NATIONAL CONSENSUS PROJECT
STAKEHOLDER STRATEGIC DIRECTIONS SUMMIT

Community-Based Palliative Care

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

Summary Report

Special thank you to the Gordon and Betty Moore Foundation for their financial support
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 Community-based Palliative Care Guidelines. The Guidelines will be modeled on the success and strategies of the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care, 2013 and is scheduled for publication July 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.
II. Summit Attendees, Objectives, and Agenda

Attendees

Since community-based 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).

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

<table>
<thead>
<tr>
<th>DAY 1: Thursday, June 29, 5:00 – 8:00 PM</th>
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<tbody>
<tr>
<td>5:00 – 5:45 PM</td>
<td>Registration &amp; Networking</td>
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<tr>
<td>5:45 – 6:00 PM</td>
<td>Welcome &amp; Introductions (name, organization, where were you born, where do you live now?)</td>
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<tr>
<td>6:00 – 7:15 PM</td>
<td>Small Group Discussion: Defining Community</td>
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<tr>
<td></td>
<td>▸ Why are community-based guidelines important to you and/or your organization?</td>
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<td>▸ How do you define “community”?</td>
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<td></td>
<td>▸ What are unique elements of community-based palliative care?</td>
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<td>7:15 – 8:00 PM</td>
<td>Networking</td>
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</table>
### DAY 2: Friday, June 30, 7:30 AM – 4:00 PM

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>7:30 - 8:15 AM</td>
<td><strong>Breakfast &amp; Networking</strong></td>
</tr>
<tr>
<td>8:15 - 8:45 AM</td>
<td>Welcome &amp; Day 2 Kick-off: Key Themes from Day 1</td>
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<tr>
<td>8:45 - 9:30 AM</td>
<td>Why Are We Here? What Has Been Accomplished?</td>
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<td>9:30 - 10:15 AM</td>
<td>Panel: What’s Unique About Community-based Palliative Care?</td>
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<tr>
<td>10:15 - 10:30 AM</td>
<td>Break &amp; Networking</td>
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<tr>
<td>10:30 - 11:30 AM</td>
<td>Small Group Discussion: How will the NCP Guidelines be Used? (Stakeholder Perspectives)</td>
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<td></td>
<td>▶ What is the value of incorporating community-based guidelines into the existing guidelines?</td>
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<td></td>
<td>▶ What does the stakeholder need from this process?</td>
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<td></td>
<td>▶ What are 2-3 opportunities and/or challenges in adopting community-based guidelines that the writers should consider?</td>
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<td>11:30 - 12:00 PM</td>
<td>Morning Recap / Key Insights</td>
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<td>12:00 - 12:30 PM</td>
<td><strong>Lunch &amp; Networking</strong></td>
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<td>12:30 - 1:45 PM</td>
<td>Small Group Discussion: Incorporating Community into the Guidelines (Breakout by Domains PLUS one “Wildcard” Domain)</td>
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<tr>
<td></td>
<td>▶ How is this palliative care domain supporting community?</td>
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<td>▶ What does not need to change?</td>
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<td></td>
<td>▶ What is missing?</td>
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<td></td>
<td>▶ How can this palliative care domain better incorporate community?</td>
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<tr>
<td>1:45 - 2:00 PM</td>
<td><strong>Break &amp; Networking</strong></td>
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<td>2:00 - 3:00 PM</td>
<td>Small Group Report Out</td>
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<td>3:00 - 3:30 PM</td>
<td>NCP Writing Workgroup</td>
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<td>3:30 - 4:00 PM</td>
<td>Final Reflections &amp; Next Steps</td>
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III. Key Themes and Considerations

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)

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

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<th>Timeline/Details</th>
<th>2017</th>
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<th>2018</th>
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<td>Project kick-off</td>
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<td>Summit prep and completion</td>
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<td>Synthesis and initial drafting</td>
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<td><strong>DRAFT 1 Guidelines (1/31/18)</strong></td>
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<td>Review by External Stakeholders</td>
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<td>Final Guidelines for endorsement</td>
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<td><strong>Publish Guidelines (7/1/18)</strong></td>
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<td>Disseminate Guidelines</td>
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Updates and key milestones will periodically be published on the NCP web site 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

Appendix A:
Summit Participant Roster
National Consensus Project Stakeholder Strategic Directions Summit

Community-Based Palliative Care

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

Participant Roster

Academy of Integrative Pain Management
Bob Twillman, PhD
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 and 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 & CEO

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 and Research

American Cancer Society
Lynne Padgett, PhD
Strategic Director, Hospital Systems

American Geriatrics Society
Joseph Shega, MD
Senior Vice President and National Medical Director
VITAS Healthcare

American Health Care Association
Dianne Timmering, MBA, MFA, CNA
Spirituality Co-Founder & VP of Legislative Affairs and Health Policy

American Health Care Association
Gail Sheridan, RN
Chief Clinical Operations Officer

American Medical Group Association
David Introcaso, PhD
Senior Director, Regulatory and Policy
American Medical Group Association
Elizabeth Ciemins, PhD, MPH, MAA
Director, Research & Analytics

Association of Professional Chaplains
Margie Atkinson, DMin, BCC
Director Pastoral Care/Palliative Care and Ethics

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

Coalition for Compassionate Care of California
Judy (Citko) Thomas, JD
CEO

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
Thomas Valuck, MD, JD
Partner

Duke University School of Medicine
Kimberly Johnson, MD
Associate Professor of Medicine

Family Cargiver Alliance
Leah Eskenazi, MSW
Operations Director

Gordon and Betty Moore Foundation
Beth Berselli,
Program Officer

Health Care Service Corporation
Bruce Himelstein, MD
Senior Medical Director, Government Programs

HealthCare Chaplaincy Network
Rev. George Handzo, BCC, CSSBB
Director of Health Services Research & Quality

HealthCare Chaplaincy Network
Rev. Susan Wintz, MDiv, BCC
Director of Health Services

Hospice and Palliative Nurses Association
NCP Steering Committee Co-Chair
Betty Ferrell, PhD, RN, FAAN, FPCN, CHPN
Director & Professor
City of Hope, Nursing Research & Education

Hospice and Palliative Nurses Association
Denise Stahl, MSN, ACHPN, FPCN
Chief Clinical Officer

Hospice and Palliative Nurses Foundation
Sally Welsh, MSN, RN, NEA-BC
President/CEO

Leaders Engaged on Alzheimer’s Disease
Ian Kremer, JD
Executive Director

LeadingAge
Janine Finck-Boyle, LNHA
Senior VP, Public Policy and Health Services
Long-Term Quality Alliance
Larry Atkins, PhD
Executive Director

National Alliance for Caregiving
Gail Gibson Hunt,
President & CEO

National Association for Home Care and Hospice
Andrea Devoti, MSN, MBA, RN
Vice President, Policy, Meetings and Education

National Association for Home Care and Hospice
John McIlvaine,
Senior Vice President

National Association of Social Workers
Carrie Dorn, LMSW, MPA
NASW Senior Practice Associate for Health care

National Committee on Quality Assurance
Maureen Henry, JD, PhD
Research Scientist

National Hospice and Palliative Care Organization
John Mastrojohn III, RN, MSN, MBA
Executive Vice President and Chief Operating Officer

National Hospice and Palliative Care Organization
Judi Lund Person, MPH, CHC
Vice President, Regulatory and Compliance

National Palliative Care Research Center
Nathan Goldstein, MD
Professor, Gerald J. and Dorothy R. Friedman Chair in Palliative Care, Mount Sinai Medical Center

National Patient Advocate Foundation
Rebecca Kirch, JD
EVP Healthcare Quality and Value

National Pediatric Hospice and Palliative Care Collaborative
Tammy Kang, MD
Co-Chair

National Pediatric Hospice and Palliative Care Collaborative
Kathie Kobler, MS, APN, PCNS-BC, CHPPN, FPCN
Co-Chair

National Quality Forum
Karen Johnson,
Senior Director

Oncology Nursing Society
Michele Galioto, RN, MSN
Assistant Chief Clinical Officer

Physician Assistants in Hospice and Palliative Medicine
Judy Knudson, PA-C
Physician Assistant

Physician Assistants in Hospice and Palliative Medicine
Richard Lamkin, MPH, MPAS, PA-C
President

ProHEALTH Care, an Optum Company
Dana Lustbader, MD
Chief, Department of Palliative Care

Society of Palliative Care Pharmacists
Rabia Atayee, PharmD, BCPS
President

Social Work Hospice and Palliative Care Network
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Associate Professor

Supportive Care Coalition
Denise Hess, BCC
Executive Director
The Joint Commission
Kathy Clark, MSN, RN
Associate Project Director Specialist, SBU Lead
for Home Care and Palliative Care

The Pew Charitable Trusts
Katy Barnett,
Principle Associate, Improving End-of-Life Care

Visiting Nurse Associations of American/
Elevating Home
Danielle Pierotti, RN, PhD, CENP
Vice President of Quality

Staff

National Coalition for Hospice
and Palliative Care
Amy Melnick, MPA, Executive Director
Gwyn Sullivan, MSN, NCP Project Director
Cozzie King, NCP Coordinator
Kathy Brandt, MS, NCP Writer/Editor

Summit Facilitator
Thomas Gualtieri-Reed, MBA
Appendix

Appendix B: Summit Discussion Worksheets

1. Defining Community
2. Stakeholder Perspective
3. Domain Input
National Consensus Project Stakeholder Strategic Directions Summit
Community-Based Palliative Care

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
Community-Based Palliative Care

WORKSHEET #2: Stakeholder Perspective

Name & Organization __________________________________________________________

<table>
<thead>
<tr>
<th>Stakeholder Perspective</th>
<th>Organization Providers</th>
<th>Individual Providers</th>
<th>Quality/Accreditation/Health Plans</th>
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<tbody>
<tr>
<td></td>
<td>Other Stakeholders</td>
<td>People with serious illness /Family Caregivers</td>
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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

## Community-Based Palliative Care

### WORKSHEET #3: Domain Input

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<tr>
<td><strong>Domain</strong> (circle one)</td>
<td>1. Structure and Process</td>
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<td>2. Physical</td>
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<td>3. Psychological and Psychiatric</td>
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<td>4. Social</td>
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<td>5. Spiritual, Religious, Existential</td>
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**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

<table>
<thead>
<tr>
<th>How is this palliative care domain supporting community? What does not need to change?</th>
<th>What is missing? How can this palliative care domain better incorporate community?</th>
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Other comments or considerations:

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NATIONAL CONSENSUS PROJECT STAKEHOLDER STRATEGIC DIRECTIONS SUMMIT

Community-Based Palliative Care

June 29–30, 2017
Chicago Marriott O’Hare, Chicago, IL

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