




**The Palliative Care Research Cooperative Group:
a flourishing community of research and
investigator development**

December 3, 2016
Christine Seel Ritchie, MD, MSPH
PCRC Co-Principal Investigator

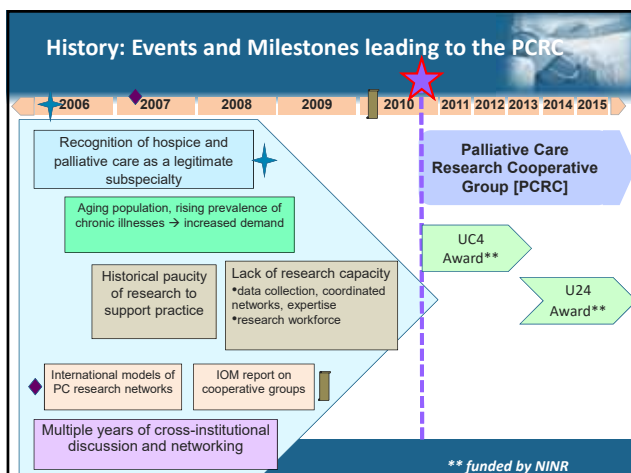
Funded by National Institute of Nursing Research
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History: Development of the PCRC


Urgent Needs in Palliative Care Research

- Randomized efficacy & effectiveness studies
- Consensus on palliative care outcome measures
- Qualitative and quantitative methodologies
- Strategies to ensure ethical treatment of patients as research participants
- More generalizable studies=multisite studies
- Implementation and dissemination
- Support of overall investigator development





Palliative Care Research Cooperative (PCRC)



- Founded in January 2010
 - Started with 25 participants from 10 disciplines
- First research cooperative in the US focused on palliative care and end of life (PCEOL)
- Infrastructure provides centralized support services
- Funded through the National Institute for Nursing Research

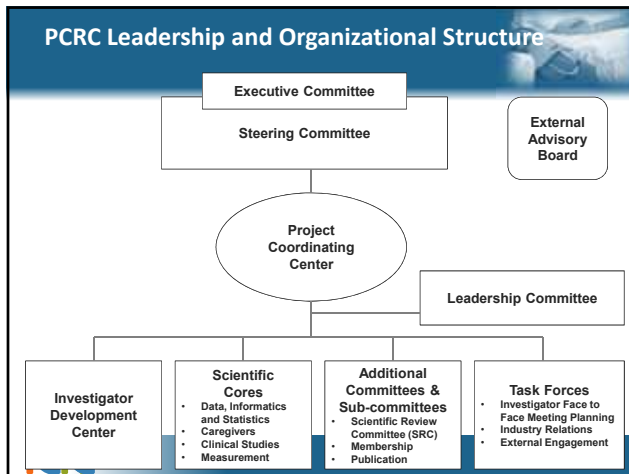
Abernethy AP, Aziz NM, Basch E, Bull J, Cleeland CS, Currow DC, Fairclough D, Hanson L, Hauser J, Ko D, Lloyd L, Morrison RS, Olin-Green S, Parliat S, Portenoy RK, Ritchie C, Rucker G, Wheeler JL, Zagar SY, Kutner JS. A strategy to advance the evidence base in Palliative Medicine: Formation of a palliative care research cooperative group. J Palliat Med. 2010; 13(12): 1-7



PCRC Overarching Strategy

1. Develop **efficient** palliative care **research capacity** nationally.
 - Infrastructure
 - Data systems and procedures
 - Metrics
2. Support the conduct, analysis, and dissemination of **high-quality research** in palliative care.
3. Train and mentor **new, existing, and future clinician-scientists** committed to advancing palliative care research.

 PCRC Proprietary



PCRC Resources and Infrastructure

<p>PCRC Leadership</p> <ul style="list-style-type: none"> • Executive Committee • Steering Committee <p>Centralized PCRC Resources</p> <ul style="list-style-type: none"> • Project Coordinating Center • Investigator Development Center (IDC) <p>Active Task Forces</p> <ul style="list-style-type: none"> • Face-to-Face Investigator Meeting • Industry Relations 	<p>Core Resources</p> <ul style="list-style-type: none"> • Data, Informatics & Statistics Core (DISC) • Caregivers Research Core • Clinical Studies Core • Measurement Core <p>Active Committees</p> <ul style="list-style-type: none"> • Scientific Review Committee • Membership Committee • Publications Committee
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 Directors & Committee Chairs also serve on Leadership Committee

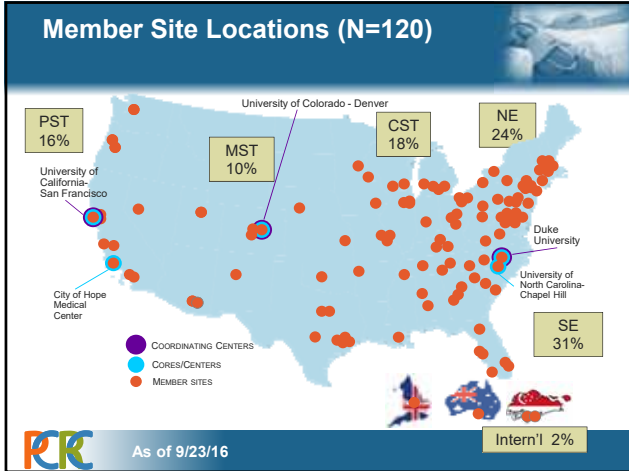
PCRC Membership Metrics

- Full Members: 45%
- Junior Member: 45%
- Affiliate Members: 10%

Membership Growth
[n=283] 9/23/16

Year	Existing	New	Total
2010	25	0	25
2011	30	5	35
2012	35	5	40
2013	40	10	50
2014	55	15	70
2015	70	20	90
2016	100	100	200

 As of 9/23/16 <http://palliativecareresearch.org/members/interested-in-pcrc-membership/summary-of-pcrc-members/>



PCRC Grant Collaboration

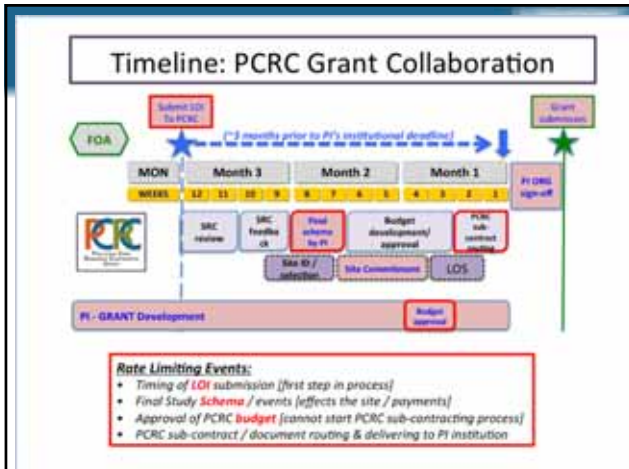
Includes: Post-award Core consulting, Project Coordinating Center activities, Recruitment Sites

Submission Support of:		
Grant Cycle	N	Type
March 2014	17	R01s
June 2015	1	R01
October 2015	2	R01s
November 2015	18	R21s
February 2016	1	R21
June 2016	2	R01 & R18
October 2016	2	R01s
TOTAL	43	
<i>Planned (Dec)</i>	<i>-9</i>	<i>PCORI</i>

Letters of Support:
N=59
(~8 pending)

- NIH grant submissions
- Career Development Award awards
- Foundation grant submissions

PCRC Proprietary Information



Investigator Development Center (IDC) Webinars

Monthly webinars hosted online, slides and video posted to:
<http://palliativecareresearch.org/corescenters/idc/idc-webinars/>

Webinar Topics examples:

- Developing Your Specific Aims
- Developing Your Behavioral Intervention
- Developing a Budget for Multi-Site Studies
- How to Submit a Sparkling Grant Application
- How to Develop a Sound Analysis Plan
- Data & Data Safety Monitoring
- Optimizing Recruitment and Improving Retention
- Finding Patterns in Health Data – A Gentle Introduction to Machine Learning
- PCRC New Member Orientation
- Implementation Science
- Family Caregiving Research
- Disseminating Your Work
- Effective Mentor and Menteeship

Investigator Development Center (IDC) Clinical Trials Intensives

Focus: Planning, design, & execution of randomized clinical trials in palliative care

Program: 3 days of focused lectures, individual and group consultations with experts in the field, & small group work.

Target audience: early career researchers or other mid-career researchers and health professionals.

- January 11-13, 2016 – Chicago: 12 scholars participated
- May 3-5, 2016 – Denver: 15 scholars participated

Participant feedback:

- Intensive was a huge success.
- Lectures by faculty, content, length, practical value, and networking opportunity were all "excellent"
- Best parts included the multi-disciplinary nature of the process, increasing sense of community in this field, learning pearls from the facilitators was so informative!



<http://palliativecareresearch.org/who/idc/>

Summary: How PCRC Facilitates PCEOL Research

- **Grant / Study Development**
 - Letters of Support
 - Guiding research questions from concept to study design
 - Connect investigators with appropriate methodologies, metrics and measures
 - Pilot grant awards
 - Assisting with enrollment initiation
 - Ensuring high quality data collection
 - Regular tracking of performance metrics
 - Streamlining of programming code
- **Investigator and Site Development**
 - Training site-based study personnel
 - Investigator training and mentoring
 - Consistent variables across data sets and studies
 - Standardize data collection
 - Enhance data utility for secondary use
- **Efficient Study Conduct**
 - Replicable research infrastructure
 - Access to multiple sites and investigators across the country
 - Development of comprehensive protocol & study-specific materials
- **Leverage across studies**
- **Dissemination**
 - Publication in accordance with PCRC Authorship Protocol



<http://palliativecareresearch.org/research/investigators/investigator-support-information/>

PCRC Opportunities for the Future

- **Collaboration with international research networks**
 - Conducting multi-site studies across countries and international networks
 - Engaging with international partners around data and data analyses
 - Mentor/investigator matching
 - Cross-national protocol development initiatives
- **Collaboration with funders**
 - Leveraging PCRC relationships/partners to identify new sources of funding for international studies and collaboration



<http://palliativecareresearch.org/research/investigators/investigator-support-information/>

Palliative Care Research Cooperative Group



palliativecareresearch.org



@pcrcgroup



pcrcgroup



pcrc@duke.edu



PCRC Projects: Completed

Active secondary analysis

Study #	Title	PI (Institution)	Type	Funding
PCRC 10-01	Statin Discontinuation	Amy Abernethy, MD, PhD (Duke Univ) Jean Kutner, MD, MPH (Univ Colorado)	Randomized Control Trial	NINR UC4

Publications associated with PCRC Pivotal Trial:

- Safety and benefit of discontinuing statin therapy in the setting of advanced, life-limiting illness: a randomized clinical trial. Kutner JS, Blatchford PJ, Taylor DH Jr, et al. *JAMA Intern Med.* 2015;175(5):691–700.
- The burden of polypharmacy in patients near the end of life. McNeil MJ, Kamal AH, Kutner JS, Ritchie CS, Abernethy AP. *J Pain Symptom Manage.* 2015; Volume 51, Issue 2, 178 - 183.e2



PCRC Proprietary Information

PCRC Projects: Active

Enrollment Complete – Analysis Phase

Study #	Title	PI (Institution)	Type	Funding
PCRC 14-01	Best Supportive Care	Yousuf Zafar, MD, MHS (Duke Univ)	Implementation	American Cancer Society (ACS)
PCRC 14-02	QDACT Feasibility	Arif Kamal, MD, MBA, MHS (Duke Univ)	Quality	Agency for Healthcare Research & Quality (AHRQ)



PCRC Proprietary Information

PCRC Projects: Active

Study #	Title	PI (Institution)	Type	Funding
PCRC 14-07	Caregiver-guided Pain Management	Laura Porter, PhD (Duke Univ)	Randomized Control Trial	NINR RFA-NR-14-003
PCRC 14-08	Legacy Intervention in Pediatric Palliative Care	Terrah Foster-Akard, PhD, RN (Vanderbilt)	Intervention	NINR RFA-NR-14-003
PCRC 14-09	Lung Cancer Palliative Care Intervention	Betty Ferrell, PhD, RN (City Of Hope)	Intervention	NINR RFA-NR-14-003
Grant R18	The Value of Information and the PCRC (Implementing Best Practice in Palliative Care)	Kimberly Johnson, MD, MPH (Duke University)	Quality Improvement	Agency for Healthcare Research & Quality (AHRQ)



PCRC Proprietary Information

PCRC Projects: Active

Study #	Title	PI (Institution)	Type	Funding
PCRC 16-02	Cancer Caregivers interactions with the Hospice team: implications for end of life and bereavement outcomes	Lee Ellington, PhD, RN (University of Utah)	Multi-site, multi-method prospective longitudinal study	NINR (R01)
PCRC 16-10	Barriers to Hospice and Palliative Care Utilization among Adolescent and Young Adult Cancer Patients Living in Poverty	Jennifer Mack MD MPH (Harvard)	retrospective observational design; qual interviews of FCG; questionnaire based interviews	NINR (R21)
PCRC 16-11	Exploring Palliative Care Communication with Alaska Native and American Indian People at Two Primary Care Sites	Jennifer Shaw PhD (Southcentral Foundation, Alaska)	mixed methods, prospective, interventional, randomized design	NINR (R21)



PCRC Proprietary Information

Publications: Journals [n=7]

Strategies to support recruitment of patients with life-limiting illness for research: the Palliative Care Research Cooperative Group. Hanson, LC. et al. Journal of Pain and Symptom Management , Volume 48 , Issue 6 , 1021 - 1030

The Burden of Polypharmacy in Patients Near the End of Life McNeil, Michael J. et al. Journal of Pain and Symptom Management , Volume 51 , Issue 2 , 178 - 183.e2


Safety and benefit of discontinuing statin therapy in the setting of advanced, life-limiting illness: a randomized clinical trial. Kutner JS, Blatchford PJ, Taylor DH, Jr, et al. JAMA Intern Med. 2015;175(5):691-700. doi:10.1001/jamainternmed.2015.0289.

The quality imperative for palliative care. Kamal AH. et al. Journal of Pain and Symptom Management , Volume 49 , Issue 2 , 243 - 253.

Ethical conduct of palliative care research: enhancing communication between investigators and institutional review boards. Abernethy AP et al. Journal of Pain and Symptom Management , Volume 48 , Issue 6 , 1211 - 1221

A Strategy To Advance the Evidence Base in Palliative Medicine: Formation of a Palliative Care Research Cooperative Group Abernethy AP et al. Journal of Palliative Medicine. December 2010, 13(12): 1407-1413. doi:10.1089/jpm.2010.0261.

Developing the evidence base for palliative care: formation of the palliative care research cooperative and its first trial. LeBlanc TW et al. Hospital practice (1995). 2010;38(5):137-143. doi:10.3810/hp.2010.06.320.




PCRC Proprietary

Publications: Abstracts [n=3]

High Symptom Burden and Low Functional Status in the Setting of Multimorbidity. Accepted for poster presentation at the 9th World Research Congress of the EAPC -- June 2016. Dublin, Ireland.

Safety of discontinuing statins among patients with life limiting illness. Kutner JS. 8th World Research Congress of the European Association for Palliative Care. 2014 June. Lleida, Spain.

Managing comorbidities in oncology: A multisite randomized controlled trial of continuing vs discontinuing status in the setting of life-limiting illness. Abernethy AP. American Society of Clinical Oncology. 2014 May. Chicago, IL., United States.




PCRC Proprietary

PCRC Projects: Upcoming

Investigator Initiated Project [pending IRB approval]


- Jim Cleary MD, University of Wisconsin
 - Patient-related Barriers to Pain Management: Revisiting the Pain Barriers Questionnaire



PCRC Proprietary Information

Other PCRC Grant Collaboration

Title	PI (Institution)	Type	Funding
Evaluation of implementation of point of care palliative care quality measures	Sydney Dy, MD, MPH (Johns Hopkins)	Developmental; feasibility testing	NCI (R21)




PCRC Proprietary Information

PCRC 2014 Pilot Grant Awardees [U24 Yr 2] N=4

Funding Period: July 1, 2014 – June 30, 2015


PI	Institution	Title	Amt	Type	Population
Nrupen Bhavsar, PhD	Duke University	Implications of Increased Statin Use Among Patients w/ Limited Prognosis	\$15K	Survey + Decision Model	statin registry
JJ Furuno, PhD	Oregon State	Anticoagulation Therapy on Discharge to Hospice Care	\$15K	Retrospective Cohort + In-depth Interviews	patients discharged directly to hospice care; patients / discharging physician dyads
Ann Long, MD, MS	University of Washington	Experiences of Family Members of Patients Admitted to the ICU From the Acute Care Floor	\$25K	Semi-structured Interviews	surrogate decision-makers for patients admitted to the acute care floor
Virginia Sun, RN, PhD	City of Hope	Feasibility of an Interdisciplinary Palliative Care Planning Intervention in Pancreatic Cancer	\$25K	Feasibility Pilot Planning Intervention	advanced/metastatic pancreatic cancer

 PCRC Proprietary Information

PCRC 2015 Pilot Grant Awardees [U24 Yr 3] N=6

Round 1: two (2) awardees
Funding Period: Aug 1, 2015 – July 31, 2016


PI	Institution	Title	Amt	Type	Population
Thomas Leblanc, MD	Duke University	Identifying Palliative Care Needs Through Patient-Reported Distress in Myelodysplastic Syndromes	\$15K	Retrospective Cohort Study	Myelodysplastic Syndromes
Ryan Nipp, MD	Dana Farber / Harvard Cancer Center	The Impact of Age on Early Palliative Care for Patients with Advanced Lung and Non-Colorectal Gastrointestinal Malignancies	\$15K	Randomized control trial (secondary analysis)	Advanced Lung and Non- Colorectal Gastrointestinal Malignancies

 PCRC Proprietary Information

PCRC 2015 Pilot Grant Awardees [U24 Yr 3] N=6

Round 2: four (4) awardees
Funding Period: Feb 17, 2016 – February 16, 2017


PI	Institution	Title	Amt	Type	Population
Krista Harrison, PhD	UCSF	Advance care planning in hospice organizations: a qualitative pilot study	\$25K	Qualitative interviews	Hospice clinicians, administrators, and executive leaders
Arif Kamal, MD, MHS	Duke University	Testing PCforMe: a Web-Based Tool to Prepare Patients for Palliative Care	\$25K	Usability testing; pilot trial	Outpatient palliative care
Ramona Rhodes, MD, MPH, MSCS	UTSW	Pilot Testing of a Culturally Sensitive End-of-Life Care Intervention for African American Advanced Cancer Patients and their Caregivers	\$25K	Pilot RCT	African American advanced cancer patients and their caregivers
Nick Wysham, MD	Duke University	Interdisciplinary Models for Delivering High-Quality Palliative Care in the ICU	\$15K	Retrospective case-control + modified Delphi process	ICU patients and critical care clinicians

 PCRC Proprietary Information

PCRC 2016 Pilot Grant Awardees [U24 Yr 4] N=7

Funding Period: October 15, 2016 – October 14, 2017

PI	Institution	Title	Amt	Type	Population
Charlotta Lindvall MD PhD	DFCI	Using Natural Language Processing to Extract Data from Medical Notes to Quantify Quality of Life and Improve Mortality Prediction in Patients with Heart Failure	\$15K	cohort; retrospective	Heart Failure
Lori Muffly MD MS	Stanford	Pilot Randomized Clinical Study Comparing the Effectiveness of the Stanford Letter to the Traditional Advance Directive in Bone Marrow Transplant Recipients	\$19K	intervention	Blood and bone marrow transplant recipients
Nina Wagner-Johnston MD	Johns Hopkins	Perspectives on the adolescent, young adult, and adult experience as donors for their parent undergoing haploidentical bone marrow transplants	\$15K	Qualitative	Bone marrow transplant recipients

 PCRC Proprietary Information

PCRC 2016 Pilot Grant Awardees [U24 Yr 4] N=7

Funding Period: October 15, 2016 – October 14, 2017


PI	Institution	Title	Amt	Type	Population
Monica Krishnan MD	Harvard	Refinement of a Prognostic Model for Patients with Metastatic Cancer	\$25K	retrospective	Palliative radiation
Tatianna Sadak PhD PMHNP ARNP	Univ of Washington	Experiences and Outcomes of Dementia Caregivers: Developing Dementia Palliative Care Approach	\$25K	Qualitative	Dementia Caregivers
Crystal Brown MD	Univ of Washington	Understanding the perspectives of palliative care and advance care planning in patients with pulmonary arterial hypertension and the physicians caring for them	\$18K	Qualitative	Pulmonary arterial hypertension
Pam Stephenson PhD RN AOCNS	Kent State	Determining the Feasibility of the State of Spirituality Scale	\$18K	Qualitative	Palliative and hospice care providers

PCRC 2017 Pilot Grant Program [U24 Yr 5]

HEADS UP:

N = 9 Pilot awards to be funded in 2017

- FOA announcement ~December 2016
- Applications due: ~February 2017
- Funding Period: July 2017 – June 2018

 PCRC Proprietary Information