Development of the NHPCO Research Agenda

National Hospice and Palliative Care Organization

Abstract
In April 2003, a group of 35 leading researchers in hospice and palliative care participated in a research conclave to promote collaboration in our emerging field through a review of the current research priorities. The conclave was organized to pursue the following objectives: 1) to improve communication among existing centers of research excellence, 2) to explore opportunities for creating practice-based research networks, and 3) to identify critical areas of need for investigation. The conclave highlighted numerous areas of unexplored research and identified important issues in the field. Based on the input from participants in the conclave, and from other constituencies, NHPCO has developed a research agenda with the goal of framing important research objectives and questions that, if answered, would make an important contribution to our field. This report summarizes key issues identified by participants in the research conclave and presents the NHPCO research agenda, which is designed to further our goal of improving access to quality hospice and palliative care for patients who are at the end of life.

NHPCO Research Conclave
On April 13, 2003, the National Hospice and Palliative Care Organization (NHPCO) convened a research conclave and invited a group of leading researchers in hospice and palliative care in order to afford an opportunity to share their expertise, knowledge, and wisdom. The research conclave was held in conjunction with NHPCO’s 4th Joint Clinical Conference on Hospice and Palliative Care in Denver, Colorado. Thirty leading researchers, educators and clinicians working in hospice and palliative care and five key NHPCO staff members participated in the meeting. The purpose of the meeting was to promote collaboration in our emerging field through review of the current research priorities with the intent of meeting three key objectives. The first objective was to improve communication among existing centers of research excellence. Learning what other researchers are addressing will help to identify gaps and opportunities for collaboration. The second objective was to explore opportunities for creating practice-based research networks. There are many researchers in our field who...
could help advance the science of end-of-life care but who need access to study populations in settings where research can be done. The third objective was to identify research priorities for which NHPCO could advocate and pursue funding. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration, and with private foundations and individuals interested in supporting research to advance the field.

The one-day meeting was structured to address 6 key topics related to research in palliative care. For each topic, a 15-minute presentation was given by an expert in the field, followed by a 15-minute response by three conclave participants, who also had expertise in the topic area. Following each 30-minute presentation/response, the discussion was opened to all participants of the research conclave. Table 1 presents an overview of the key agenda items with the presenter and respondents for each topic. Prior to the meeting, participants in the conclave were provided with a briefing book that described current research activities of the presenters and respondents. By the conclusion of the meeting the goal was to have identified the critical issues and to have deliberated the important research questions that, if answered, would make important contributions to our field. The following is a summation and synthesis of the thoughts and ideas expressed by the conclave participants.

### Research Issues in the Area of Hospice and Palliative Care Identified by Participants

#### Access to Hospice and Palliative Care

**General Issues.** Several issues were identified with respect to access to hospice and palliative care. Attitudes and behaviors of treating clinical staff were identified as important challenges for improving access to hospice and palliative care. Specifically, a practitioner’s unwillingness or difficulty with truth-telling, reluctance to relinquish relationships with patients, and inexactness of prognostication were noted to be contributing factors. It was noted that factors in addition to clinical judgment contribute to the difficulty in determining prognosis. For example, physicians may not perceive the patient as dying until all treatment options have been exhausted; and it was suggested that the longer the physician has a relationship with the patient, the more likely the prognosis will be over-estimated.

The patient and family’s fear of acknowledging the inevitability of dying from illness, and the perception that hospice admission means imminent death were identified as important access issues. It was noted that hospice and palliative care become relevant when there is a new understanding about disease progression and treatment limitations. This is a time of increased patient/family vulnerability and a need that can be lessened by providing a sense of continuity. It was suggested that continuity might be achieved by maintaining the ongoing care structure with the patient’s primary clinicians in addition to co-management by the palliative care team, and then transition to solely

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**Table 1**

<table>
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<th>Key Workshop Agenda Items, Speakers, and Respondents</th>
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<td>How can the payment system be risk adjusted in order to allow hospice patients to receive more appropriate disease-modifying therapies?</td>
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| **Presenter:** Susan Miller  
**Respondents:** Fred Meyers, John Finn, Susan Block |
| How can hospice and palliative care programs improve their competence to increase outreach to diverse populations including people of color, children, and at-risk populations? |
| **Presenter:** Gwendolyn London  
**Respondents:** Joanne Hilden, Steven Passik, Karen Steinhauser |
| How to improve length of service in hospice: A critical examination |
| **Presenter:** True Ryndes  
**Respondents:** Perry Fine, Barry Kinzbrunner, Cameron Muir |
| Development of practice based research networks in the field of hospice and palliative care |
| **Presenter:** Jean Kutner  
**Respondents:** Elizabeth Pitorak, Patti Theilemann, Lenora Johnson, Sean Morrison |
| What are the most critical elements to include in measuring the performance of hospice and palliative care providers? |
| **Presenter:** David Casarett  
**Respondents:** Stephen Connor, Joanne Lynn, Kathy Egan |
| Where are the gaps in our evidence base for improving symptom management?  
Nutritional research as an example |
| **Presenter:** Neil MacDonald  
**Respondents:** Diana Wilke, William Breitbart, Bob Milch |
palliative care if/when aggressive treatment is discontinued.

The participants recognized that there was wide variation in community norms and hospice care across local markets. Also noted were possible conceptual approaches to increasing access including a health promotion model, a public health model, and a social marketing model. The potentially most salable point in terms of “value added” included the attention given by hospice to the psychosocial, spiritual, and emotional dimensions of care. However, it was noted that no clearly delineated conceptual framework currently exists for measuring experiences and outcomes in these areas.

Regulation/Reimbursement. Several barriers resulting from the current regulatory and reimbursement system were noted. In the current environment, patients are forced to choose between disease-modifying treatment (“curative”) and hospice care. Significant changes in treatment practices for palliation in the past 5 years were noted (i.e., the multitude of new supportive and better tolerated therapies that can be appropriately used for patients with advanced disease). However, access to hospice care is frequently denied to patients who are receiving expensive treatments or therapies that are characterized as aggressive. In addition, access to hospice is often denied to patients enrolled in Phase I clinical trials.

It was also noted that skilled care patients in nursing homes have difficulty accessing hospice care. Physician incentive to continue treatment was identified as another barrier resulting from the current system (e.g., monetary, desire to continue to manage patient, desire to cure). Moreover, payment for palliative care may be denied to one physician if management is concurrent with another physician practicing in the same specialty.

Much work lies ahead in modifying the reimbursement system. However, several considerations towards this end were proffered. These considerations included cost neutrality, incentives for early referral/timely access to palliative care, minimization of inappropriate utilization, reduction in paperwork burden, and development of a reimbursement system that is fair and workable for all types of hospices (i.e., large/small, rural/urban).

Special Populations. Participants in the research conclave noted that the state of knowledge regarding use of hospice by minority populations is based on a very small number of studies, many of which were of poor methodological quality. It was noted that patients and their families may mistrust the healthcare system and view palliative care as “second rate care” or believe that patients forfeit their options when accessing palliative care. The lack of acceptance of the need for palliative care by parents of terminally ill children and their physicians was noted because the desire to treat aggressively is especially strong in the case of children. The group emphasized the importance of treating race, ethnicity, and culture as separate influences when designing and interpreting research.

It was recognized that it is difficult to create an infrastructure for conducting research in rural areas. Potential solutions proffered were to connect physicians who graduated from the same medical school into an informal practice-based research network; to use existing clinical trial networks; and to use telemedicine for particular areas of inquiry, such as end-of-life mental health interventions.

Clinical Research

Quality Management. The quality of care provided by hospice and palliative care providers was identified as a key area of focus in research. Participants noted that continuity of care is frequently neglected as a quality indicator in research, and that this indicator is particularly important at the time of enrollment and disenrollment/revocation, during changes in care setting, and during the 24 hours preceding death. Communication with other providers was noted as a particularly important element in ensuring continuity of care. It was proposed that access to care should be used as a quality indicator measured on the community/population level. Quality indicators used for accountability should have significance for providers, relevance for consumers, and utility for payers. Documented errors and consumer complaints should be used to inform the quality improvement process. Ipsitive measures (i.e., defined from the individual’s perspective) were considered to be appropriate when studying many areas of hospice palliative care. That is,
the quality of care delivery outcomes should be examined in terms of the patient and families’ expectations and experiences rather than solely in terms of quality defined by hospice and palliative care professionals.

The need to measure all aspects of quality of care (emotional, psychosocial, life closure, spiritual, etc.) was emphasized. Outcome measures should reflect the totality of care.

In designing accountability measures, it was agreed that there is a need to consider the similarities and differences between home care programs that provide palliative care and those that do not (for example, some standards, such as functional decline and weight loss, cannot be applied in the same way). In cases where multiple providers are delivering care to the patient, the effects/outcomes of other care providers should be differentiated from those of hospice/palliative care. It was acknowledged that variable performance and admission criteria among hospice providers continue to exist.

**Symptom Management.** Participants in the research conclave acknowledged that there is huge disproportion in the amount of funding, and subsequent research, dedicated to drug trials for disease management (i.e., tumor size reduction) compared with symptom management.

It was noted that there is a lack of standardization regarding symptom measurement, both in relation to how research tools are selected for use and how they are implemented. Regarding the evaluation of pain, it was noted that there is a need to ensure that the study population is being accurately identified in evaluating efficacy of interventions. For example, patients with nociceptive pain comprise a different population than patients with neuropathic pain or patients with a combination of both types of pain. It was suggested that to improve the efficiency of data collection, the use of the pain model for research in other areas of symptom management should be considered, especially in use of electronic data systems and patient autonomy/participation.

It was noted that hospice and palliative care patients do not experience symptoms in isolation, but have a constellation of concurrent symptoms. Consequently, interventions aimed at one symptom are likely to affect others. This fact must be taken into consideration when designing studies that focus on mechanisms of symptom expression and effectiveness of symptom management. To this point, it was noted that many symptom management tools are one-dimensional. However, in order to capture the complete picture of symptom experience, multidimensional measures should be used in symptom research.

**Uniqueness of Population**

The difficulty of doing research with vulnerable populations and people whose circumstances are changing very rapidly was acknowledged. Many hospice and palliative care patients have or develop impaired ability to communicate and/or cognitive deficits as a result of disease progression. Consequently, there is a need to find ways to include this population in research. One solution suggested was to explore, develop, and improve the use of proxy measures.

Another issue raised was the impact of “life conditions” that are often concomitant with progressive, life-limiting diseases (e.g., boredom, living in a debilitated state, humiliation, lack of meaning, burden of illness). The implications of these life conditions for end-of-life care were proposed as an area for investigation.

**Caregivers**

The need to investigate the family caregiver experience was recognized, not only in terms of providing support for the caregiver, but also in terms of focusing on the experience in its entirety from the perspective of the caregiver. Several questions regarding research for caregivers of hospice or palliative care patients were posed. First, what is the experience of the family caregiver in caring for a dying individual? What is the caregiver’s experience of “relationship closure” and what are its consequences? How do pre-death interventions affect survivors post-death? What is the impact of hospice/palliative care on bereavement outcomes? What are the economic/labor force issues that are specific to family caregivers caring for patients at the end of life?

**Provision of Care**

Several questions regarding provision of hospice and palliative care were identified. For example, are there differences between hospice/palliative care program staff’s perception and understanding of communication of service
goals and delivery and consumer perception? What organizational systems and structures are needed to create and maintain hospice/palliative care staff that can consistently deliver quality care? What are the effects of the nature of the work, the effects of patient/family chaos, constantly changing interpersonal relationships, and cumulative grief on staff? How does an effective interdisciplinary team operate? What are its core functions? What are the outcomes are of an effective team versus an ineffective one? How can teams be supported in optimizing their function so they can optimize the care they deliver?

Approaches to Conducting Research

It was noted that current funding, particularly through NIH, takes a disease specific approach. In order to take advantage of existing funding sources, hospice/palliative care researchers should do the same. In that vein, it was proposed that the study population of choice should be the cancer population as this is the largest single patient group and because of the abundance of associated organizations available for partnering (e.g., ACS, ASCO, NCI). AIDS patients were also identified as a special population that should receive research attention. The need to have a well-defined, focused research question and patient population for each study was emphasized in order to enhance the appeal of palliative care research to funders. It was suggested that, initially, a homogenous population should be studied, such as patients with glioblastoma or pancreatic cancer, because, for this population, goals of care and informed consent can be delineated more easily, and well-defined measurable outcomes can be studied. From this patient population, research can be expanded to a more broad-based group of patients with more ambiguous disease trajectories and treatment options.

Participants at the research conclave discussed the importance of collaboration with researchers outside the field of end-of-life care. Developing relationships with basic researchers was identified as a potential benefit to the field of hospice/palliative care research, because these researchers have a “flow-through” to clinical research that is currently absent in hospice/palliative research. Recognition was given to the challenge of partnering with academic or university teams in pursuing research because of differences in their culture and the hospice/palliative clinical culture. Therefore, the need to be sensitive to both in embarking on research projects was emphasized.

Several issues relevant to the process of data collection and clinical trial management were discussed. It was suggested that sites not solely be viewed as a source of data, but that they be included in research analysis and dissemination. In addition, it was noted that the cost and burden of data collection must be considered, particularly for symptom research. For example, asking the same question in the same way repeatedly about the same symptom or a number of symptoms may be part of a research protocol, but may be viewed as redundant and difficult for the patient by the investigator, who may be tempted to substitute his or her own judgment for the patient’s response. It was also agreed that there is a need for database development for patient level data at the provider and organization level that can be used for research. Specifically, there is a need to determine what data should be collected; how it will be collected; and how it can be stored. It was noted that the entire process needs to be standardized so that data can be aggregated beyond provider and organization level.

Some conclave participants asserted the need to start exploring ways of being quicker, reflexive, and more creative in achieving results than is permitted by existing mechanisms, such as clinical trials. It was suggested that the use of quality improvement initiatives as sources of data should be considered, although it was recognized that data from quality improvement initiatives are less robust than data from clinical trials.

It was also noted that federal funding priorities are likely to change as the elderly population continues to grow and Medicare expenditures in last year of life increase. The rise in end-of-life care expenditures is likely to pave the way for increased use of hospice and palliative care, intensifying the need for research in this area. Finally, it was acknowledged that, while the conclave participants might disagree on many other issues, there was total agreement on the need for research in the area of palliative care. It was noted that this unanimity offers a unique opportunity for lobbying, providing information to the public, and social marketing around the research issues.
Participant Evaluation of the Research Conclave

Participants were invited to complete a survey during the conclave to ensure that all recommendations for research topics were included. Twenty-one of the 30 participants returned an evaluation form at the end of the meeting. Results of this survey indicated that 71% of the respondents felt that the meeting provided opportunity for constructive communication, and almost half felt they had an opportunity for exploration of potential collaboration. One-third of the respondents felt that the meeting effectively identified priorities and research questions for future research in end-of-life care, and 62% felt that their own objectives for attendance were met and that they gained information relevant to their research activities. More than half (57%) felt that gaps in current research in end-of-life care were identified, and 81% felt that the research areas selected for discussion were important and meaningful to the field of end-of-life care. While a variety of positions regarding research priorities and courses of action were articulated, there was general agreement that there is much to do.

Need for Research on End-of-Life Care

Changes to our health care system must be based on data and demonstrations that allow one to test in advance the impact of changes that are hoped to ultimately improve access to hospice and palliative care. This conclave provided important input for the NHPCO Research Committee to develop a clear research advocacy agenda. The following official NHPCO research agenda, created by the Research Committee, was approved by the NHPCO Board June 19, 2004. It was developed based on information gleaned from the research conclave and from input from key leaders in the hospice community. Three key areas of focus were identified: improving access to hospice and palliative care, improving the quality of hospice and palliative care, and improving the conduct of research in hospice and palliative care. For each of these areas, several key objectives were identified and these objectives are considered to be the emphasis of the research agenda. For each objective, examples of research questions are provided to guide research efforts, though the examples should not be considered an exhaustive listing of pertinent research questions.

The NHPCO Research Agenda

Improving Access to Hospice and Palliative Care

Eligibility and Election

Research Objective: To identify factors that influence patients and family decision-making related to election of hospice care.

- What are the characteristics of patients who decline hospice care?
- What components of the patient’s illness experience influence the acceptance of hospice care?
- What factors influence the timing of admission to hospice?
- What is the effect of a continuity of care model (maintaining initial care structure with added palliative team co-management) on acceptance of hospice care?

Research Objective: To identify optimal methods for determining eligibility for hospice.

- What is the utility of non-clinical prognostication criteria compared to clinical prognostication criteria?
- What proportion of deaths could benefit from hospice and palliative care?
- What factors, in addition to clinical judgment, influence accuracy of determining prognosis?

Research Objective: To identify optimal models of end-of-life care based on disease and/or functional trajectories.

- What are the optimal criteria for initiation of palliative care for patients in the critical care setting?
- What functional status criteria for patients with non-cancer diagnoses will result in appropriate timely access to hospice care?
- What are the patient and healthcare system effects of over-treatment and futile care?
- What model of care best meets the end-of-life care needs of individuals with chronic progressive life-limiting illnesses (e.g., frailty/dementia, advanced CHF, multi-system failure)?
Regulatory/Reimbursement Barriers
Research Objective: To identify effective and efficient modifications of the current reimbursement system that will result in increased access to hospice and palliative care.

- What is the effect of a system of concurrent curative/palliative care on access to service, quality of care, and cost of care?
- What is the effect of the existing hospice eligibility structure on timeliness of hospice referral and length of service?
- What are the characteristics of a model outlier payment system for hospice providers?
- What is the effect of an outlier payment system for hospice providers on the burden associated with the provision of high cost palliative therapies?

Needs of Special Populations
Research Objective: To identify unmet end-of-life care needs of racial, ethnic and cultural minority populations and implications for modification and reorganization of delivery of hospice and palliative care services.

- What do various ethnic and cultural populations value and want from health care when faced with life-limiting illness?
- What factors explain the variation in minority use of hospice care?
- What are the racial and cultural differences in the various palliative care domains, including symptom distress, psychological/emotional distress, social-familial concerns, spiritual distress, access to care, continuity of care, and bereavement?

Research Objective: To identify unmet end-of-life care needs of vulnerable populations (children, long-term care residents, prison inmates, rural residents) and implications for modification and reorganization of delivery of hospice and palliative care services.

- How can hospice and palliative care programs work with the healthcare system to increase access to service for children?
- What modifications to delivery of hospice services will effectively address the identified unmet needs of long-term care residents?

Research Objective: To identify unmet end-of-life care needs of individuals with AIDS.

- What is the location of death for individuals with AIDS?
- What is the quality of death for individuals with AIDS?

Community Engagement and Social Marketing
Research Objective: To identify key concepts and social, cultural, and behavioral factors that should inform social marketing and community engagement strategies.

- Who should the target audiences/markets be for social marketing interventions?
- What are the focus and components of the social marketing message for specific audiences?
- What insights can be gathered from minority community social, political, religious, and service organizations for reframing hospice and palliative care concepts to make them more acceptable and culturally sensitive?
- What are the optimal methods of message delivery for specific audiences?

Research Objective: To identify effective approaches for community outreach, education, and engagement strategies which improve access to care.

- What is the effect of community caregiver education on provider hospice referral patterns?

Improving the Quality of Hospice and Palliative Care

Quality Measurement
Research Objective: To identify methods for evaluation of quality of end-of-life care that have utility for all healthcare settings.

- What are the quality indicators at the structure, process, and end-result outcome levels for which validated measures exist?
- What are the areas of end-of-life care for which quality of care measures are needed?
- What are the outcomes of discontinuity of care for patients and families?
- What are the structures and processes of care that facilitate continuity across settings?
Research Objective: To explore the relationship between evidence-based practice and quality end-of-life care.

- What are the methods for translating evidence into practice that have utility in hospice and palliative care?
- What is the effect of evidence-based practice on patient outcomes?

Clinical Practice
Research Objective: To identify effective and feasible approaches to patient symptom assessment and management.

- What is the effect on patient outcomes of the implementation of a standardized set of symptom assessment tools by multiple hospice and palliative care providers?
- What is the safety, efficacy, and cost-effectiveness of single fraction radiation therapy for hospice and palliative care patients?
- What are the multidimensional factors that affect assessment of a given symptom?
- What is the effect on patient outcomes of screening for various types of distress (e.g., symptom burden, psychological, spiritual) and early implementation of interventions?
- What is the relationship of the non-physical dimensions of symptom expression to symptom management?

Research Objective: To identify effective approaches to ensuring and enhancing the caregiver’s well-being.

- What are the positive caregiver outcomes (e.g., satisfaction, self-efficacy, personal growth) that are the result of experiencing hospice/palliative care?
- What is the effect of specific interventions aimed at reducing caregiver distress and burden?
- What are the consequences for the caregiver of not accessing hospice or palliative care?

Research Objective: To identify approaches to effective bereavement care.

- What is the effect of hospice/palliative care on bereavement outcomes?
- What are the effects of bereavement interventions in families with uncomplicated bereavement?
- What bereavement interventions are effective in preventing health problems and promoting well-being in individuals at risk of poor outcomes?
- What are the components of a predictive, reliable bereavement risk assessment tool?

Improving the Conduct of Research in Hospice and Palliative Care
Research Objective: To identify ways to promote and increase participation in end-of-life care research by hospice and palliative care providers.

- What methods will promote, effectively utilize, and expand practice-based research networks in hospice and palliative care?
- What methods will increase involvement of hospices in clinical trials research?

Research Objective: To identify methodological approaches and modifications that will facilitate end-of-life care research.

- What types of infrastructure and informatics systems are needed to support end-of-life healthcare services research?
- What data gathering methods will facilitate the inclusion in research of hospice/palliative care patients with communication and cognitive deficits?
- What modifications to the current data collection/reporting system will facilitate end-of-life healthcare services research?

Summary

In sum, the agenda highlights numerous areas of unexplored research. There is clearly great potential to improve hospice and palliative care for patients. The field of end-of-life care badly needs research that is relevant to the issues faced by practicing clinicians. By establishing a research agenda, NHPCO is making an important statement to the field that conducting research in the care of those with life-threatening illness is both feasible and necessary. The agenda also allows NHPCO to focus its advocacy efforts to contribute to the overall efforts underway to improve care at the end of life in our country and internationally.

The scientific community and the NHPCO have the opportunity to substantially close the
gap between current and ideal practice. Although much work remains to be done, it is our hope that this research agenda will provide a meaningful roadmap for directing research that will ultimately translate into improved end-of-life care for patients and their families.

Acknowledgments

Participants in the NHPCO Research Conclave

Kim Acquaviva, PhD, MSW, Director of Research, The Hospice Institute of the Florida Suncoast
Susan Block, MD, Chief, Dana-Farber Cancer Institute, Adult Psychosocial Oncology Program
William Breitbart, MD, Chief, Psychiatry Service, Memorial Sloan-Kettering Cancer Center
Ira Byock, MD, Director, Promoting Excellence in EOL Care, a national program of RWJF, University of Montana
*David Casarett, MD, MA, Assistant Professor, Philadelphia VA Medical Center, University of Pennsylvania
*Kathy Egan, MA, BS, RN, Vice President, The Hospice Institute of the Florida Suncoast
*Perry G. Fine, MD, National Medical Director of VistaCare & Professor at University of Utah
*John Finn, MD, Chief Medical Director, Hospice of Michigan, Maggie Allesee Center for Quality of Life
Kathleen Foley, MD, Director, Project on Death in America, Open Society Institute
Joanne Hilden, MD, The Children’s Hospital at The Cleveland Clinic
Lenora Johnson, MPH, Acting Director, National Cancer Institute, Office of Education/Special Initiatives
Barry Kinzbrunner, MD, Vice President, VITAS Healthcare Corp., Clinical Research Analysis and Audit
*Jean S. Kutner, MD, MSPH, Assoc. Professor, Director of PoP-CRN, Univ. of CO Health Sciences Center
Gwendolyn W. London, D.Min, Interim Director, Duke Institute on Care at the End of Life
Joanne Lynn, MD, MA, MS, Director, The Washington Home Center for Palliative Care Studies

Neil MacDonald, MD, Director, McGill University, Cancer and Rehabilitation Program
*Melanie Merriman, PhD, MBA, Consultant, Touchstone Consulting
*Frederick Meyer, MD, Professor and Chair, University of California, Davis, Department of Internal Medicine
Robert Milch, MD, Medical Director, The Center for Hospice & Palliative Care
*Susan Miller, PhD, MBA, Asst. Professor, Brown University, Center for Gerontology/Health Care Research
R. Sean Morrison, MD, Mt. Sinai, Center to Advance Palliative Care, AAHPM Research Chair
Cameron Muir, MD, Medical Director, The Hospices of the National Capital Area
*Steve D. Passik, PhD, Director, University of Kentucky, Chandler Medical Center, Markey Cancer Center
*Elizabeth Pitorak, MSN, APRN, CHPN, Director, Hospice of the Western Reserve, Hospice Institute
Christina Puchalski, MD, MS, Director, The George Washington Institute for Spirituality and Health (GWish)
True Ryndes, ANP, MPH, President, National Hospice Work Group
*Karen Steinhauser, PhD, Asst. Research Professor, VA/Duke Medical Centers, Duke Univ. Medical Center
Patti Thielemann, RN, PhD, Director of Research, LifePath Hospice & Palliative Care, Inc.
*Diana Wilke, PhD, RN, FAAN, Professor/Harriet Werley Endowed Chair for Nursing Research, University of Illinois

NHPCO Attendees

Carla Alexander, MD, Medical Director, NHPCO
Stephen Connor, PhD, Vice President, Access for End-of-Life Care, Research, & International Development, NHPCO
Mary Hale, PhD, Meeting Facilitator
David Introcaso, PhD, NHPCO Consultant
Don Schumacher, PsyD, President and CEO, NHPCO
Carol Spence, RN, MS, Senior Research Associate, NHPCO

*NHPCO Research Committee Member