The National Palliative Care Research Center: Ten Years of Promoting and Developing Research in Palliative Care

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Abstract

Background: The evidence base to support high-quality clinical care and number of scientists available to develop this evidence base are inadequate.

Objective: To describe the first 10 years of the National Palliative Care Research Center's (NPCRC) programs and their outcomes.

Design: Established in 2005, NPCRC was created in direct response to the recommendations of the Institute of Medicine. Specifically, NPCRC was created to expand the palliative care evidence-based needed for both health policy and clinical practice by supporting research scientists, stimulating research and innovation, and creating a community of researchers focused on the needs of persons with serious illness and their families.

Measurements: Subsequent grant funding following NPCRC investment (web searches of NIH Research Portfolio Online Reporting Tools [RePORT], Veterans Administration and Patient Centered Outcomes Research Institute [PCORI] grant databases, grantee on-line surveys, and grantee annual reports) promotions (grantee on-line surveys and annual reports), publications (PubMed searches), and NPCRC participant satisfaction (grantee questionnaires).

Results: As of July 2017, NPCRC has funded 47 junior investigators representing over 10 disciplines. These investigators have leveraged NPCRC's \$7.8 million investment into 52 federal grants totaling \$74.8 million dollars and 69 foundation grants totaling \$16 million. Thirty-five grants (\$5.8 million) have been awarded to experienced investigators, resulting in additional grant funding of \$104.5 million dollars (\$78.5 million federal, \$26 million nonfederal). Satisfaction with NPCRC's program has been uniformly high and policy efforts have resulted in enhanced federal funding opportunities in palliative care research.

Conclusions: NPCRC's focus on people and infrastructure in conjunction with a top-down bottom-up strategy has been critical in improving the palliative care evidence base.

Keywords: faculty development; palliative care; palliative care evidence base; research training

WHILE MEDICAL ADVANCES have transformed previously fatal conditions such as cancer and heart disease into illnesses that people can live with for many years, they have not been accompanied by corresponding improvements in quality of life for these patients and their families—particularly in late stage disease.^{1–4} For most with serious illness, the time following diagnosis is characterized by months to years of physical and psychological symptom dis-

tress; progressive functional dependence and frailty; family support needs; and high healthcare resource utilization.^{5–8}

Living with serious illness should not equate to such suffering, yet, the evidence base that would appropriately improve quality of life for the seriously ill is inadequate. To that end, investment is needed in research directed toward helping people with serious illness and their families live in comfort and dignity over the course of their lives.

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The National Palliative Care Research Center (NPCRC) is a unique national organization whose mission is to strengthen the evidence-based foundation needed for health policy and clinical practice in palliative care. NPCRC does this by supporting research scientists, stimulating research and innovation, and creating a community of researchers focused on the needs of persons with serious illness and their families. Established by the Emily Davie and Joseph S. Kornfeld Foundation in 2005, NPCRC was created in response to the Institute of Medicine's (now National Academy of Medicine) 1997 report's recommendations that called for a "cadre of experts whose numbers and talents are sufficient to (a) supply leadership for scientifically-based and practically useful medical education and (b) organize and conduct clinical, behavioral, and health services research for patients with serious and chronic illness."⁹ In this article, we report on the first 10 years of NPCRC, including a description of its programs, collaborations, and outcomes.

The Need for a NPCRC

There was (and is) a national shortage of qualified investigators conducting research in palliative care. The 1997 Institute of Medicine report⁹ on palliative care cited the lack of trained investigators as a major impediment to the growth of the field. In 2005, when NPCRC was created, most of the existing 51 fellowship training programs in the United States were small (1 or 2 fellows), one-year clinical programs that followed an apprenticeship model of education with limited to no research training. Following Accreditation Council for Graduate Medical Education in 2009, palliative care fellowship programs remain one-year clinical programs without adequate time or support for research training. Those interested in pursuing research careers must seek additional training and support through philanthropic dollars, institutional intramural funding, related training grants in other fields (e.g., oncology, geriatrics, heart disease), or most commonly under the auspices of a senior investigator's grant funding. Given the few established senior investigators and the limited research dollars available to them, the ability of the field to sustain and grow itself has been limited.

Creating NPCRC: Visionary Philanthropy

NPCRC resulted from the visionary philanthropy of the Emily Davie and Joseph S. Kornfeld Foundation who established the Center with an initial challenge grant of \$2.25 million in 2005 at the Icahn School of Medicine at Mount Sinai, New York, NY. Subsequent investments by over 20 organizations and individual donors (Table 1) more than doubled NPCRC's initial annual operating budget. Over the past decade, NPCRC has focused on accomplishing three main goals for the field of palliative care: (1) creating a new cadre of scientific leaders to address known workforce needs; (2) providing technical assistance for palliative care investigators to better compete for and access federal research funding (e.g., National Institutes of Health) to address documented gaps in the evidence base, and (3) establishing and nourishing a national community of palliative care scientists to reinforce and support goals 1 and 2. Table 2 outlines NPCRC programs and their alignment with each of the above stated goals.

TABLE 1. NATIONAL PALLIATIVE CARE RESEARCH CENTER FUNDERS

Emily Davie and Joseph S. Kornfeld Foundation
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
Trudy Elbaum Gottesman and Robert W. Gottesman
Hearst Foundations
Y.C. Ho/Helen and Michael Chiang Foundation
Hospice and Palliative Nurses Association
Betty and Norman Levy Foundation
LIVESTRONG
Cameron and Hayden Lord Foundation
Thelma Lyon
The Mill Park Foundation
Gordon and Betty Moore Foundation
National Institute on Aging
The Olive Branch Foundation
Open Society Institute
U.S. Cancer Pain Relief Taskforce

Guiding Strategy

The core strategy of NPCRC is depicted in Figure 1. Specifically, NPCRC employs a reinforcing bottom-up and top-down strategy. Bottom-up initiatives focus on helping researchers develop the evidence base of palliative care and on supporting the development of new science leaders. NPCRC is composed of 3 core programs focused on this goal—grant funding, technical assistance, and community building. Through its grants program, NPCRC funds early-stage investigators through two-year career development awards and experienced investigators through two-year pilot/exploratory awards to support subsequent NIH or other large research applications. NPCRC's technical assistance program provides research training, grant writing support, and research consultancy. Finally, NPCRC promotes the palliative care research community through an annual meeting, web-based seminars, and *ad hoc* research workshops. These programs are described in greater detail below.

Top-down initiatives support policy, public awareness, and federal and private sector philanthropy funding opportunities to embed and formalize palliative care within the nation's research infrastructure. Partnerships with organizations such as the American Cancer Society (ACS) and ACS-Cancer Action Network, the American Academy of Hospice and Palliative Medicine (AAHPM), the Hospice and Palliative Care Nursing Association, the Brookings Institute, the Center to Advance Palliative Care, the National Coalition for Hospice and Palliative Care, the Palliative Care Research Cooperative, and the Patient Quality of Life Coalition strengthened NPCRC's reach and impact by providing a united collaborative voice focused on palliative care research. For example, partnership with the ACS-Action Network and the Center to Advance Palliative Care soon after NPCRC's was established and led to the formation of the Patient Quality of Life Coalition—an organization now composed of over 30 patient advocacy, professional societies, and disease focused organizations. In collaboration with

TABLE 2. NATIONAL PALLIATIVE CARE RESEARCH CENTER KEY PROGRAMS AND OUTCOMES AS OF JULY 2017

<i>Program</i>	<i>Description</i>	<i>Participating faculty/institutions</i>	<i>Selected outcomes</i>
<i>Workforce development</i> CDA (2006-present)	Two-year grants to support 60% effort for early-stage investigators	53 grantees representing 33 Institutions \$7.8 million expended	Within two years of completing NPCRC funding: 52 federal grants received (\$75 million) 69 foundation grants received (\$16 million) 70% received NIH/PCORI/VA funding 598 peer-reviewed articles published Return on investment: 10:1
Pilot/Exploratory Awards (2006-present)	Two-year grants to fund pilot/exploratory research for experienced investigators	33 grantees representing 22 Institutions \$5.8 million	Within two years of completing NPCRC funding 71 Federal grants received (\$78.5 million) 65 Foundation grants received (\$26 million) 90% received NIH/PCORI/VA funding Return on investment: 18:1
<i>Technical assistance</i> Research Methods Webinars and Workshops (2014-present)	In-person and videoconferences seminars focusing on research methods specific to palliative care	12 Workshops and 14 training webinars involving 25 early stage investigators from 17 institutions	Postworkshop responses and comments 2016: 91% of participants stated that they were “very satisfied” with the workshops overall “group discussion pushed my understanding and introduced new concepts” “the quality of presentations was exceptional” “Interactive, excellent speakers” “I loved the interactive nature of the workshops”
Works in progress webinars (2014-present)	Video-conferenced presentations by early-stage investigators of ongoing research with feedback from peers and mentors	34 works in progress webinars involving 25 early stage Investigators from 17 Institutions	
Grant writing workshops and grant reviews (2006-present)	Grant writing/peer review workshops, peer review training for CDA graduates, prereview of NIH grant proposals	11 grant writing workshops; 25 grant reviews for 18 investigators.	
<i>Community building</i> Research priorities and strategy (2010-present)	Small focused consensus conferences to identify and outline research priorities and stimulate federal palliative care research funding	2010: Developing a palliative care clinical trials network (PIs: Kutner J, Abernethy A) 2011, 2012: Palliative Care for Advanced Dementia (PI: Mitchell) 2013a: Geriatrics Palliative Care (in collaboration with NIA) 2013b: Using the HRS for Palliative Care Research (PI: Kelley, Covinsky, Langa) 2014: Spirituality (PI: Balboni, Steinhauser) 2015: Communication Res (Tulsky, Pollack) 2015b: Palliative Care for HF (Bakitas, Gelfman)	22 published articles ^{19–40} Amendment to the National Alzheimers Project Act to promote clinical care and research for advanced dementia ¹² NIH Program Announcements in palliative care ¹⁴ Development of the NINR supported Palliative Care Research Cooperative Group (palliativecareresearch.org) ¹⁹

(continued)

TABLE 2. (CONTINUED)

<i>Program</i>	<i>Description</i>	<i>Participating faculty/institutions</i>	<i>Selected outcomes</i>
Kathleen M. Foley Research Retreat and Symposium (2006- present)	Annual retreat jointly sponsored by the American Academy of Hospice and Palliative Medicine, American Cancer Society, Hospice and Palliative Nurses Association	2017a: Developing a T32 Palliative Care Network (PIs: Curtis, Kutner, Tulskey, Arnold, Casarett)	100% of participants state that retreat met (23%) or exceeded expectations (77%) and 100% would return again Representative comments: “Wonderful experience” “Such a superb retreat!” “Always an amazing meeting!” “Great people/networking/ best small size”; “High expectations met” “Always exceeds expectations!”
		2017b: Geriatric Palliative Care in Surgery and Medical Sub-specialties (co-hosted with NIA, NINR, NHLBI, NCI, NIMHD)	
		11 retreats involving over 1100 interdisciplinary scientists	

CDA, Career Development Awards; NPCRC, National Palliative Care Research Center's; PCORI, Patient Centered Outcomes Research Institute.

AAHPM, the Patient Quality of Life Coalition (PQLC) has successfully introduced legislation in the U.S. congress to enhance NIH research funding through the palliative care and hospice education and training act.^{10,11} Further examples of outcomes from these collaborations and others are the inclusion of research focused on the needs of persons living with advanced dementia and their families and caregivers in the National Alzheimer's Project Act¹²; development of National Institutes of Health and Patient Centered Outcomes Research Institute (PCORI) Program Announcements and Funding Opportunities

in palliative care research;^{13,14} and inclusion of palliative care in the National Quality Forum's quality initiatives.¹⁵

In addition to a formalized guiding strategy, NPCRC has routinely tracked outcomes of its programs to demonstrate impact and to ensure continuous quality improvement. Grantees are surveyed every two years to record foundation grants, awards, honors, and promotions. Searches are conducted every five years of EMBASE, PsycINFO, CENTRAL, PubMed, CINAHL, and EconLit to identify publications by NPCRC grantees and of NIH

FIG. 1. NPCRC's guiding strategy: top-down and bottom-up. NPCRC's, National Palliative Care Research Center's.

(RePORTER), VA (Office of Research and Development), PCORI, and relevant foundation websites (e.g., ACS) to identify research funding obtained by NPCRC grantees. Participants in each NPCRC program are asked to evaluate their experiences with the relevant program. Finally, NIH funding of palliative care research is reviewed every five years.^{16–18}

NPCRC Structure

NPCRC (along with its partner organization, the Center to Advance Palliative Care) sits within the Brookdale Department of Geriatrics and Palliative Medicine at the Icahn School of Medicine at Mount Sinai. It is overseen by a Scientific Advisory Council (SAC) that is responsible for development and approval of NPCRC's research agenda, grant funding, and other center activities. Comprised of an interdisciplinary team (nursing, medicine, behavioral health, and epidemiology) of eight international experts in palliative care and related specialties, the SAC provides overall guidance to NPCRC and oversees its grant programming. Specifically, the SAC approves funding for all grants based upon recommendations by the Scientific Review Committee (SRC) (detailed below), collaborative projects, and new initiatives. Members of the SAC are listed at www.npcrc.org.

The SRC reviews pilot/exploratory and career development proposals annually. The committee is composed of 10–15 experienced National Institute of Health (NIH)-funded palliative care scientists, who serve three-year renewable terms. NPCRC career development grantees are invited to sit on the SRC after completing their awards and are mentored by senior SRC members. In this manner, early-stage investigators learn the process of peer review and gain insight as to the mechanisms of study sections. The SRC follows NIH review panel procedures and scoring. The SRC roster is available at www.npcrc.org.

NPCRC staff consist of its Director, Deputy Director, Director of Technical Assistance and Career Development Programs, and an administrative assistant who are responsible for the day-to-day operations of the Center. Salaries, benefits, and other center expenses (e.g., travel, marketing, web development) are supported by NPCRC's budget. Office space, supplies, IT support, and overhead are funded through indirect costs payable to Mount Sinai on grants and donations received by NPCRC.

NPCRC Review Processes

NPCRC solicits letters of intent for its funding mechanisms in the fall of each year. Letters of intent are screened to ensure compliance with the NPCRC's funding guidelines. Eligible applicants are invited to submit full proposals for funding consideration for a January submission deadline. Applications require a 12-page proposal that follows the format of the NIH R01 (pilot/exploratory grants) or K (career development award) mechanisms. Applications are reviewed by NPCRC's SRC in a process similar to an NIH study section in early March of each year. Applications are scored and reviewed using NIH criteria. Scores, comments, and funding recommendations are forwarded to the SAC who make final decisions regarding funding and allocation of NPCRC resources.

NPCRC Programs and Outcomes

Investigator development and support

A major barrier to the growth of palliative care is the lack of a pipeline for the development of scientific investigators. Historically, externally funded research by senior investigators has cross-subsidized mentoring and pilot studies for their mentees, which helped establish a mentee's publication track record and provided access to data to support NIH project and career development award proposals. Recent reductions in NIH funding, downwardly negotiated budgets, expectations of contributed time on the part of nongovernment funders, reduced indirect costs, and the reluctance of institutions to support contributed time, have all made cross-subsidization of early-stage investigators difficult. This challenge is magnified for the field of palliative care given its small size and the inability of senior palliative care investigators to support multiple mentees.

To address this challenge, NPCRC's career development awards provide two years of support to junior faculty, thus allowing early-stage investigators the protected time needed to conduct pilot research and develop pilot data that are necessary to be competitive for an NIH award. As of July 2017, NPCRC has funded 47 early-stage investigators from 33 different institutions representing over 10 disciplines (Table 3). These investigators have leveraged NPCRC's \$7.8 million investment into 52 subsequent federal grants for a total of \$74.8 million dollars and 69 foundation grants for a total of \$16 million—a 10:1 return on investment. Seventy percent of junior investigator grantees received federal funding within two years of their NPCRC award, and over 90% received either federal or foundation funding (Table 2). Twenty-four of 47 grantees (51%) have been promoted since their award (20 to associate professors and 4 to professors). The 41 grantees who had fully completed their awards by July 2017 have published a total of 598 peer-reviewed articles supported by their NPCRC award—an average of 15 articles per investigator.

NPCRC also funds experienced investigators conducting research projects whose purpose is to test interventions, develop research methodologies, and explore novel areas of palliative care research. A condition of funding is a clearly defined plan as to how the investigator will use the results of the project to develop larger, federally (e.g., NIH, VA) funded research projects. In this manner, NPCRC has sought to provide experienced investigators with support to strengthen their federal and other large grant submissions to better compete with investigators from more established fields of biomedical research. As of July, 2017, NPCRC has awarded 36 grants to 33 experienced investigators from 22 different institutions representing over 10 research disciplines (Table 4). These investigators have leveraged NPCRC's \$5.8 million investment into 136 subsequent grants for a total of \$104.5 million dollars (\$78.5 million federal, \$26 million nonfederal)—an 18:1 return on NPCRC's investment (Table 2).

Technical assistance

Research in palliative care presents a number of unique challenges for investigators. First, the study population

TABLE 3. NPCRC CAREER DEVELOPMENT GRANT AWARDEES 2007–2017

<i>Year Funded</i>	<i>Name</i>	<i>Institution^a</i>	<i>Discipline (Sub-Specialty)^b</i>
2007	Melissa Aldridge, MBA, PhD Kimberly Johnson, MD, MSHS Helene Starks, MPH, PhD Christina Ullrich, MD	Icahn School of Medicine at Mount Sinai Duke University University of Washington Boston Children's Hospital/Harvard University	Health Services Research Medicine (Geriatrics) Health Services Research Pediatrics (Oncology) ^b
2008	Wendy Anderson, MD, MS Marie Bakitas, PhD, DNSc Elisabeth Dellon, MD, MPH Joseph Shega, MD	University of California San Francisco Dartmouth University University of North Carolina Chapel Hill Northwestern University	Medicine (Hospital) ^b Nursing Pediatrics (Pulmonary) Medicine (Geriatrics) ^b
2009	Jane Givens, MD, MSCE Scott Irwin, MD, PhD Ramona Rhodes, MD, MPH Alexander Smith, MD, MS, MPH	Hebrew Senior Life/Harvard University San Diego Hospice University of Texas Southwestern University of California San Francisco	Medicine (Geriatrics) Psychiatry ^b Medicine (Geriatrics) Medicine (General) ^b
2010	Robert Gramling, MD, DSc Yael Schenker, MD Anne Walling, MD, PhD Alexi Wright, MD	University of Rochester University of Pittsburgh University of California Los Angeles Dana Farber Cancer Institute/Harvard Univ	Medicine ^b Medicine (General) ^b Medicine ^b Medicine (Oncology)
2011	Rebecca Aslakson, MD, MSci Susan Enguidanos, MPH, PhD Melissa Garrido, PhD	Johns Hopkins University University of Southern California James J. Peters Bronx VA, Icahn School of Medicine at Mount Sinai	Anesthesia (Critical Care) ^b Gerontology Health Services Research
2012	Kathleen Unroe, MD, MHA Sangeeta Ahluwalia, MPH, PhD Abraham Brody, RN, PhD, GNP Harleah Buck, PhD, RN John Cagle, MSW, PhD Laura Gelfman, MD, MPH C. Torre Simons, MD, PhD	Indiana University University of California Los Angeles New York University Pennsylvania State University University of Maryland Baltimore Icahn School of Medicine at Mount Sinai Stanford University	Medicine (Geriatrics) Health Services Research Nursing (Geriatrics) ^b Nursing Social Work Medicine ^b Medicine ^b
2013	Kira Bona, MD, MPH Andrew Epstein, MD Shigeko Izumi, PhD, RN Thomas LeBlanc, MD, MA Prema Menon, MD	Boston Children's Hospital/Harvard University Memorial Sloan Kettering Cancer Center Oregon Health Science University Duke University University of Vermont	Pediatrics (Oncology) Medicine (Oncology) ^b Nursing Medicine (Oncology) ^b Medicine (Pulmonary/ Critical Care)
2014	Areej El-Jawahri, MD Elana Evan, PhD Dio Kavalieratos, PhD Katherine Ornstein, MPH, PhD Melissa Wachterman, MD, MPH, MSc	Massachusetts General Hospital/Harvard University University of California Los Angeles University of Pittsburgh Icahn School of Medicine at Mount Sinai Brigham & Women's Hospital/Harvard University	Medicine (Oncology) Psychology (Pediatrics) Health Policy Epidemiology Medicine ^b
2015	J. Nicholas Dionne-Odom, PhD, RN, MSN Ann Long, MD, MS Hillary Lum, MD, PhD Gail Towsley, PhD Jennifer Walter, MD, MS, PhD	University of Alabama Birmingham University of Washington University of Colorado Denver University of Utah Children's Hospital of Philadelphia, University of Pennsylvania	Nursing Medicine (Pulmonary/ Critical Care) Medicine (Geriatrics) ^b Gerontology/Nursing Pediatrics
2016	Kavita Dharmarajan, MD, MS Stephanie Gilbertson-White, PhD, APRN Monica Lemmon, MD Charlotta Lindvall, MD, PhD Oreofe Odejide, MD, MPH Nicole Pensak, PhD	Icahn School of Medicine at Mount Sinai University of Iowa Duke University Dana Farber Cancer Institute/Harvard University Dana Farber Cancer Institute/Harvard University University of Colorado Denver	Radiation Oncology Nursing Pediatrics (Neurology) Medicine ^b Medicine (Oncology) Psychology (Oncology)

^aAt time of funding.^bBoard Certification in Palliative Medicine.

TABLE 4. NPCRC PILOT EXPLORATORY GRANT AWARDEES AS OF JULY 1, 2017

<i>Year Funded</i>	<i>Name</i>	<i>Institution^a</i>	<i>Discipline (sub-specialty)^b</i>
2007	Robert Arnold, MD	University of Pittsburgh	Medicine ^b
	Marcia Grant, DNSc, RN	City of Hope Cancer Center	Nursing
2008	Sheryl Zimmerman, PhD	University of North Carolina Chapel Hill	Social Work
	Kathleen Puntillo, PhD, RN	University of California San Francisco	Nursing
2009	Greg Sachs, MD	Indiana University	Medicine (Geriatrics) ^b
	Kyle Allen, DO	Summa Health Center	Medicine (Geriatrics)
2010	Jennifer Mack, MD, MPH	Boston Children's Hospital/Harvard University	Pediatrics (Hematology/Oncology)
	Cynthia Gerhardt, PhD	Nationwide Children's Hospital	Psychology (Pediatrics)
2011	Laura Hanson, MD, MPH	University of North Carolina Chapel Hill	Medicine (Geriatrics) ^b
	Kelly Michelson, MD, MPH	Children's Memorial Hospital, Northwestern University	Pediatrics (Critical Care)
2012	Renee Stapleton, MD, PhD	University of Vermont	Medicine (Pulmonary/Critical Care)
	Tracy Balboni, MD, MPH	Dana Farber Cancer Institute/Harvard University	Radiation Oncology
2013	Ruth Engelberg, MA, PhD	University of Washington	Education
	Steven Pantilat, MD	University of California San Francisco	Medicine (Hospital Medicine) ^b
2014	Rebecca Sudore, MD	University of California San Francisco	Medicine (Geriatrics) ^b
	Amber Barnato, MD, MPH, MS	University of Pittsburgh	Medicine (Preventive)
2015	Savithri Nageswaran, MD, MPH	Wake Forest School of Medicine	Pediatrics ^b
	Lynn Reinke, PhD, ARNP	University of Washington	Nursing
2016	Marie Bakitas, PhD, DNSc, APRN	University of Alabama Birmingham	Nursing
	Ardith Doorenbos, PhD, RN	University of Washington	Nursing
2017	Brie Williams, MD, MS	University of California San Francisco	Medicine (Geriatrics) ^b
	Jane Givens, MD, MSCE	Hebrew Senior Life/Harvard Univ	Medicine (Geriatrics)
2018	Nathan Goldstein, MD	Icahn School of Medicine at Mount Sinai	Medicine (Geriatrics) ^b
	Christine Ritchie, MD, MSPH	University of California San Francisco	Medicine (Geriatrics) ^b
2019	Dena Schulman-Green, PhD	Yale University	Nursing
	Karen Steinhäuser, PhD	Duke University	Sociology
2020	Anthony Back, MD	University of Washington	Medicine (Hematology/Oncology) ^b
	Laura Hanson, MD, MPH	University of North Carolina Chapel Hill	Medicine (Geriatrics) ^b
2021	Scott Irwin, MD, PhD	University of California San Diego	Psychiatry ^b
	Amy Kelley, MD, MSHS	Icahn School of Medicine at Mount Sinai	Medicine (Geriatrics) ^b
2022	Alexander Smith, MD, MS, MPH	University of California San Francisco	Medicine (General) ^b
	Abby Rosenberg, MD, MS, MA	University of Washington	Pediatrics (Hematology/Oncology, Bioethics) ^b
2023	Gretchen Schwarze, MD, MPP	University of Wisconsin Madison	Surgery (Vascular)
	Rebecca Sudore, MD	University of California San Francisco	Medicine (Geriatrics) ^b
2024	Brie Williams, MD, MS	University of California San Francisco	Medicine (Geriatrics) ^b
	Alexi Wright, MD, MPH	Dana Farber Cancer Institute/Harvard University	Medicine (Hematology/Oncology)

^aAt time of funding.^bBoard certified in Palliative Medicine.

consists of individuals facing serious illness, including advanced cancer and dementia, and their families, which gives rise to a number of issues. These include the inability of subjects to complete lengthy interviews, incomplete or missing data, use of proxy respondents, and the complexities of conducting postdeath bereavement interviews. Second, for many types of palliative care interventions it is either unethical or feasible to randomize individuals to interventions, thus necessitating alternatives to the gold-standard randomized clinical trial study design. These alternatives include the analysis of observational data, data from quasi-experimental designs, and data from qualitative studies, which each requires specific research methods ex-

pertise to accurately and reliably answer important research questions in the field of palliative care. Third, inherent in palliative care is recognition of the need to care for the whole person—their clinical, social, spiritual, and family needs. As such, appropriate outcomes to measure in palliative care research encompass far more than mortality and the absence of symptoms or disease. The incorporation of outcomes such as quality of life, quality of death, preference and goals of care concordance, and patient and family satisfaction with care is challenging, yet, vital to high-quality palliative care research.

To address these challenges and ensure that the evidence base for palliative care is built on the most rigorous study

designs and analytics, NPCRC developed a research technical assistance program. This program has included (1) a stable of national experts in study design, instrument development, and analytic techniques specific to palliative care research that are available to investigators without charge; (2) research training that has included in-person and web-based seminars; (3) work-in-progress webinars for junior faculty to seek advice and assistance with ongoing research; and (4) grant review by experienced NIH reviewers before submission to the actual funding agency. In addition, NPCRC provides focused training in peer review for early-stage investigators. Specifically, following the final year of their career development award, early stage investigators are invited to join the SRC, are paired with experienced NIH investigators, and participate in the review of new applications. Feedback is provided to new reviewers by both their mentors, fellow review panelists, and the NPCRC director. Table 2 details NPCRC's research technical assistance programs.

Creating community and research priorities

NPCRC has developed a vital community of palliative care researchers through an annual research retreat and through its efforts to create shared and consensus driven research priorities for the field of palliative care. The Kathleen M. Foley Research Retreat and Symposium convenes researchers for presentations of cutting edge research, establishing research priorities, and promoting collaboration. Since 2007, over 1000 individuals representing over 10 different disciplines and specialties have attended. Postretreat evaluations have been consistently excellent. On average over the first 11 meetings, 100% of participants stated that the retreat met (23%) or exceeded (77%) expectations and that they would like to return the following year. In addition to hosting the Foley retreat, NPCRC has convened small working groups either by itself or in collaboration with other intuitions (e.g., the National Institutes of Health) to address palliative care research priorities in key populations and subject areas. Outcomes stemming directly from these meetings are detailed in Table 2.

Future Directions and the Next Stages of NPCRC

When first founded, NPCRC's plan was to complete its work by 2020. At the time NPCRC was launched, we believed that it would no longer be needed after 15 years, as its work would have become embedded in established federal funding structures. What we could not predict in 2005 was the unprecedented reductions in NIH funding that have continued to exist throughout NPCRC's existence. In addition, the increasing financial constraints placed on academic medical centers due to exponentially rising healthcare costs significantly hamper their ability to support emerging researchers. As NPCRC approached its 10th anniversary and the deadline to develop a thoughtful exit strategy drew nearer, its SAC became concerned about the impact of these external funding trends on the further development and sustainability of palliative care researchers and their programs if NPCRC were to close as planned in 2020. In 2015, upon the recommendation of its SAC and with the generous support of the Kornfeld Foun-

dation, the NPCRC engaged an outside consultant specializing in nonprofit organizations to survey NPCRC grantees, leaders in the field, and partner organizations; conduct interviews with leading scientists, health policy experts, and strategic partners (including the ACS, AAHPM, and Hospice and Palliative Nursing Association) regarding the importance and success of NPCRC and its programs; and develop recommendations for NPCRC's future.

The results of the consultants' report helped shape a new strategic plan for the future of the NPCRC. Survey and interview respondents were unanimous in their belief that NPCRC's leadership and existing programs were a resounding success. Furthermore, based upon their interviews, the consultants concluded that NPCRC was critically needed for at least the next 8–10 years if high-quality palliative care was to become universally accessible to all Americans in need. The consultant's recommendations were discussed at NPCRC's SAC meetings in the spring and fall of 2017. The Council strongly recommended that NPCRC seek funding for an additional eight years of programming in conjunction with a strategy to transition NPCRC programs that were believed to be needed by the field post-2025 to external organizations. In response to these recommendations, NPCRC initiated a new fundraising campaign to secure its next stage of work and begun work on a comprehensive transition strategy that will relocate NPCRC's key products and programs into existing and self-sustaining organizations.

Summary

The original goal of the NPCRC was both visionary and ambitious: to strengthen the evidence-based foundation for health policy and clinical practice in palliative care. At its core, this mission is about people—providing the right people the funding, resources, training, protected time, mentorship, collaborative opportunities, strategic focus, and dissemination tools to bring the highest quality palliative care to those with serious illness. This article focuses mostly on the initiatives and outcomes of the NPCRC, and yet, the careful process of choosing the investigator and mentor teams for the career development awards and the collaborative teams for the pilot/exploratory grants are what ultimately led to the success of the Center. The efforts of the SRC, which included 70 different researchers over the 12-year period, and the SAC were crucial. This multi-pronged approach has been a success and the people who now comprise the field of palliative care are without a doubt more cohesive, collaborative, and scientifically rigorous than we had even anticipated.

External factors, however, particularly those impacting the economics of research funding at both the federal and academic medical center levels, remain a substantial challenge for the field. The success of NPCRC is derived from the dual tasks of creating a multifaceted research infrastructure *and matching it* to people with the potential and drive to achieve success. Either component alone, comprehensive infrastructure and support without the right people or great people without the necessary infrastructure and support, will fail. As we plan for the future of NPCRC and palliative care research, this ongoing focus on people and infrastructure in conjunction with a top-down bottom-up strategy will be

critical to attaining the evidence base essential to provide the highest quality palliative care.

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