

Building Research Capacity: A Case Example

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The Next 30 Minutes...

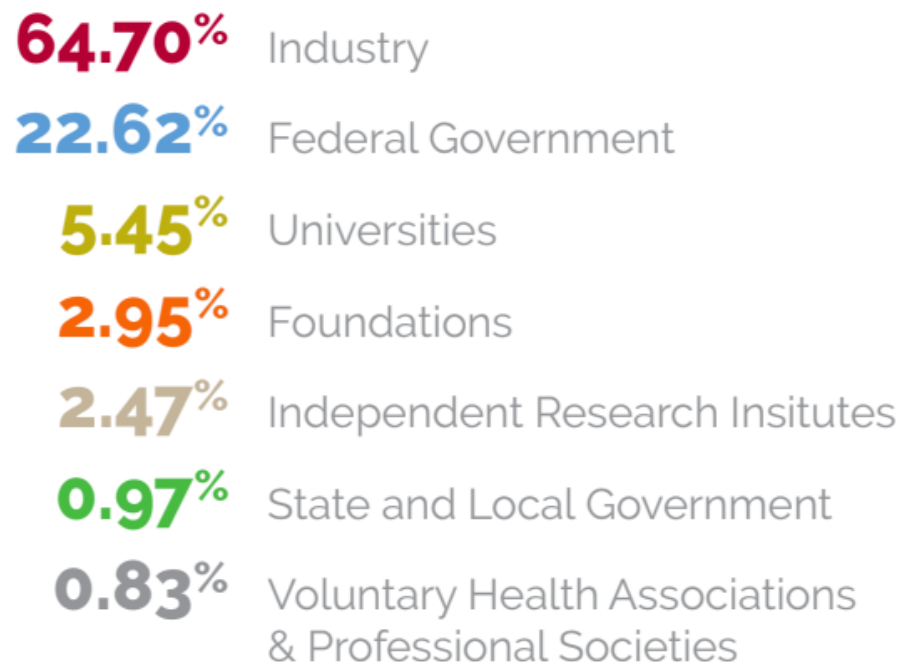
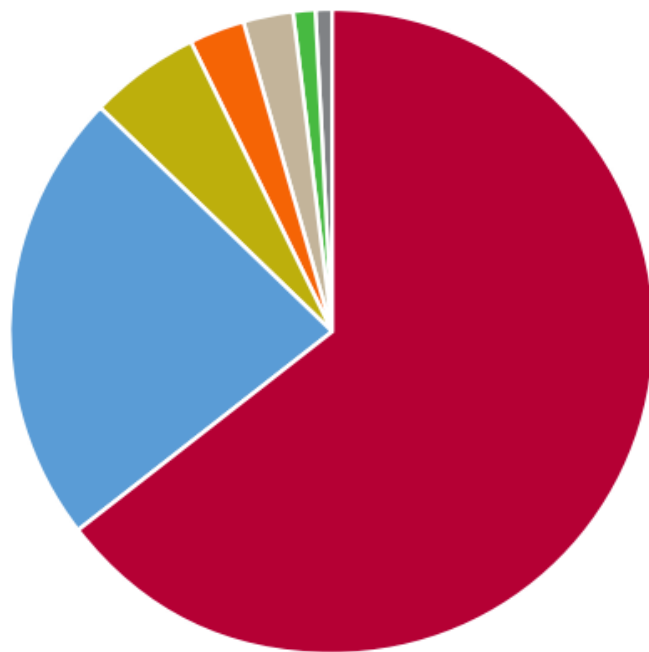
- How Research is Funded in the United States
- The Status of Palliative Care Research: 2005
- A Case Study in Building Research Capacity: The National Palliative Care Research Center

A Brief Introduction to Research Funding in the U.S.

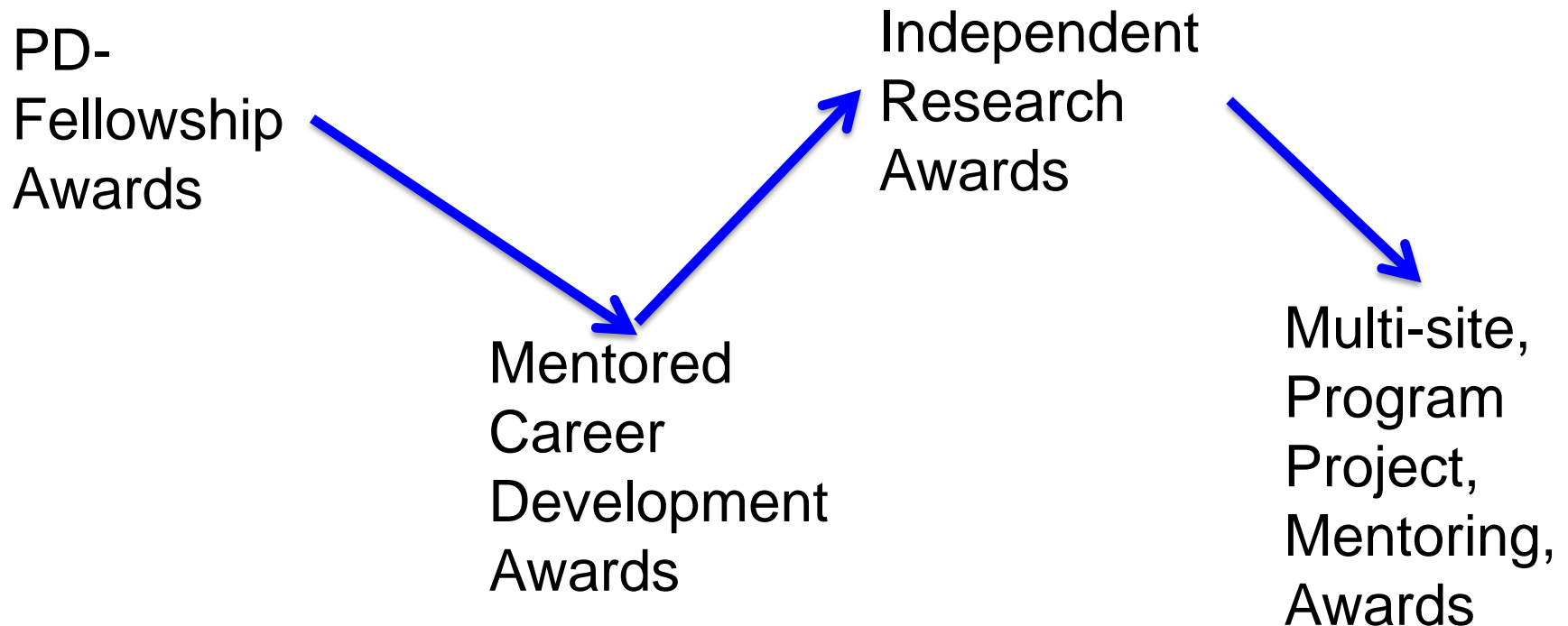
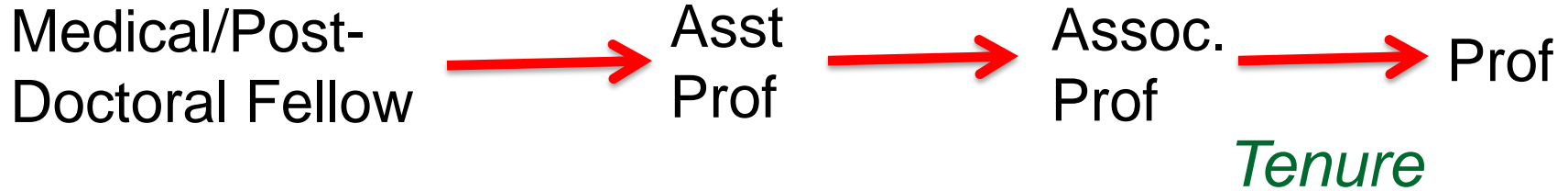
Sources of U.S. Biomedical Research Funding (2015)

Total Funding = €135 billion

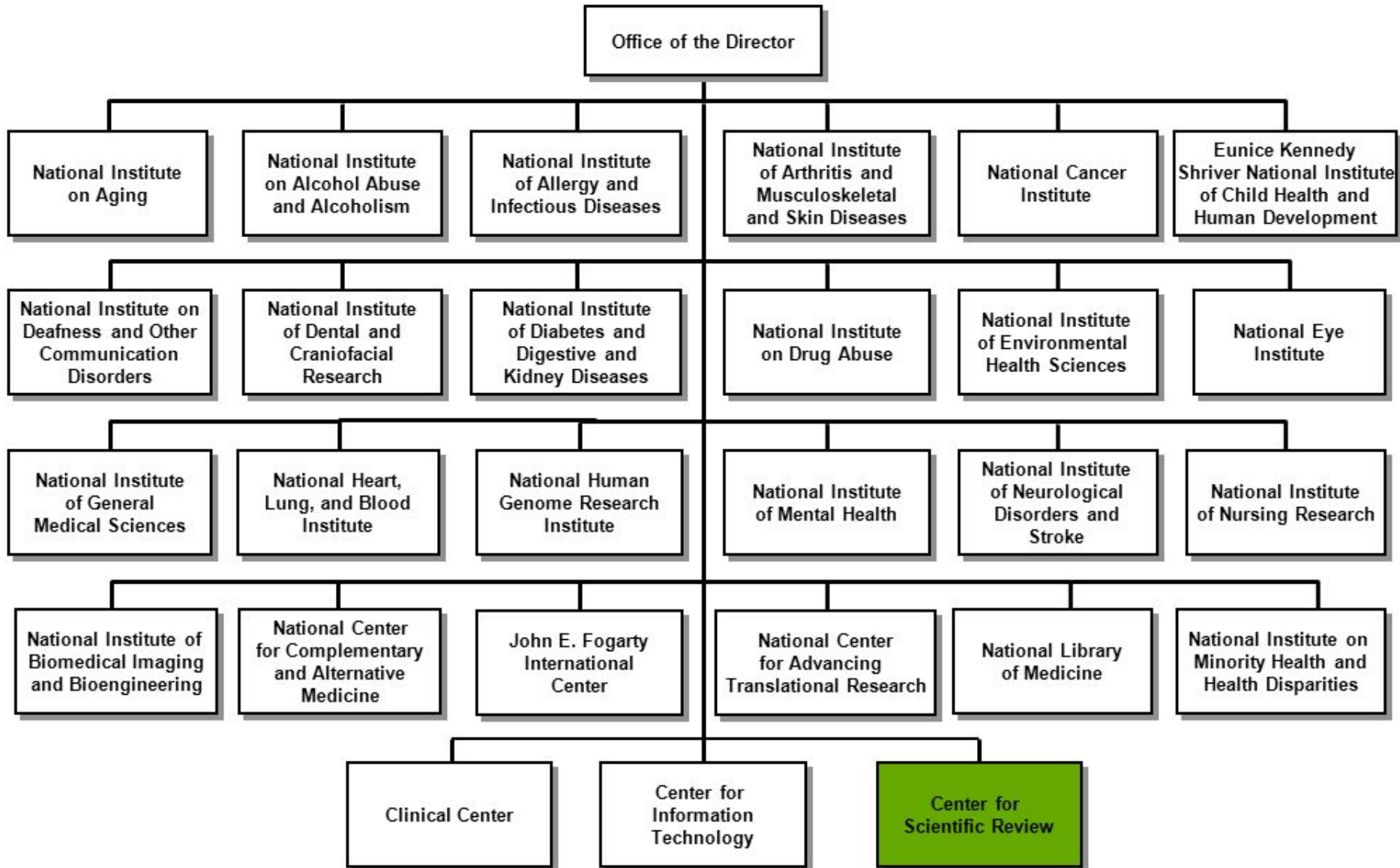
National Institutes of Health Funding = €25 billion (86% of all federal funding)



It's all about NIH funding.....



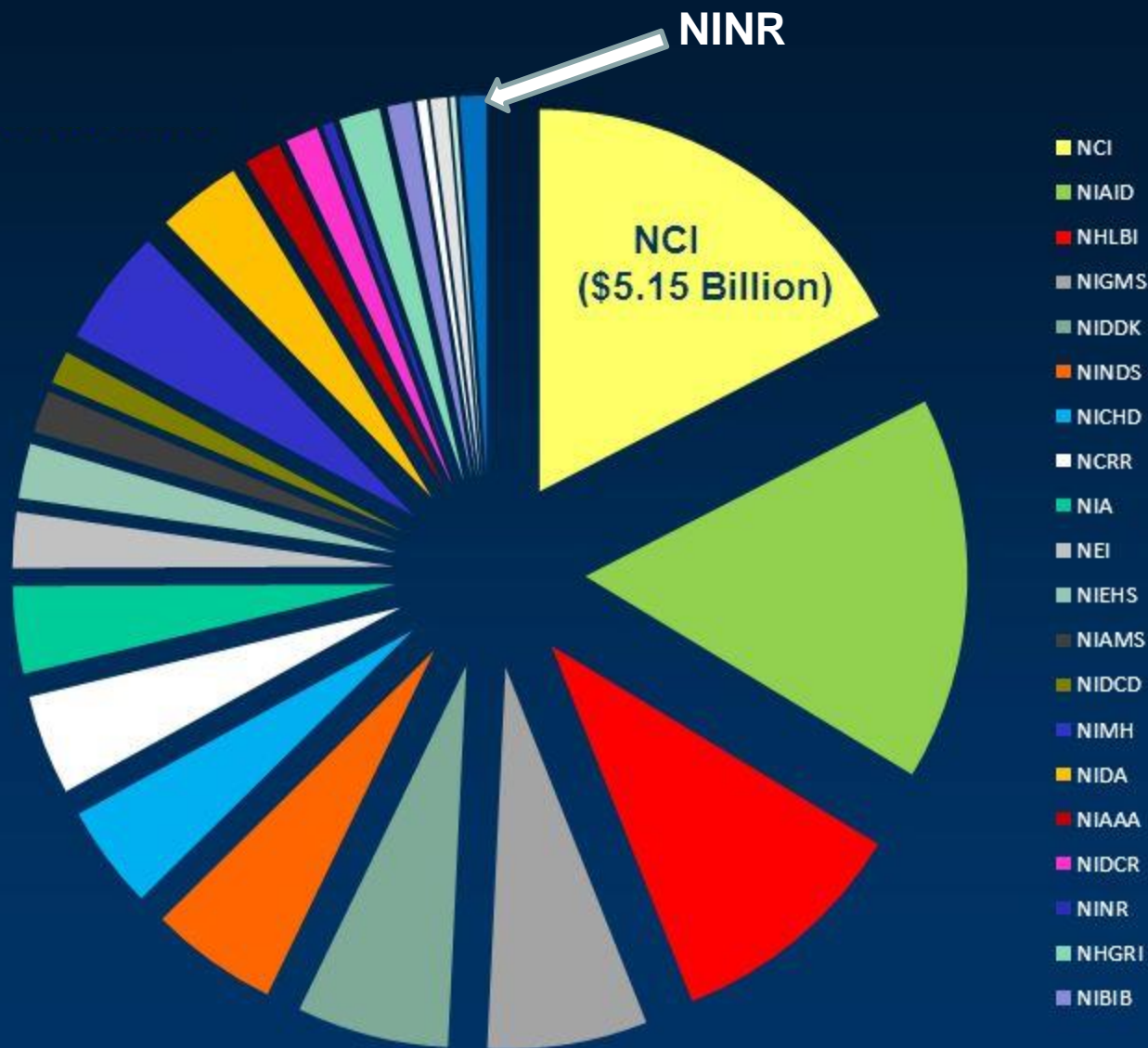
National Institutes of Health



National Institute of Nursing Research



NIH Budget Allocation by Institute



NIH Peer Review: 2005

- Palliative care grants distributed to 6 review panels
 - Mean panel size = 15 members
- Reviewers with palliative care expertise=8
 - 1.3 reviewers/panel
 - 0/panel if member conflict

U.S. Palliative Care Research in 2005....

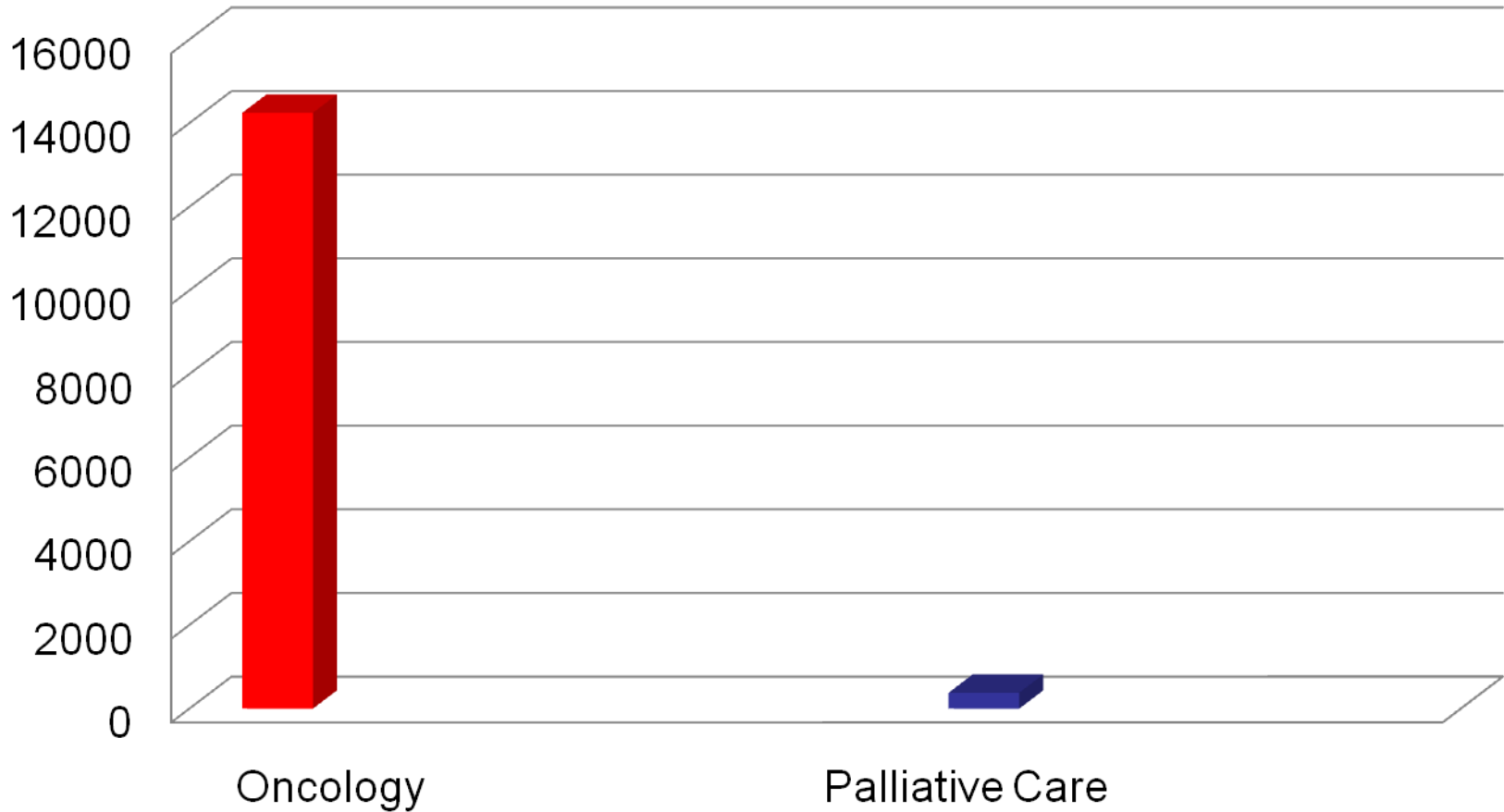
NIH Funding for Palliative Care (2001-2005)

- 418 Funded Grants
 - 189 (45%) were funded by NCI
 - 0.4% of all NCI grants
 - 94 (22%) by NINR
 - 3% of all NINR grants
 - 74 (18%) by NIA
 - 0.5% of all NIA grants
 - 61 (15%) were funded by 8 other Institutes
 - NIDDK did not fund a single grant in palliative care

Medical/Nursing Schools with R01 Funded Investigators in 2005

- Three or more – 5 ($\approx 3\%$ of all schools)
 - Brown, Harvard, Duke, Mount Sinai School of Medicine, University of California San Francisco
- Two or more – 8 ($\approx 6\%$ of all schools)
 - Case Western Reserve University, City of Hope Cancer Center, Dartmouth, Memorial Sloan Kettering Cancer University, University of Nebraska, University of Pennsylvania, University of Rochester, Yale University

Research Publications: Oncology and Palliative Care (2003-2005)



A Case Example....

The National Palliative Care
Research Center (www.npcrc.org)

National Palliative Care Research Center 2007

- Established in 2007 by the Kornfeld Foundation at ISMMS in response to:
 - Shortage of palliative care funding structures;
 - Shortage of palliative care investigators;
 - Need for a national organizational home for palliative care research
- Five year challenge grant of €2.1 million
 - €400 thousand/year

NPCRC Areas of Focus

- Pain and other distressing symptoms
- Communication between persons living with serious illness, their families, and their health care providers
- Developing and evaluating new clinical models of care for patients living with serious illness and their families

NPCRC Vision and Mission

NPCRC's vision is to relieve suffering and enhance quality of life for people with serious illness and their families by bringing an evidence-based approach to palliative care clinical practice.

NPCRC's mission is to establish, support, and sustain a robust, scientific community for palliative care research that will serve as the foundation for health policy and clinical practice.

Grant Programs (2007-present)

- Pilot/Exploratory Grants
 - Goal is to provide experienced investigators with pilot/exploratory data that will lead NIH funded research grants
- Junior Investigator Career Development Awards
 - Provides 2 years of protected time for junior investigators in palliative care
 - Covers 60% of awardee's salary
- Transition to Independence Award
 - One year bridge funding for promising mid-stage investigators with funding gaps

Technical Assistance

- Research consultancy
 - Up to 10 hours of free research consultation
 - Biotstats, design and methodology, grant writing
- Grant pre-review
 - NIH style peer review of planned grant submission
- Grant writing workshop
- Research methods training (2014-present)
 - One day pre-conference for junior investigators focused on key issues in palliative care research
 - Bi-monthly reverse classroom videoconferences

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 - Quarterly webinars
- Grant writing workshops

Conferences/Workshops (2012-present)

- Conferences/workshops on key research priorities
 - Geriatric palliative care (NIA)
 - Dementia (Hebrew Senior Life)
 - Spirituality (DFCI/Duke University)
 - Communication (Duke University)
 - Health and Retirement Survey (UM, UCSF)
 - Surgery, Critical care, Advanced Heart, Kidney and Lung Disease (NIH)

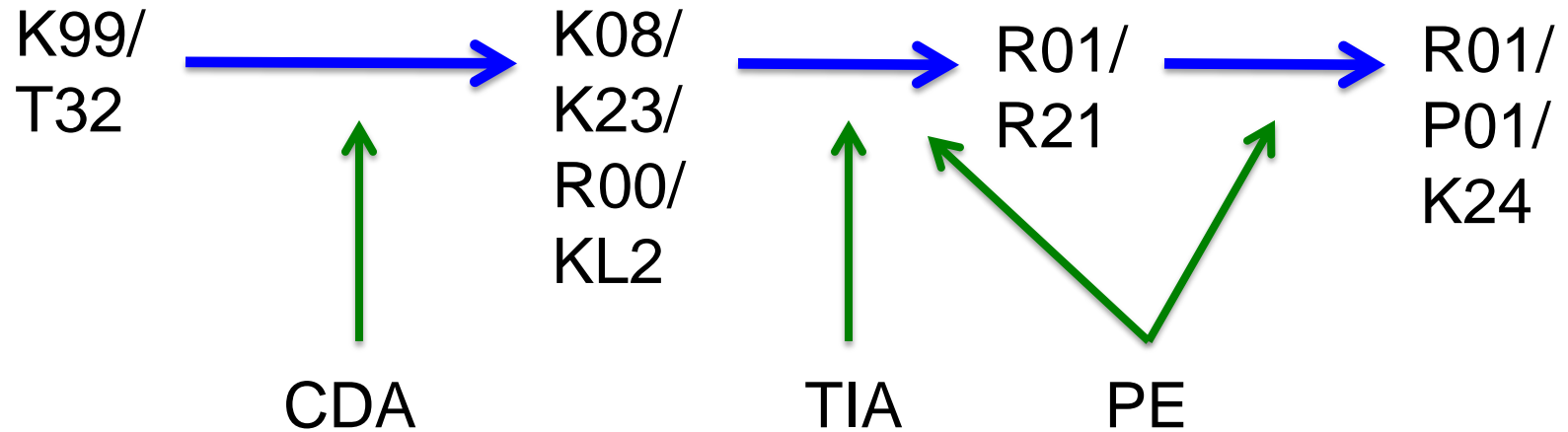
Community Building

- Kathleen M. Foley Research Retreat and Symposium
- Work in progress (WIP) seminars
 - Bimonthly WIP videoconferences for NPCRC and affiliated early stage investigators
 - Opportunity for community feedback on research ideas and ongoing work

Research Consultancy, Grant Reviews, Kathleen M. Foley Retreat



Research Workshops and
Webinars, Work in Progress
Webinars



NPCRC Outcomes...

National Palliative Care Research Center 2017



- **Funders (Past and Present):**
 - Anonymous donors
 - American Academy of Hospice and Palliative Medicine
 - American Cancer Society
 - American Express Foundation
 - Atlantic Philanthropies
 - Pat and Jay Baker Foundation
 - The Brookdale Foundation
 - Hearst Foundations
 - Y.C. Ho/Helen and Michael Chiang Foundation
 - Hospice and Palliative Nursing Association
 - Emily Davie and Joseph S. Kornfeld Foundation
 - Betty and Norman Levy Foundation
 - LIVESTRONG
 - Cameron and Hayden Lord Foundation
 - The Gordon and Betty Moore Foundation
 - The Mill Park Foundation
 - National Institute on Aging
 - The Olive Branch Foundation
 - Open Society Institute
 - U.S. Cancer Pain Relief Taskforce
- **Annual Operating Budget: €2.1 million**

10 YEARS

\$13.7m

in NPCRC Grants
awarded to

83
palliative care
researchers

83 RESEARCHERS

124
government and

134
non-government
research
grants awarded

1,800+
papers published

\$157m
in government and
\$41.6m
in non-government
research funding
secured

14.5 TO 1 RETURN ON INVESTMENT

258
total research
grants obtained

\$199m
in additional palliative
care research funding
secured

OVER 95% of grantees leverage their NPCRC funding to obtain federal or private foundation research grants

Career Development



\$7.6m

**NPCRC
Investment**



48

**CDA
Grantees**



\$74.8m

**In grants from other
funders**





Pilot/Exploratory



\$5.9m > **35** > **\$78.5m**
NPCRC Investment PE In grants from other funders



Summary (2007-17)

- Stimulated over \$150 million in federal palliative care research funding through its \$14 million investment in 83 palliative care investigators.
- Helped grow the number of sustainable palliative care research programs from 6 to 23 in 10 years.
 - 3 or more independent researchers (tenured faculty)
- Led a tripling of the palliative care evidence base through NPCRC grantee publications
- Stimulated new funding initiatives in palliative care at NIH, Patient Centered Outcomes Research Institute (PCORI) and the American Cancer Society

Potential Discussion Questions

- Could this model work outside of the U.S.?
- What were key factors leading to success?
- What would you have done differently?
- What is the administrative structure and staffing?
- Do you have international participants?