



# NATIONAL CONSENSUS PROJECT STAKEHOLDER STRATEGIC DIRECTIONS SUMMIT

June 29 - 30, 2017  
Chicago Marriott O'Hare,  
Chicago, IL

**Hosted by:**



## Summary Report

Special thank you to the Gordon and Betty Moore Foundation for their financial support



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## I. BACKGROUND AND PURPOSE

In January 2017, the Gordon and Betty Moore Foundation awarded the [National Coalition for Hospice and Palliative Care](#) a two-year grant to support a stakeholder summit and the development, endorsement, dissemination and implementation of the 4th edition of the *National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care*. The Guidelines will be modeled on the success and strategies of the [3rd edition](#) (published 2013) and is scheduled for publication Fall 2018. ([Read the press release.](#))

To launch this effort, a [NCP Stakeholder Strategic Directions Summit](#) was held June 29-30, 2017 in Chicago IL, to bring together key national organizations to discuss and define essential elements of quality primary and specialty palliative care services in the community. The Summit was attended by 58 representatives from 43 national/regional organizations, that covered a broad range of care settings, provider associations, accrediting bodies, payers, and community services organizations.

The Stakeholder Strategic Directions Summit was the first major step to solicit input for the [2018 NCP Clinical Practice Guidelines for Quality Palliative Care \(4th edition\)](#). The NCP Steering Committee and Writing Workgroup will use the input from the Summit to refine and/or revise the current 2013 NCP Guidelines (3rd edition) to improve access to quality palliative care for all in need, regardless of setting, diagnosis, prognosis, or age.

This Summary Report captures key themes, considerations, and ideas that were discussed during the Summit. Summit participants also provided an extensive amount of written input through small group discussions and worksheet exercises. That input combined with this report will be consolidated and synthesized, and made available for the [NCP Steering Committee](#) and [Writing Workgroup](#) to use over the course of this project.



**Summit participants having small group discussions to define “community.”**



**From left to right: Stacie Sinclair and Tracy Schroeffer, NCP Writing Workgroup Co-Chairs; Martha Twaddle and Betty Ferrell, NCP Steering Committee Co-Chairs**

## II. Summit Attendees, Objectives, and Agenda

### Attendees

Since palliative care should be available to any patient with a serious illness in any care setting, the potential audience for the NCP Clinical Practices Guidelines for Quality Palliative Care includes health systems, small/rural hospitals, office practices, cancer centers, dialysis units, long-term care facilities, assisted living facilities, home health and hospice agencies, and other care providers as well as hospitals. Also, payers, accrediting organizations, and quality measurement organizations are seeking to support accountability standards for quality palliative care across settings. In addition, patient and family advocate organizations, social service agencies, and other community organizations serving individuals with palliative care needs are critical in ensuring the Guidelines align with and meet the needs of patients and family caregivers of those with serious illness.

Therefore, significant efforts were taken to invite attendees that represented stakeholders outside of the hospice and palliative care field, and other organizations that also will be critical “customers” of the Guidelines.

#### Of the 58 organizational representatives who attended the Summit:

- ▶ 75% were from organizations that are not members of the National Coalition for Hospice and Palliative Care;
- ▶ Over 50% did not previously have a formal role with the NCP project (i.e. not on the NCP Steering Committee or Writing Workgroup); and
- ▶ All represented a diverse range of stakeholder organizations (see table below).

Attendees Organization Type	% of Attendees
<b>Provider Organizations</b> (e.g. American Health Care Association, National Association for Home Care and Hospice)	<b>23%</b>
<b>Individual Professionals</b> (e.g. Hospice and Palliative Care Nurses Association, HealthCare Chaplaincy Network)	<b>35%</b>
<b>Patient and Family Caregivers</b> (e.g. Alzheimer’s Association, American Cancer Society, National Patient Advocate Foundation)	<b>14%</b>
<b>Health Plans/Quality/Accreditations</b> (e.g. Blue Shield of California, The Joint Commission, National Quality Forum)	<b>14%</b>
<b>Other Stakeholders</b> (e.g. The Pew Charitable Trusts, National Palliative Care Research Center, Coalition to Transform Advanced Care)	<b>14%</b>

A complete listing of attendees is included in [Appendix A](#) of this report and a listing of all organizations represented are listed on the [website](#).

## Objectives

To build a strong foundation for consensus over the course of the project, thoughtful consideration was made to the objectives and agenda for the Summit.

**The following objectives were used to guide the design of the Summit:**

1. Build relationships among participants and across national stakeholder organizations
2. Provide a highly interactive forum for candid and creative discussion
3. Solicit input from all stakeholders to prioritize unique areas of focus and critical gaps for the project

## Agenda

There was an intentional design of the Summit agenda to provide participants the opportunity to network and build relationships through general introductions, alternating table assignments, small group exercises, large group report outs, and informal networking throughout the Summit.

In addition to the small and large group discussions, worksheets were provided for participants to provide individual input throughout the Summit (See [Appendix B](#)). These worksheets were collected at the end of each exercise so all the written input could be collated and synthesized.

The Summit agenda included the following:

### DAY 1: Thursday, June 29, 5:00 – 8:00 PM

5:00 – 5:45 PM

#### Registration & Networking

5:45 – 6:00 PM

Welcome & Introductions (*name, organization, where were you born, where do you live now?*)

6:00 – 7:15 PM

Small Group Discussion: Defining Community

- ▶ Why are community-based guidelines important to you and/or your organization?
- ▶ How do you define “community”?
- ▶ What are unique elements of community-based palliative care?

7:15 – 8:00 PM

#### Networking

**DAY 2: Friday, June 30, 7:30 AM – 4:00 PM**

7:30 – 8:15 AM	<b>Breakfast &amp; Networking</b>
8:15 – 8:45 AM	Welcome & Day 2 Kick-off: Key Themes from Day 1
8:45 – 9:30 AM	Why Are We Here? What Has Been Accomplished?
9:30 – 10:15 AM	Panel: What’s Unique About Community-based Palliative Care?
10:15 – 10:30 AM	Break & Networking
10:30 – 11:30 AM	<p>Small Group Discussion: How will the NCP Guidelines be Used? (Stakeholder Perspectives)</p> <ul style="list-style-type: none"> <li>▶ What is the value of incorporating community-based guidelines into the existing guidelines?</li> <li>▶ What does the stakeholder need from this process?</li> <li>▶ What are 2-3 opportunities and/or challenges in adopting community-based guidelines that the writers should consider?</li> </ul>
11:30 – 12:00 PM	Morning Recap / Key Insights
12:00 – 12:30 PM	<b>Lunch &amp; Networking</b>
12:30 – 1:45 PM	<p>Small Group Discussion: Incorporating Community into the Guidelines (Breakout by Domains PLUS one “Wildcard” Domain)</p> <ul style="list-style-type: none"> <li>▶ How is this palliative care domain supporting community?</li> <li>▶ What does not need to change?</li> <li>▶ What is missing?</li> <li>▶ How can this palliative care domain better incorporate community?</li> </ul>
1:45 – 2:00 PM	<b>Break &amp; Networking</b>
2:00 – 3:00 PM	Small Group Report Out
3:00 – 3:30 PM	NCP Writing Workgroup
3:30 – 4:00 PM	Final Reflections & Next Steps

### III. Key Themes and Considerations

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A significant amount of ideas and perspectives were shared during the Summit during large and small group discussions, and collected through the worksheet exercises. (See Appendix B) Outlined below are the key themes that are representative of the input and discussions. The detailed information was collected through the corresponding worksheets of each key theme and will serve as the foundation for creating the 4th edition of the NCP Guidelines.

**The key themes and corresponding considerations outlined in this section are:**

- A. Defining “Community”
- B. Stakeholder Perspectives (re: current and future use of the Guidelines)
- C. Domain Input

#### A. Defining “Community”

A significant amount of discussion occurred regarding how to define “community,” what is unique about the needs outside of hospitals and hospices, and whether it was important to define it. (Refer to [Worksheet 1](#) in [Appendix B](#))

**Some of the points raised included:**

- ▶ Community should be defined by the person; however, needs can change based on the setting of care and other factors (e.g. in the ICU, home, etc.).
- ▶ It is helpful to define community as a lens through which people’s needs can be assessed.
- ▶ Given current workforce limitations and access, the Guidelines should be inclusive of primary and specialty palliative care.
- ▶ Some define community as anything outside of large, academic hospitals while others define it to be any setting outside of any hospital.
- ▶ However community is defined, the Guidelines should be person-centric and not “medicalized.”
- ▶ The Guidelines need to be written in such a way as they can apply across all settings.
- ▶ If there are distinctions made as to settings or any other definitions, the Guidelines need to be able to be operationalized.
- ▶ It is important to have the Guidelines include family caregivers as part of “community.”
- ▶ Critical or unique elements to community-based palliative care include: 24/7 access, training, limited or no access to specialists, payment, caregiver support, and community-resource needs.

- ▶ Guidelines should remain focused on clinical standards and not define operational standards given the variability in needs of populations, settings, and use (e.g. key is to make sure clinical elements are in place to ensure quality, but not try to define how a clinical standard is implemented).
- ▶ A distinction made was whether it was more important to define the “community” or a “population.”
- ▶ New models of care and organizations are quickly entering the market, creating both tension around the definition of quality and new, innovative approaches that may prove very effective.

The graph below highlights the range of dimensions to define “community.”



### Considerations

Based on the overall discussion of “community” and scope, the following are key considerations for the **2018 NCP Guidelines**:

- ▶ Guidelines should be written such that they can be applied across settings wherever possible, preferably in one set of Guidelines.
- ▶ Guidelines should be written to incorporate both primary and specialty level palliative care. Careful consideration needs to be made to address access, particularly in remote or underserved geographies where specialty level palliative care may not be available. This includes achieving the appropriate balance on training or certification requirements.
- ▶ Careful consideration should be made to keep the Guidelines focused on clinical standards (the “what”) and not be overly prescriptive on operational standards (the “how”).
- ▶ If the Clinical Guidelines are to be person-centric, they will need to accommodate a level of ambiguity as to how a person may define their needs based on multiple factors.



- ▶ Given the pace of change and growth in need, the Guidelines should be flexible and adaptable over time as need grows and models evolve.

## **B. Stakeholder Perspectives (re: current and future use of the Guidelines)**

The following are specific examples and perspectives that the Summit attendees shared for how the 2013 NCP Guidelines are currently being used and their expectations for the 2018 NCP Guidelines. (Refer to [Worksheet 2](#) in [Appendix B](#))

### **Providers**

Provider practices, including accountable care organizations (ACOs) are using the Guidelines to design home-based and other community-based programs. A specific patient case example was provided by ProHEALTH, a provider practice, to demonstrate how they have designed their home-based palliative care program using the domains and standards in the Guidelines.

### **Education**

Clinical Guidelines establish the expectations for the skills and knowledge needed to practice.

- ▶ End-of-Life Nursing Education Consortium (ELNEC) training incorporates the Guidelines.
- ▶ Curriculum for training oncology advanced practice nurses (APNs) is based on the domains and standards in the Guidelines.
- ▶ The Guidelines will serve as the foundation for new disciplines who are looking to offer specialized training programs and certifications (e.g. Physician Assistants).

### **Measurement**

Guidelines are needed to establish a baseline for measuring where you are and then measuring change. The measurements are then incorporated into quality improvement initiatives, value-based payment models, and benchmarking programs.

- ▶ In 2006 the National Quality Forum (NQF) developed a palliative care measurement framework using the Guidelines.
- ▶ 38 preferred practices for palliative and end-of-life care were NQF endorsed using the Guidelines.
- ▶ NQF framework was recently updated to reflect community-based settings and will look to the revised Guidelines to further develop the framework.

### **Accreditation**

The Guidelines have been used to define the care that should be expected for those with serious illness.

- ▶ Guidelines were used by the Accreditation Commission for Health Care (ACHC) to establish expectations for home health agencies delivering palliative care services.

- ▶ The Joint Commission (TJC) used the Guidelines in 2003 to establish the Advanced Certification in Palliative Care standards for hospitals. TJC has started the certification process for non-hospital settings and is awaiting the release of new Guidelines.
- ▶ It was noted that the Guidelines have heavily influenced home health (serving over 17 million people a year) by requiring interdisciplinary teams (IDTs) and advance care planning (ACP).

### Health Plans and Payment

The Guidelines are used to ensure health plans, working with providers in their networks, are responsive to the needs of their members with serious illness. Blue Shield of California shared the following examples of how they are using the Guidelines:

- ▶ Developing standards for payment (rolling out a state-wide payment bundle for serious illness)
- ▶ Using in medical policy to authorize services
- ▶ Including in member and consumer education materials
- ▶ Supporting regulatory and legislative efforts to improve access
- ▶ Incorporating the specific standards, word for word, into provider contracts

### Research

The existence of the NCP Guidelines validates the level of importance and provides credibility to research. However, the challenge is that research is needed to create the evidence for the Guidelines, and the Guidelines are needed to establish credibility for the research. It was stated during the Summit to make sure that the Guidelines are evidence-based and should not outpace the evidence.

### Other Examples

- ▶ Physician Assistants (PA) representatives stated the Guidelines are important in defining skills and knowledge as their specialized training programs are developed.
- ▶ Pediatric representatives stated the need to establish Guidelines that are appropriate for the situation (e.g. appropriateness of an advance care discussion with parents of a new born with cystic fibrosis).
- ▶ Pharmacy representatives stated the Guidelines need to be “trans-disciplinary” and appropriately recognize the varying levels of involvement some professionals may have in the interdisciplinary team model. For example, need to strike a balance between highlighting pharmacy as a valuable team member, but realizing that we don’t want to penalize programs that can’t afford a dedicated pharmacist.

### Considerations

Based on the overall discussion of the use of the Guidelines, the following are key considerations for the **2018 NCP Guidelines**:

- ▶ Examples stated above demonstrate and validate the value of the 2013 Guidelines.

- ▶ Expediting the next release of the 2018 Guidelines is important as organizations are holding off on implementing initiatives anticipating Guidelines that will incorporate community settings.
- ▶ Careful consideration will need to be made to any significant changes or additions to the existing domains since the current Guidelines are being used by providers, quality and accrediting organizations, research projects, and health plans.
- ▶ There is significant growth in the number of organizations providing some level of palliative care (both primary and specialty-level) and therefore it will be important to establish an appropriate balance that provides enough guidance to ensure quality (establish a “floor”) without such specificity that unrealistic expectations are set that are not measurable or achievable.
- ▶ Careful consideration will need to be made in the wording and the level of specificity that is included in the Guidelines to establish benchmarks that can be incorporated into payment models, etc.
- ▶ The Guidelines need to be flexible enough to address varying needs and access across settings, age, etc. (e.g. what is needed for a newborn is different than a young child), and provider types. Including practical case studies was also recommended.

## C. Domain Input

Specific attention (through small/large group discussion) was given to each of the following eight domains that are included in the **2013 Guidelines**:

1. Structure and Processes for Care
2. Physical Aspects of Care
3. Psychological and Psychiatric Aspects of Care
4. Social Aspects of Care
5. Spiritual, Religious and Existential Aspects of Care
6. Cultural Aspects of Care
7. Care of the Patient at the End of Life
8. Ethical and Legal Aspects of Care

In addition to the eight domains, a “Wildcard” small group discussion was held to brainstorm other domains that may need to be considered. (Refer to [Worksheet 3](#) in [Appendix B](#))

## Considerations

**Key themes re: the domains that emerged from the discussions included:**

- ▶ Address how to integrate the palliative care specialist interdisciplinary team and the community resources
- ▶ Make the language consistent throughout the current Guidelines re: the interdisciplinary team

- ▶ Expand family caregiver focus to include unit of care, assessment, and education
- ▶ Provide more on comprehensive assessment and integration of community services
- ▶ Address different populations, e.g. pediatrics and geriatrics
- ▶ Focus on a comprehensive approach to palliative care; avoid being too medicalized
- ▶ Incorporate culture, communication, coordination and transitions of care throughout all domains
- ▶ Include use of technology to improve patient and family care
- ▶ Maintain flexibility without compromising quality

**Recommendations for the structure of the Guidelines included:**

- ▶ Provide flexibility in application of Guidelines based on resources, setting, etc.
- ▶ Make it practical! Include practical application examples and case studies as a means of illustrating application of Guidelines in different settings/communities
- ▶ Create a user-friendly electronic version and use hyperlinks
- ▶ Provide references and resources (e.g., sample assessment tools, particularly since this may vary in a community-based setting)
- ▶ Balance the tension between too general and too specific
- ▶ Add “why this domain” at the beginning of each domain
- ▶ Clarify the difference between clinical and operational guidelines in the ‘Preface’ section
- ▶ Include a glossary

**Specific domain considerations included:**

***Domain 1: Structure and Processes for Care***

- ▶ Expand the focus, as it is highly medicalized and instead focus on the structures needed to care for the patient and family with serious illness
- ▶ Explore creative solutions so that 24/7 access to care is mandatory
- ▶ Incorporate community resources into the interdisciplinary team
- ▶ Emphasize workforce development
- ▶ Strengthen care transitions processes
- ▶ Focus on care coordination
- ▶ Identify triggers for palliative care referrals

***Domain 2: Physical Aspects of Care***

- ▶ Focus on physical well-being and function as the framework, not pain and symptoms
- ▶ Emphasize comprehensive assessment and integration of community services
- ▶ Add information related to improving assessment and management of functional status
- ▶ Reframe opioids to solutions that are more long-term (patients living years with serious illness in the community)

- ▶ Add anticipatory care to avoid pain and suffering
- ▶ Identify the patient's role in pain and symptom management

### ***Domain 3: Psychological and Psychiatric Aspects of Care***

- ▶ Restructure to focus on screening, assessment, treatment, and education
- ▶ Add assessment of family caregiver
- ▶ Add information about capacity for decision making, including patients with developmental disabilities as well as caregiver capacity
- ▶ Emphasize PTSD, trauma, post-illness survivorship, post-illness psychosis, dual diagnosis, and behavioral disturbances/dementia
- ▶ Discuss scope of practice, safety of patient, caregiver and health care team

### ***Domain 4: Social Aspects of Care***

- ▶ Revise interdisciplinary assessment so it isn't a medical model
- ▶ Define patient and family as the unit of care so that it's clear who the patient identifies as the caregiver and who is included as the identified family
- ▶ Add assessment of family caregiver
- ▶ Expand the domain to focus on community resources and social determinants of health
- ▶ Assess developmental needs of adults

### ***Domain 5: Spiritual, Religious and Existential Aspects of Care***

- ▶ Describe the importance of incorporating community spiritual clergy (without implying that this is THE representative on the team)
- ▶ Define the roles of spiritual professionals
- ▶ Reorient the content upstream of end-of-life care
- ▶ Add age-appropriate spiritual care
- ▶ Make the language consistent spiritual/religious/existential

### ***Domain 6: Cultural Aspects of Care***

- ▶ Broaden the definition of culture
- ▶ Incorporate language of disparities
- ▶ Ensure that all the domains describe how to serve traditionally underserved groups
- ▶ Describe culturally-inclusive care
- ▶ Add the importance of availability of education, training, and competencies of the professionals
- ▶ Emphasize the importance of a community needs assessment and cultural brokers
- ▶ Include a discussion on intersectionality
- ▶ Ensure that access to care is referenced in the Guidelines

***Domain 7: Care of the Patient at the End of Life***

- ▶ Describe end-of-life care when patients aren't eligible for or choose not to elect hospice
- ▶ Emphasize community-based care
- ▶ Ensure content focuses on pediatrics
- ▶ Add more information on assessment
- ▶ Add prognostication
- ▶ Rename this domain?

***Domain 8: Ethical and Legal Aspects of Care***

- ▶ Describe ethical principles at the beginning
- ▶ Discuss importance of clinician education relative to legal treatment options
- ▶ Enhance proactive advance care planning process
- ▶ Reorient advance care planning to focus on maximizing the ability of the patient to achieve stated goals
- ▶ Describe how to access an ethics committee in the community
- ▶ Ensure that the team has a framework for processing emerging ethical dilemmas and issues
- ▶ Discuss the team conflict management process
- ▶ Identify current best practices related to advance care planning
- ▶ Add professional burnout as an ethical issue
- ▶ Identify the importance of assessing caregiver capacity
- ▶ Add financial issues to this domain
- ▶ Add references to professional position statements and other ethical resources

***Other suggested domains (from the 'Wildcard' discussion group)***

- ▶ Serious illness communication
- ▶ Practical aspects of daily living
- ▶ Caregiver assessment and care
- ▶ Coordination of care across settings
- ▶ Assessments/care plan
- ▶ Renewal/team care

All recommendations for the eight domains plus any possible new domains will be consolidated and synthesized for the NCP Steering Committee and Writing Workgroup to use over the course of this project.

## IV. Summit Feedback

Of the 58 attendees, 39 (67%) completed the Summit evaluation that was distributed online immediately after the Summit. The evaluation included a rank order of specific features of the Summit plus open-ended questions to obtain individual comments.

The overall results are provided in the table below. (Scale: 1 = strongly disagree to 5 = strongly agree)

Summit Evaluation Statements	Rating
I was provided with sufficient information and communication before the Summit.	4.56
The Summit achieved its stated objectives.	4.69
The Summit was relevant to the work of my organization.	4.77
The design and facilitation of the Summit was effective.	4.74
The Summit increased my knowledge about Community-Based Palliative Care.	4.46
I look forward to engaging my organization with the National Consensus Project Palliative Care Guidelines after the Summit.	4.85
<b>Total Overall Rating</b>	<b>4.68</b>

The following are some of the additional quotes from the evaluation:

*Re: attendee's experience of the Summit*

- ▶ *"Organization and facilitation of summit was superb. It was an effective format to ensure all voices were included. Terrific stakeholder feedback process!"*
- ▶ *"This was a great event both in terms of the particular project at hand and in terms of building community across lots of stakeholders who are very seldom if ever in the same room."*
- ▶ *"Very well planned and executed. Productive use of everyone's time. Objectives and expectations exceeded. Hearing about everyone's work and commitment was inspiring."*
- ▶ *"Excellent and diverse group of people actually in the field doing palliative care which was great. Would have liked a few more academic voices in the room to challenge strong feelings about how teams should look for what should be required, especially if the data is lacking to support those recommendations."*
- ▶ *"The care and planning that went into to preparing for this meeting was evident. Big thanks for your hard work! I felt that there wasn't nearly enough time - is there ever? - to leave you with a more robust set of proposals for the incorporation of*

*“community” into the Guidelines. But for the work that we did accomplish, there couldn’t have been a more skilled, thoughtful and kind group of people. It was a pleasure working with this convened palliative care dedicated force.”*

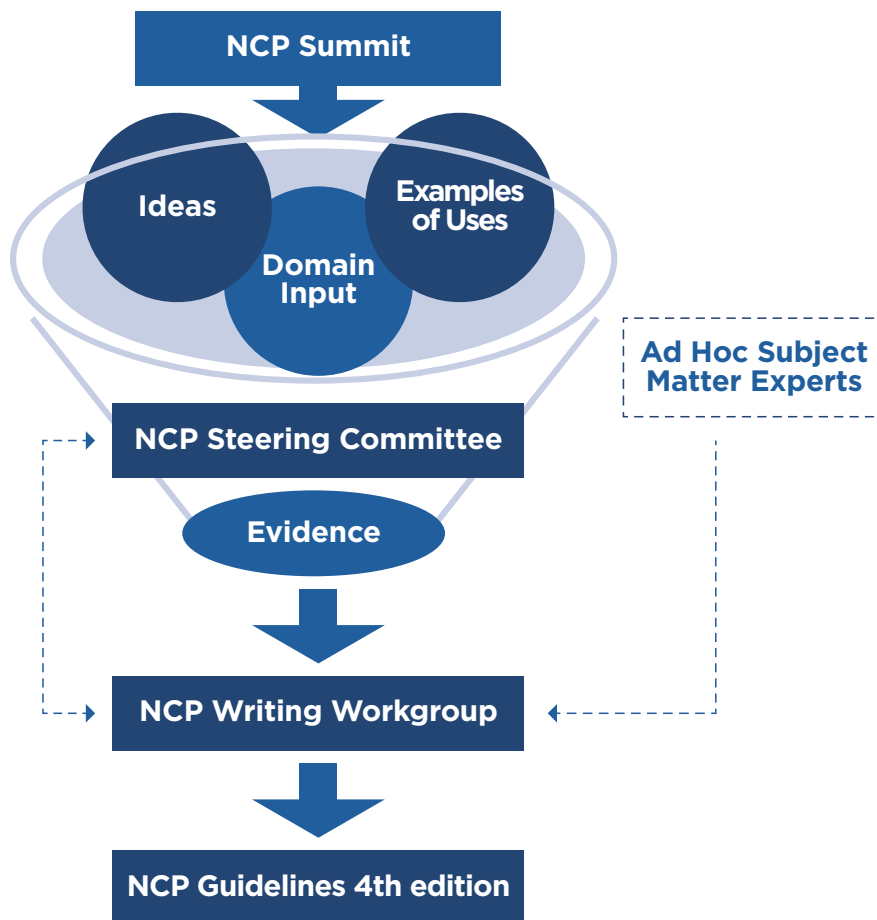
**Re: key messages Summit attendees will share with their organization**

- ▶ *“A thoughtful revision of the guidelines is in process that promises to further advance best practices in palliative care across all settings.”*
- ▶ *“There has been an ongoing movement toward community-based palliative care for a long time but it’s finally coming to fruition with these guidelines that will hopefully broaden the reach and increase the impact of palliative care in the community. And with the shift from volume to value there’s no better time!”*
- ▶ *“The 3rd edition is great; the 4th edition will be amazing. Now is the time to use these as a springboard for quality incentive discussions.”*
- ▶ *“It’s not just about palliative care providers, but the many others in the community who are providing support and services to people with serious illness.”*
- ▶ *“The strategic support provided by Gordon and Betty Moore Foundation to advance quality improvement for all ages and all care settings to improve care for seriously ill patients and caregivers is remarkable, and the summit that captured input from across stakeholder populations was an essential step to change the game and draw on the momentum of value-based care reform to get this right. This project will help put people at the heart of healthcare reform.”*



## V. Next Steps and Project Timeline

Beginning July 2017, the NCP Steering Committee and Writing Workgroup will synthesize the input from this Summit and begin the drafting process of the 4th edition of the NCP Clinical Practice Guidelines for Quality Palliative Care that are scheduled to be published by July 1, 2018. Summit participants may be contacted to serve as subject matter experts as the Guidelines are being developed and revised. In addition, NCP staff will continue their outreach to other national stakeholder organizations that did not attend the Summit to engage for future endorsements of the 2018 NCP Guidelines.




Below is an overall timeline for the project:

Timeline/Details	2017				2018			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Project kick-off	■							
Summit prep and completion		■						
Synthesis and initial drafting			■					
<b>DRAFT 1 Guidelines</b>				■				
<b>DRAFT 2 Guidelines</b>					■			
Review by External Stakeholders					■			
Final Guidelines for endorsement						■		
<b>Publish Guidelines</b>							■	
Disseminate Guidelines							■	■

Updates and key milestones will periodically be published on the [NCP web site](http://www.nationalcoalitionhpc.org/guidelines-2018/) at [www.nationalcoalitionhpc.org/guidelines-2018/](http://www.nationalcoalitionhpc.org/guidelines-2018/).

For more information about NCP, contact Gwynn Sullivan, NCP Project Director at [gwynns@nationalcoalitionhpc.org](mailto:gwynns@nationalcoalitionhpc.org).



The National Coalition for Hospice and Palliative Care would like to thank **Tom Gualtieri-Reed**, MBA, for his invaluable guidance with the Summit design; expert facilitation of the Summit; and helpful drafting of this Summary Report.

## **VII. Appendix**

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### **Appendix A: Summit Participant Roster**



## National Consensus Project Stakeholder Strategic Directions Summit

June 29 - 30, 2017

Chicago Marriott O'Hare, Chicago, IL

### Participant Roster

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#### Academy of Integrative Pain Management

**Bob Twillman**, PhD, FAPM  
Executive Director

#### Accreditation Commission for Health Care

**Teresa Harbour**, RN, MBA, MHA  
Director, Home Health, Hospice & Private Duty

#### Alzheimer's Association

**Sam Fazio**, PhD  
Director, Alzheimer's & Dementia Care

#### American Academy of Home Care Medicine

**Carla Perissinotto**, MD, MHS  
University of California San Francisco

#### American Academy of Hospice and Palliative Medicine

*NCP Steering Committee Co-Chair*  
**Martha L. Twaddle**, MD, FACP, FAAHPM, HMDC  
Senior Vice President, Education and Quality,  
Home Centered Care Institute  
Senior Medical Director, Aspire Health

#### American Academy of Hospice and Palliative Medicine/National Coalition for Hospice and Palliative Care Executive Committee

**Steve Smith**, MS, CAE  
Executive Director & Chief Executive Officer

#### American Academy of Hospice and Palliative Medicine

**Joe Rotella**, MD, MBA, HMDC, FAAHPM  
Chief Medical Officer

#### American Academy of Hospice and Palliative Medicine Registries Collaborative Project

**Katherine Ast**, MPH  
Director, Quality & Research

#### American Cancer Society

**Lynne Padgett**, PhD  
Strategic Director, Hospital Systems

#### American Geriatrics Society

**Joseph Shega**, MD  
Senior Vice President & National  
Medical Director  
VITAS Healthcare

#### American Health Care Association

**Dianne Timmering**, MBA, MFA, CNA  
Spirituality Co-Founder & Vice President,  
Legislative Affairs & Health Policy

#### American Health Care Association

**Gail Sheridan**, RN  
Chief Clinical Operations Officer

#### American Medical Group Association

**David Introcaso**, PhD  
Senior Director, Regulatory & Policy

### **American Medical Group Association**

**Elizabeth Ciemins**, PhD, MPH, MA

Director, Research & Analytics

### **Association of Professional Chaplains**

**Margie Atkinson**, DMin, BCC

Director, Pastoral Care/Palliative Care & Ethics  
Morton Plant Mease/BayCare Health System

### **Blue Shield of California**

**Torrie Fields**, MPH

Senior Program Manager, Palliative Care

### **Cambia Health Solutions**

**Lee Spears**

Program Director, Personalized Care Support  
Regence

### **Center to Advance Palliative Care**

**Diane Meier**, MD

Director

### **Center to Advance Palliative Care**

*NCP Writing Workgroup Co-Chair*

**Stacie Sinclair**, MPP, LBSW

Senior Policy Manager

### **Coalition for Compassionate Care of California**

**Judy (Citko) Thomas**, JD

Chief Executive Officer

### **Coalition to Transform Advanced Care**

**Marian Grant**, DNP, ACNP-BC, ACHPN, FPCN, RN

Policy Consultant

### **College of Nursing, The University of Utah**

**Lee Ellington**, PhD

Associate Professor

### **Community Health Accreditation Partner**

**Barbara McCann**

Interim President & CEO

### **Discern Health**

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## Appendix

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### **Appendix B: Summit Discussion Worksheets**

1. Defining Community
2. Stakeholder Perspective
3. Domain Input



# National Consensus Project Stakeholder Strategic Directions Summit

## WORKSHEET #1: Defining Community

Name & Organization \_\_\_\_\_

**Purpose:** To get input on how to define community and identify essential elements to consider in community-based palliative care

1. Why are community-based guidelines **important** to you and/or your organization?

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2. How do you **define** “community”?

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3. What are **unique elements** of community-based palliative care? What are 2-3 essential elements that are critical to incorporate? (e.g. transitions of care)

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# National Consensus Project Stakeholder Strategic Directions Summit

## WORKSHEET #2: Stakeholder Perspective

**Name & Organization** \_\_\_\_\_

<b>Stakeholder Perspective</b>	Organization Providers	Individual Providers	Quality/Accreditation/Health Plans
<i>(circle one)</i>	Other Stakeholders	People with serious illness /Family Caregivers	

**Purpose:** To get input from key “customers” on how the guidelines will be used and what is important to consider when incorporating community-based guidelines

1. What is the value of incorporating community-based guidelines into the existing guidelines? How will they be used?

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2. What does the stakeholder need from this process?

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3. What are **2-3 opportunities and/or challenges** in adopting community-based guidelines that the writers should consider (e.g. feasibility constraints)?

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# National Consensus Project Stakeholder Strategic Directions Summit

## WORKSHEET #3: Domain Input

**Name & Organization** \_\_\_\_\_

**Domain**  
(circle one)

1. Structure and Process	6. Cultural
2. Physical	7. Care at End of Life
3. Psychological and Psychiatric	8. Ethical and Legal
4. Social	9. WILDCARD DOMAIN
5. Spiritual, Religious, Existential	

**Purpose:** To get input from key “customers” on how the guidelines will be used and what is important to consider when incorporating community-based guidelines

How is this palliative care domain supporting community? What does not need to change?	What is missing? How can this palliative care domain better incorporate community?
_____	_____
_____	_____
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Other comments or considerations:

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## **NATIONAL CONSENSUS PROJECT STAKEHOLDER STRATEGIC DIRECTIONS SUMMIT**

**June 29 – 30, 2017**

Chicago Marriott O'Hare,  
Chicago, IL

[www.nationalcoalitionhpc.org/ncp](http://www.nationalcoalitionhpc.org/ncp)