



Palliative Care Research Cooperative Group (PCRC)

CHARTER

VERSION 2.0

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PALLIATIVE CARE RESEARCH COOPERATIVE

CHARTER

ARTICLE I: OVERVIEW

The Palliative Care Research Cooperative Group (PCRC) was established in 2010 to advance the field of palliative care by facilitating and conducting collaborative, rigorous, interdisciplinary, multi-site, research studies. Designed to improve the care and outcomes of patients with advanced and/or life-limiting illnesses, PCRC research focuses on (1) symptoms, functional status, and quality of life of the palliative care population, including patients, family members, caregivers, and providers of care; and, (2) health services delivery models and healthcare economics, provided the studies are designed to generate new knowledge that can be used to improve care and outcomes of this population.

This Charter outlines basic elements of the PCRC structure and function. Its focus is on establishing clear organizational structure and processes to ensure efficiency of operation and ability to meet research objectives. Its purposes are to (1) serve as a reference document that lends clarity, simplicity, and definition to a complex organization, (2) articulate critical features of the PCRC as an enduring organization, and (3) govern key areas of decision-making.

ARTICLE II: GUIDING PRINCIPLES

Section 1: Vision

Excellent palliative care at the bedside is contingent on best evidence and a scientific underpinning for what we do, so that 1) no patient dies alone, in pain, or without dignity; 2) palliative care responds effectively to suffering at all points in the life/illness trajectory; and 3) palliative care enhances living.

Section 2: Mission

The mission of the PCRC is to develop scientifically based methods that lead to meaningful evidence for improving the quality of life of patients with advanced and/or potentially life-limiting illnesses, and addressing the needs of family members, other loved ones and other providers of care. To achieve this mission, the PCRC has a three-pronged strategy focused on: (1) developing palliative care research capacity nationally; (2) supporting the conduct, analysis, and dissemination of high-quality research in palliative care; and, (3) training and mentoring next / future clinician scientists committed to advancing palliative care research.

Section 3: Goals

Consistent with this mission and strategy, the goals of the PCRC are to:

- Develop and implement collaborative, multi-site, interdisciplinary, rigorously-designed and -conducted, research studies that seek to improve the care and outcomes of patients with advanced and/or potentially life-limiting illness and their caregivers (family members, loved ones, and other providers of care).
- Generate research evidence, and to build an evidence base, in palliative care through systematic design, development, facilitation, support, conduct, and dissemination of studies that will exert stepwise meaningful impact on patient care and/or healthcare policy.
- Promote research capacity in the field of palliative care through cultivating skills, resources, and expertise at the levels of investigator, organization, and national healthcare system.
- Foster the development of a coherent research agenda explicitly designed to yield answers to clinically meaningful questions arising in the practice of palliative care and end-of-life care (PCEOL), and to promote a culture of inquiry in palliative care.
- Broadly disseminate results of research studies so as to effect change in clinical practice and healthcare policy, resulting in improvements in patient care and patient-centered outcomes.

Section 4: Values

Our core values include the following:

- Patient and family centeredness – the PCRC is focused on improving care for patients, families and other caregivers.
- Appreciative enquiry – envisioning the future we are trying to achieve and then developing a roadmap to achieve it.
- Collaboration and balance – incorporating multiple perspectives and differing viewpoints to gain a fuller understanding before developing a plan.
- Action – making sure to develop a plan and accomplish it, after gathering diverse input.
- Efficiency, flexibility and learning -- providing a lean, scalable and replicable infrastructure that is efficient in terms of day-to-day operations, developing new science, and responding to identified gaps and areas for improvement.
- Self confidence and humility – recognizing that we do not always have the answer, we must seek advice and learn; when following our guiding mission, vision, values and principles, we are poised to make good decisions in the service of contributing to the evidence that results in excellent care of people affected by serious illness.

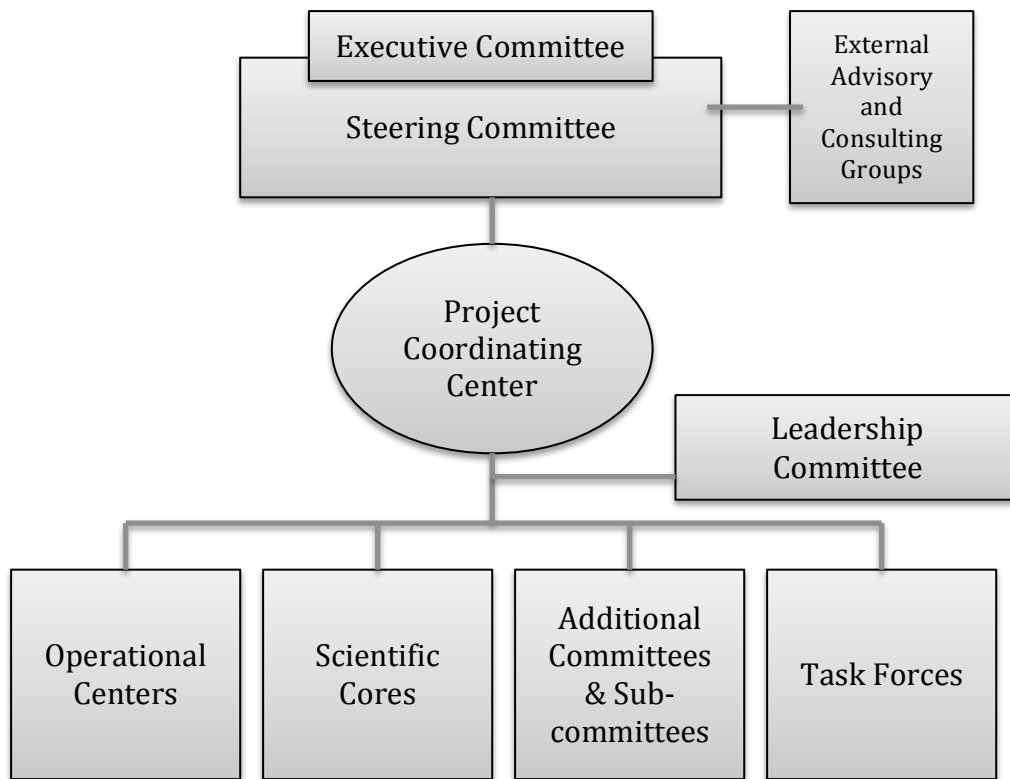
ARTICLE III: LEADERSHIP AND STRUCTURE

Section 1: Overview

The leadership philosophy of the PCRC is based upon our compelling vision, significant purpose (a.k.a., mission), and core values that guide actions and decision-making. These are reinforced by the daily actions of PCRC leaders. The PCRC leadership structure is specifically designed as a matrix to enhance integration across the PCRC, its components

and functions. We intentionally engage diverse stakeholders, internal and external to PCRC, across disciplines, representing different constituencies including community and academic palliative care and hospice, nursing, medicine, social work, spiritual care, clinicians, researchers, patients/families and patient advocates. We have a clear accountability structure to ensure that day-to-day operations are efficient, milestones and deliverables are met, and conflicts are managed thoughtfully and quickly.

The below diagram depicts the PCRC Leadership and Structure model.



Each Committee, Sub-committee, Center, Core, or Task Force and other research resources has a Terms of Reference document that is created and ratified by the Steering Committee. At a minimum, the Terms of Reference document summarizes the purpose, goals, duties, membership, decision-making process, voting, meeting frequency, communication plans, and process for dispute resolution for the PCRC structural units. The Terms of Reference documents are reviewed, updated and approved by the Steering Committee at least every other year.

Participation in a Committee, Sub-committee, Center, Core, or Task Force meets the committee participation obligation criterion for PCRC full membership.

Section 2: Leadership

Executive Committee: The Executive Committee is comprised of the PCRC Chair and Vice Chair, or Co-Chairs. With Steering Committee approval, the Executive Committee leadership

can add a third member, if appropriate, to enhance PCRC functioning or facilitate leadership succession. The purpose of the Executive Leadership is to provide primary oversight of all day-to-day operations of the PCRC, and interact with the Steering Committee with respect to overall governance of the PCRC research resource. Details of the constitution and operations of the Executive Committee are spelled out in its Terms of Reference.

Steering Committee: The Executive Leadership works in concert with a Steering Committee, providing overall governance of the PCRC research resource including overall scientific oversight. The Steering Committee functions as the PCRC's Board of Directors. It sets the strategic direction of the PCRC, ensures that the organization is aligned with its vision and mission, and provides fiduciary oversight. It is responsible for high-level decisions that determine structure and function of the PCRC, including initiation, ratification and oversight of Terms of Reference for all PCRC organizational units. This Charter and major PCRC policies and procedures are ultimately the Steering Committee's responsibility. A core purpose of this committee is to oversee the ethical conduct of research under PCRC auspices, including dissemination of results. Details of the constitution and operations of the Steering Committee are spelled out in its Terms of Reference.

Leadership Committee: The Leadership Committee will be comprised of the leaders of the PCRC Cores and Centers. The Leadership Committee provides cross-pollination and cross-cutting leadership between these important functional units of the PCRC. Other leaders [e.g.: sub-committees, task forces] may be added / amended at the discretion of the Executive Committee. Details of the constitution and operations of the Leadership Committee are described in its Terms of Reference.

Section 3: Centers and Cores

The major operational and scientific functions of the PCRC are organized into functional units called Centers and Cores. The Centers represent key infrastructural resources designed to integrally support every PCRC study, and thus to build research capacity. The Cores will differentially support investigators, studies, sites, and the PCRC overall—depending on the nature and needs of each. Cores will be responsible for methodology consultation and development in areas that are critical to strengthening of the research enterprise.

The Executive Committee will propose new Centers and Cores to the Steering Committee. The Steering Committee will vote on and approve these proposals, in accordance with its Terms of Reference. A similar process will be followed to dissolve Centers or Cores as needed.

One Center designated in the Charter is the **Project Coordinating Center**. The Project Coordinating Center is responsible for supporting PCRC investigators and sites in logistical and technical aspects of study development, management, and conduct, including trans-PCRC communication. The Project Coordinating Center supports all PCRC functional units including committees, cores, and other research resources; some PCRC functional units (e.g., other Centers) may have its own operational staff and functions that will interface with the Project Coordinating Center in order to ensure cohesive functioning of the PCRC.

Specific duties of the Project Coordinating Center and its management structure are outlined in its Terms of Reference.

Section 4: Committees, Sub-committees, and Task Forces

The PCRC has a lean and flexible structure for enacting committees that conduct critical functions; examples include the Scientific Review and Membership Committees. Committee will have its own Terms of Reference, delineating objectives, processes, and scope of activity. New Committees are proposed to the Steering Committee by the Executive Committee, and ratified by the Steering Committee.

As activities and work increases, a Committee can convene Sub-committees and Task forces to help the committee conduct its work. A Sub-committee is intended to be an enduring functional unit that has a more focused set of objectives than the parent Committee, ultimately informing the work of the parent Committee. A Task Force has a specific functional goal or task, works together to accomplish the task, and then automatically dissolves at the end of its pre-defined term and/or when the task is completed.

Committee Chairs or the Executive Committee will propose Sub-committees and Task Forces to the Steering Committee. The overarching Committee will maintain ultimate responsibility for decisions made and work completed by Sub-committees and Task Forces. Sub-committees and Task Forces will be initiated through a change, if required, in the overarching committee's Terms of Reference, and ratified by the Steering Committee.

As needed, the Executive Committee can propose to the Steering Committee to dissolve Committees, Sub-committees and Task Forces.

Section 5: Other Scientific Resources

The PCRC will expand its resources as needed in order to assist in accomplishing the organization's missions and goals. For example, an External Advisory Board and Scientific Consulting Panel may be added. These scientific resources are proposed by the Executive Committee, Terms of Reference formed, and then approved by the Steering Committee. Similar processes for dissolution are followed.

ARTICLE IV: MEMBERSHIP

Section 1: Overview

Membership in the PCRC is open to healthcare providers and researchers of any discipline who: (a) focus on the care of persons with advanced and/or life-limiting illness and of their family members, caregivers, and other loved ones, (b) share a dedication to improving care and outcomes for this population through rigorous research, and (c) actively participate in advancing the science and developing the evidence base to support palliative care.

PCRC Membership categories include:

- **Charter Member:** The PCRC was founded by a diverse and interdisciplinary core group of Charter Members who convened in January 2010 in Denver, Colorado, to explore the possibility of forming a national cooperative group focused on palliative care research. Investigators representing sites participating in the first PCRC trial are also Charter Members.
- **Institutional Member:** An Institutional Member is an organization that supports PCRC participation by any individual PCRC member OR that contributes to the research mission of the PCRC through participation as a site in PCRC studies.
- **Individual Member:** An Individual Member is a person who fits the membership eligibility criteria to be a Full, Junior Investigator, or Affiliate Member set forth in the Membership Guidelines.

Details of membership including levels of membership, rights and responsibilities, transitions in membership, review, and dispute resolution will be outlined in Membership Guidelines, which are approved by the Steering Committee and carried out by the Membership Committee.

Section 2: Voting

While institutions can have more than one person who is a PCRC Member (whether Full, Junior Investigator, or Affiliate) there can only be one vote per institution put forward on any issue requiring a vote. The vote is submitted by the Site Principal Investigator or his/her designee. Because voting is tied to institutional membership, a Member who is not located at a PCRC member institution may not vote. As it relates to members and membership, details of voting are summarized in the Membership Guidelines. Within the context of committee or other functional units, voting will occur by Individual Member as described within the unit's Terms of Reference.

ARTICLE V: SCIENTIFIC AND BUSINESS MEETINGS

In person scientific meetings of the PCRC will occur twice a year. Scientific meetings will: allow for presentation of research results; include in-depth discussion of protocols under development or clinical trials in progress; provide a forum for fielding ideas for, and canvassing interest in, new collaborative research studies; and, create opportunities for training and mentoring of junior investigators and new research sites. Additional meetings can be proposed by the PCRC Executive Committee or Steering Committee. A general Business Meeting will be held in association with each of the face-to-face scientific meetings and will be open to only Full and Junior Investigator Members.

For general business meetings, the goal is to have 10% of all PCRC individual members present to contribute in a meaningful discussion of any items that will be brought forth for a vote. Decisions made in the general business meeting will require a two-thirds majority vote by institution made in person or electronic vote within a preset timeframe to be published before the meeting. In the event that a site PI or designee is unable to vote in person at a Business meeting, that Site PI/designee may authorize a proxy to vote on the institution's

behalf; the intent of a proxy is to ensure that that site's intentions are recorded and not lost because of lack of physical presence at the business meeting.

Only those decisions that the Steering Committee deems affect PCRC function and PCRC members in a broad way will be voted upon in Business Meetings; all other business decisions will be handled in the Steering Committee or other PCRC functional unit as stipulated in their Terms of Reference.

ARTICLE VI: RATIFICATION OF THE CHARTER AND AMENDMENTS

Ratification of this Charter and its amendments is by vote of the PCRC membership during the PCRC business meeting.

Amendments to the Charter can be initiated by members of the Steering Committee, or by petition of at least three Members of any PCRC Committee, Center or Core. Amendments must be approved by a two-thirds majority of the Steering Committee, and then presented to the entire PCRC Membership for discussion at the next general business meeting. Proposed amendments must be communicated in writing (paper or electronic format) to all members of the PCRC, and must be ratified, following discussion, by a two-thirds majority of the voting membership present at the next PCRC business meeting.