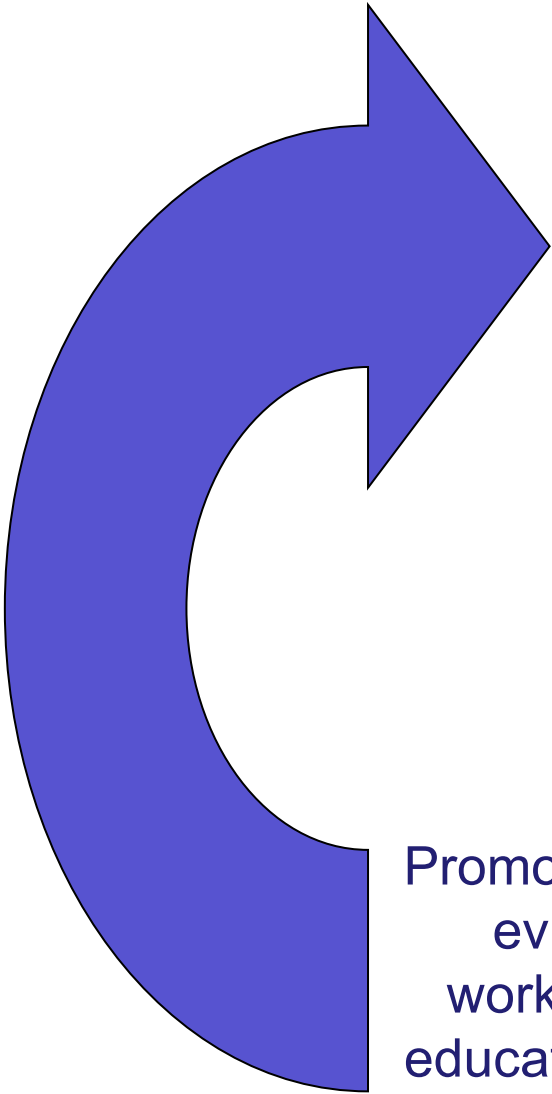
David Casarett, R. Sean Morrison, Susan McMillan, Margaret Heitkemper, James Tulsky +16 NIH staff

Presenters

David Casarett, Harvey Chochinov, LaVera Crawley, J. Randall Curtis, Paula Diehr, Betty Ferrell, Thomas Finucane, Irene Higginson, Pamela S. Hinds, Elizabeth Lamont, Karl Lorenz, Susan McMillan, R. Sean Morrison, Greg A. Sachs, Karen Steinhauser, Margaret Stroebe, Joan Teno, James Tulsky, Charles von Gunten

Recommendations

- Create a network of investigators and well-defined cohorts of patients to facilitate coordinated interdisciplinary, multisite studies
- Explore public private partnerships related to end-of-life research support
- Enhance training of a new generation of interdisciplinary scientists



Bottom-Up

Promote and develop serious illness evidence base, enhance the workforce (clinicians, scientists, educators) increase # and quality of palliative care programs via research & technical assistance



2005



National Palliative Care Research Center



MOUNT SINAI
SCHOOL OF
MEDICINE



National Palliative Care Research Center: (2005-2025)


Create a new generation of scientific leaders to address workforce needs and close knowledge gaps in serious illness care through 2-year pre-K career development awards for early stage and pilot award funding for senior investigators

Provide technical assistance for investigators to better compete for federal funding to build the evidence base

Create consensus around priorities for serious illness research across the lifespan

Establish and nourish a diverse national interdisciplinary community of serious illness scientists

A Strategy To Advance the Evidence Base in Palliative Medicine: Formation of a Palliative Care Research Cooperative Group

Amy P. Abernethy , Noreen M. Aziz, Ethan Basch, Janet Bull, Charles S. Cleeland, David C. Currow, Diane Fairclough, Laura Hanson, Joshua Hauser, Danielle Ko, Linda Lloyd, R. Sean Morrison, Shirley Otis-Green, Steve Pantilat, Russell K. Portenoy, Christine Ritchie, Graeme Rocker, Jane L. Wheeler, S. Yousuf Zafar, and Jean S. Kutner

Published Online: 14 Dec 2010 | <https://doi.org/10.1089/jpm.2010.0261>

Acknowledgments

We thank the National Palliative Care Research Center for generously supporting expenses for the meeting in Denver.



Notice of Intent to Publish a Funding Opportunity Announcement for Palliative Care Research Co-Operative (PCRC)(Limited Competition, U24)

Notice Number: NOT-NR-13-001

Key Dates

Release Date: October 10, 2012
Estimated Publication Date of Announcement: November 2012
First Estimated Application Due Date: January 2012
Earliest Estimated Award Date: July 2013
Earliest Estimated Start Date: July 2013

Issued by

National Institute of Nursing Research ([NINR](#))

Purpose

The National Institute of Nursing Research (NINR) intends to promote a new initiative by publishing a Funding Opportunity Announcement (FOA)to solicit applications for research on and resource activities of the Palliative Care Research Cooperative (PCRC) group that will facilitate cutting edge palliative care and end of life research. The PCRC will facilitate studies that need to be conducted quickly and with larger samples and multiple sites, and quantifying and better understanding the risks, issues, and impact of Life Limiting Diseases (LLDs) on patient and caregiver health outcomes.

2013



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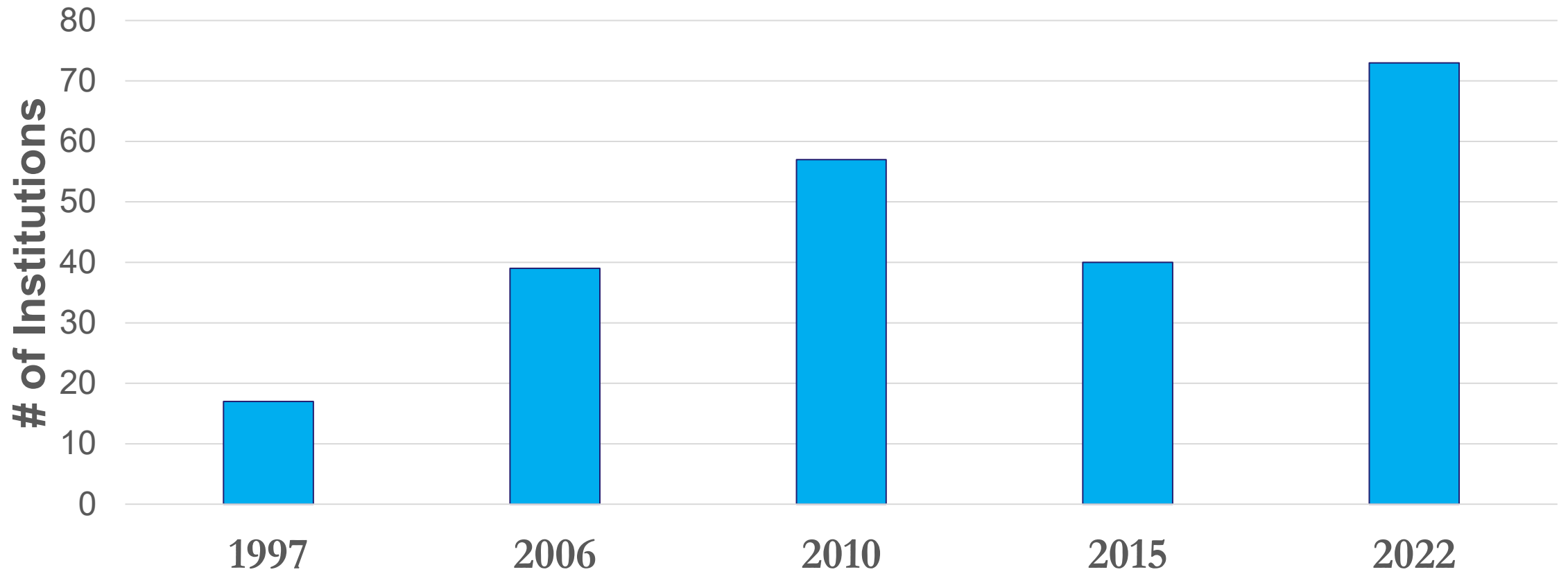
A COMMUNITY OF DISCOVERY

The Palliative Care Research Cooperative Group (PCRC) is a vibrant interdisciplinary research community committed to advancing rigorous palliative care science and improving care for people with serious illness.

Palliative Care Research Cooperative (2010-2023)

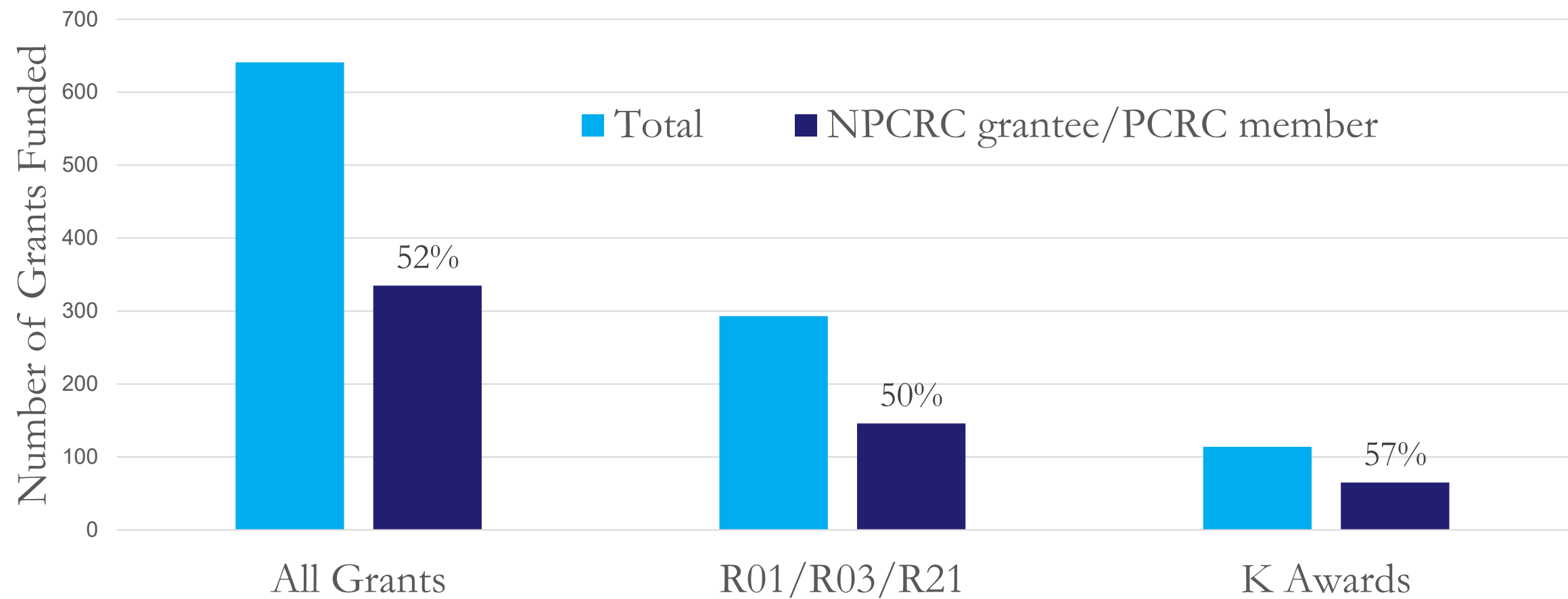
- Technical assistance, training and pilot grant awards for scientists at all levels of experience in the conduct of clinical studies.
- Coordinate and resource nationally representative, multi-institutional studies that include diverse populations.
- Provide research infrastructure
- Cooperative group-like structure to foster recruitment for clinical trials

Palliative Care Research Capacity: Institutions with R01 Funded Investigators



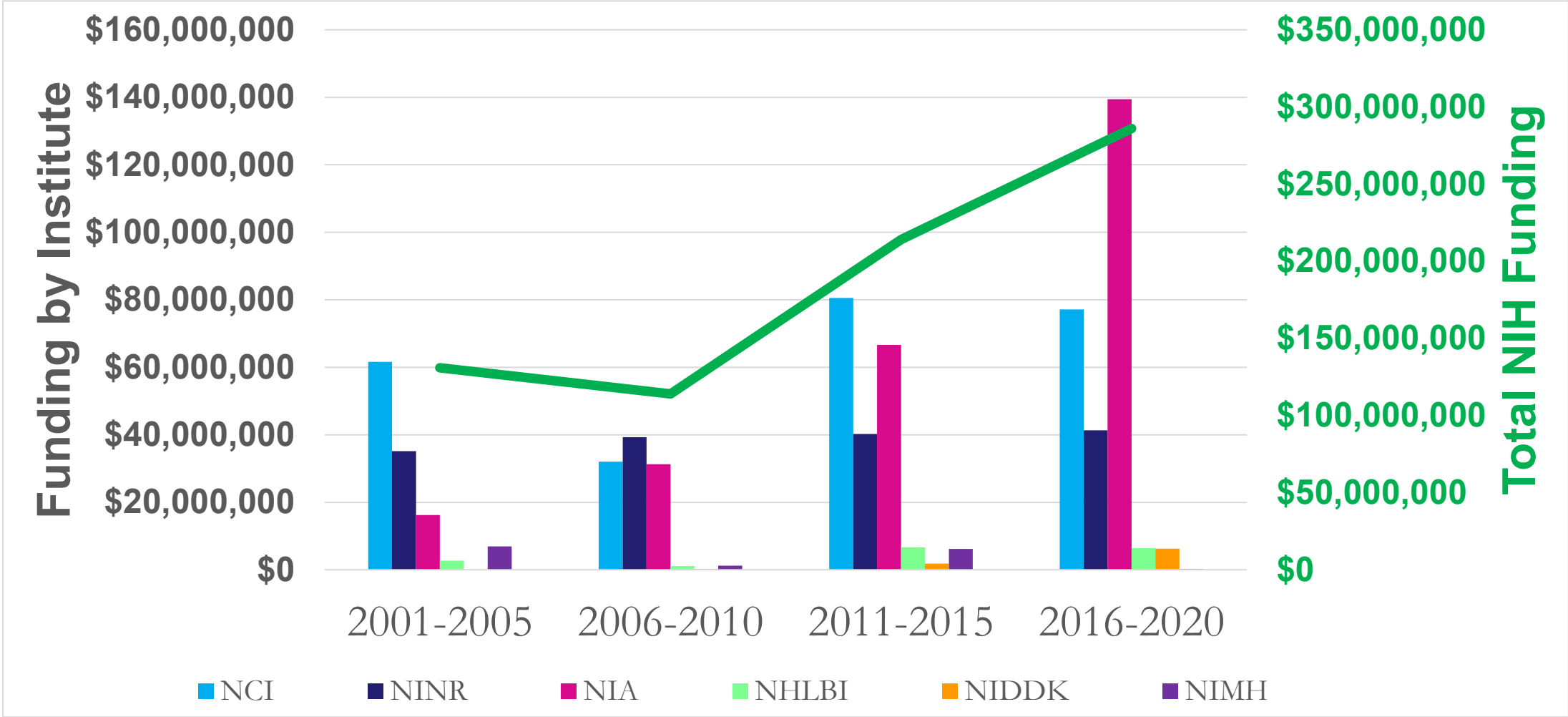
*Source: NIH RePORTER

Serious Illness Research Grants Awarded by NIH (2016-2020)



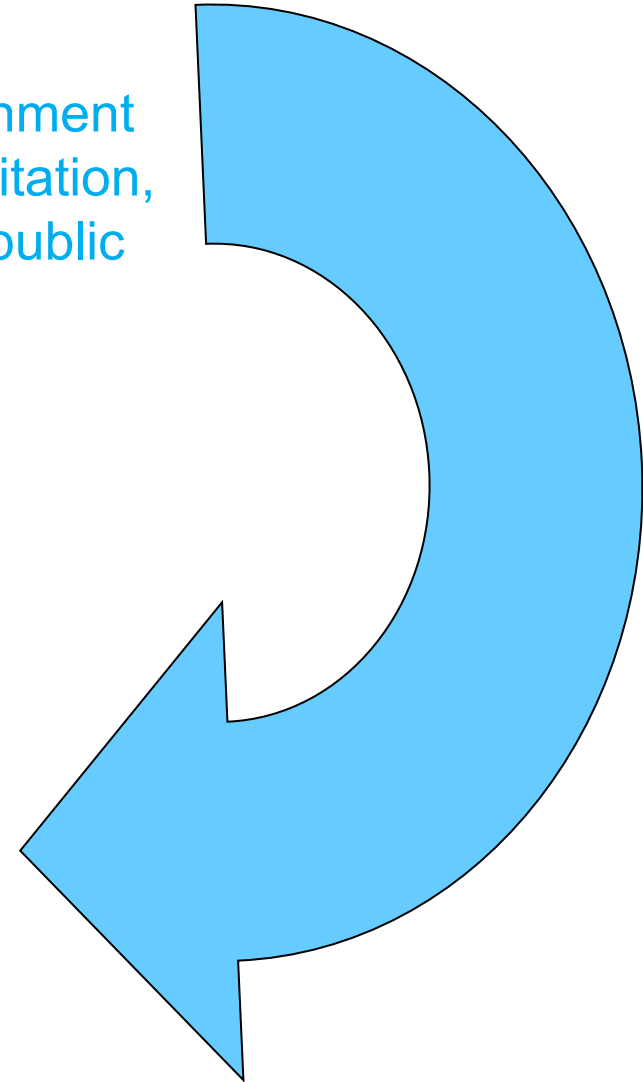
*Source: NIH RePORTER

NIH Grant Dollars Awarded for Serious Illness Research By Institute

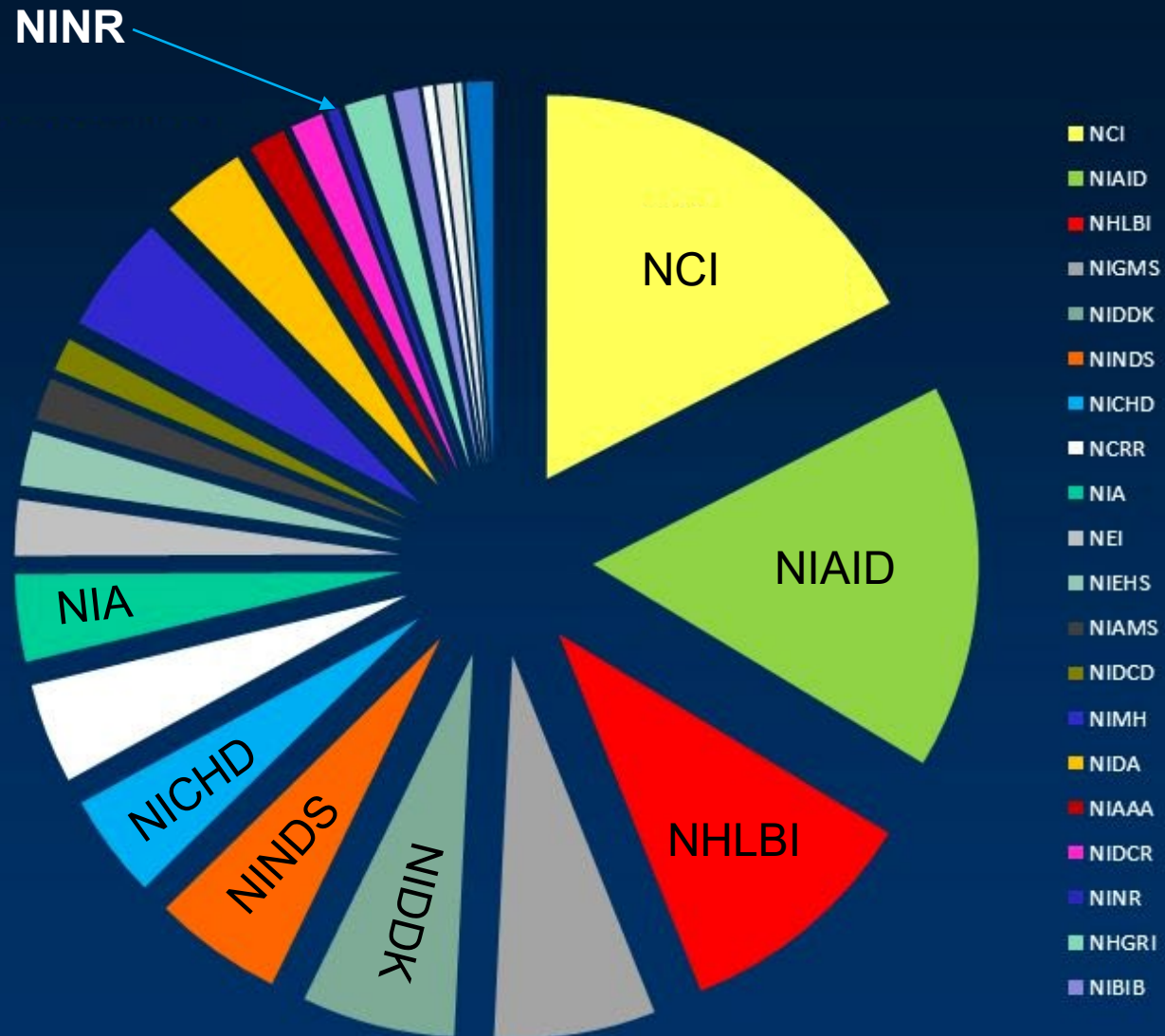


Top-Down

Create a supportive environment
via media, advocacy accreditation,
policy, regulation, payers, public
awareness



NIH Budget Allocation by Institute



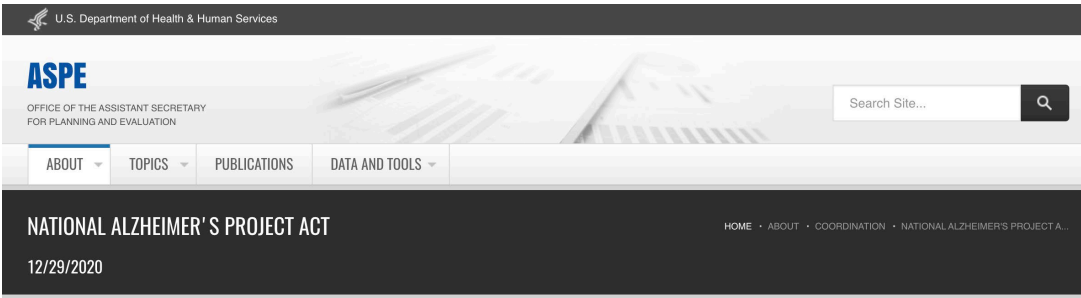
Advanced Dementia: State of the Art and Priorities for the Next Decade

Susan L. Mitchell, MD, MPH; Betty S. Black, PhD; Mary Ersek, RN, PhD; Laura C. Hanson, MD, MPH; Susan C. Miller, PhD; Greg A. Sachs, MD; Joan M. Teno, MD, MS; and R. Sean Morrison, MD

Dementia is a leading cause of death in the United States. This article outlines the current understanding of advanced dementia and identifies research priorities for the next decade. Research over the past 25 years has largely focused on describing the experience of patients with advanced dementia. This work has delineated abundant opportunities for improvement, including greater recognition of advanced dementia as a terminal illness, better treatment of distressing symptoms, increased access to hospice and palliative care services, and less use of costly and aggressive treatments that may be of limited clinical benefit. Addressing those opportunities must be the overarching objective for the field in the coming

decade. Priority areas include designing and testing interventions that promote high-quality, goal-directed care; health policy research to identify strategies that incentivize cost-effective and evidence-based care; implementation studies of promising interventions and policies; and further development of disease-specific outcome measures. There is great need and opportunity to improve outcomes, contain expenditures, reduce disparities, and better coordinate care for the millions of persons in the United States who have advanced dementia.

Ann Intern Med. 2012;156:45-51.
For author affiliations, see end of text.
www.annals.org



National Alzheimer's Project Act



Claude D Pepper Older Americans Independence Centers



Icahn School
of Medicine at
**Mount
Sinai**

JOURNAL OF PALLIATIVE MEDICINE
Volume 16, Number 7, 2013
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2013.9499

Special Report: NIA White Papers



Research Priorities in Geriatric Palliative Care:
An Introduction to a New Series



Department of Health and Human Services Part 1. Overview Information

Participating Organization(s)

National Institutes of Health (NIH)

Components of Participating Organizations

National Institute on Aging (NIA)
National Center for Complementary and Integrative Health (NCCIH)
National Institute of Nursing Research (NINR)
National Institute on Minority Health and Health Disparities (NIMHD)
National Cancer Institute (NCI)
National Heart, Lung, and Blood Institute (NHLBI)

Funding Opportunity Title

Advancing the Science of Geriatric Palliative Care (R01)



2010

2011



FY'11: Senate Labor Health and Humans Services Appropriations Report
"The Committee strongly urges the NIH to develop a trans-Institute strategy for increasing funded research in palliative care for persons living with chronic and advanced illness."

2010

2013

2023



Alzheimer's Association
AAHPM
American Association of Colleges of Nursing
American Cancer Society
Cancer Action Network
American Heart Association
American Psychological Association
American Psychosocial
Oncology Society
Association for Clinical Oncology
Association of Oncology Social Work
Association of Pediatric
Hematology/Oncology Nurses
CSU Institute for Palliative Care
Cambia Health Solutions
Cancer Support Community
Catholic Health Association
CAPC
Children's National Health System
Coalition for Compassionate
Care of California
Colorectal Cancer Alliance
Courageous Parents Network
ElevatingHOME / VNAA

GW Institute for Spirituality and Health
GO₂ for Lung Cancer
Hospice Action Network
HPNA
Leukemia & Lymphoma Society
Motion Picture & Television Fund
National Alliance for Caregiving
National Brain Tumor Society
National Coalition for Cancer Survivorship
NCHPC
National Comprehensive Cancer Network
NPCRC
National Patient Advocate Foundation
National POLST Paradigm
Oncology Nursing Society
Pediatric Palliative Care Coalition
Physician Assistants in Hospice
and Palliative Medicine
Prevent Cancer Foundation
ResolutionCare
SWHPN
St. Baldrick's Foundation
Supportive Care Coalition
Supportive Care Matters
Trinity Health

FY'19 Senate Labor Health and Humans Services Appropriations Report

“The Committee recognizes the importance of palliative care research to strengthen clinical practice and improve healthcare delivery for patients with serious or life-threatening illness or multiple chronic conditions, as well as their families/caregivers. [Research funding for palliative care, including pain and symptom management, comprises less than 0.1 percent of the NIH annual budget.](#)* Therefore, the Committee strongly urges NIH to develop and implement a trans-Institute strategy to expand and intensify national research programs in palliative care to address quality of care and quality of life for the rapidly growing population of individuals in the United States with serious or life-threatening illnesses.”

*Brown, Morrison, Gelfman, JPM 2018

FY'23 Congressional Consolidated Appropriations Act, 2023

“Palliative Care.-The agreement reiterates the need for NIH to develop and implement a trans-Institute strategy to expand and intensify national research programs in palliative care. The agreement urges NIH to ensure that palliative care is integrated into all areas of research across NIH **and requests an update on plans to realize this coordination in the fiscal year 2024 Congressional Justification.**”

In response to the congressional request included in the Consolidated Appropriations Act, 2023 the NIH provided an update regarding ongoing activities and outlined new opportunities in palliative care research, stating in part:

“Moving forward, NIA is leading efforts to convene subject matter experts from the ICOs listed above [NCI, NICHD, NIMH NINDS, NINR] to expand and intensify the strategic coordination of palliative care research efforts as well as identify future research topics and questions that pertain to palliative care.”

FY '24 Senate Appropriations Committee approved funding bill for the Department of Health and Human Services:

Palliative Care Research-The Committee provides \$12,500,000 for NIA to implement a trans-Institute, multi-disease strategy to focus, expand, and intensify national research programs in palliative care. NIH is directed to establish a comprehensive multi-Institute and multi-Center initiative aimed at a wide variety of palliative care research, training, dissemination, and implementation of projects to intensify the strategic coordination of palliative care research efforts. Funding is provided to establish an extramural-based palliative care research consortium with no less than three sites to provide technical assistance, pilot and exploratory grant funding, research dissemination on, data repositories, data analytics, and career development support for interdisciplinary palliative care. NIH shall prioritize grantees with a recognized expertise and leadership in palliative care. The Committee encourages NIH to fund several multiyear, early-career development grants. Appropriations provided in fiscal year 2024 for training are expected to cover 2 years of funding for career development awards.

The Committee requests a briefing within 120 days of enactment on how this strategy will be established and implemented, including timelines on when funding opportunities will be issued and when funding will be awarded.

Notice of Intent to Publish a Funding Opportunity Announcement for Consortium for Palliative Care Research Across the Lifespan (U54 Clinical Trial Required)

Notice Number: NOT-AG-23-050

Key Dates

Release Date: October 06, 2023

Estimated Publication Date of Notice of Funding Opportunity : December 14, 2023

First Estimated Application Due Date: February 14, 2024

Earliest Estimated Award Date: December 02, 2024

Earliest Estimated Start Date: December 02, 2024

Related Announcements

None

Issued by

National Institute on Aging ([NIA](#))

Eunice Kennedy Shriver National Institute of Child Health and Human Development ([NICHD](#))

National Institute of Mental Health ([NIMH](#))

National Institute of Neurological Disorders and Stroke ([NINDS](#))

National Institute of Nursing Research ([NINR](#))

National Cancer Institute ([NCI](#))

\$66 million over 5 years

Funding Information

Estimated Total Funding

In fiscal year (FY) 2025, NIA and partner ICOs intend to commit up to \$9,500,000 in total cost.

In FY 2026 - FY 2029, NIA and partner ICOs intend to commit \$14,000,000 per year in total cost.

Expected Number of Awards

1



*Now, this is not the end.
It is not even the
beginning to the end.
But it is, perhaps, the
end of the beginning.*

Sir Winston Churchill, Following the victory at El
Alamein North Africa, London, 10 November 1942.

Serious Illness Research: The Next Stage



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