

**American Academy of Hospice and Palliative Medicine
CMS MACRA COOPERATIVE AGREEMENT
“PALLIATIVE CARE MEASURES PROJECT”**

**Summary of:
Technical Expert Clinical User Patient Panel (TECUPP) Meeting
and Measure Specification Panel (MSP) Meeting
April 10 - April 11, 2019**

This document was prepared by the American Academy of Hospice and Palliative Medicine (AAHPM) under contract to the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy.

Palliative Care Measures Project

Project, TECUPP, and MSP overview:

Through a Cooperative Agreement from the Centers for Medicaid and Medicare Services (CMS), the American Academy of Hospice and Palliative Medicine (AAHPM) is working with partners at the National Coalition for Hospice and Palliative Care (Coalition) and RAND Health (RAND) to create new palliative care patient reported outcome performance measures. The Palliative Care Measures Project Team is composed of staff members from AAHPM, the Coalition, RAND, Center to Advance Palliative Care, and consultants Ellen Schultz (American Institutes of Research) and Rebecca Swain-Eng (Swain-Eng and Associates). Katherine Ast, MSW, LCSW, Director of Quality & Research for AAHPM, leads the team.

The AAHPM team convened a Technical Expert Clinical User Patient Panel (TECUPP) and Measure Specification Panel (MSP), which are chaired by Sydney Dy, MD, MS, FAAHPM, and Mary Ersek, PhD, RN, FPCN. The TECUPP and MSP contribute direction and thoughtful input on the development of the measures for patients with serious illness using their background as real-world clinical ‘end-users,’ patients, caregivers, family members and experts in measure development and testing methodologies. The TECUPP and MSP members represent a broad array of stakeholders including measure development experts, palliative care clinicians from the interdisciplinary team, specialty society representatives, patient advocates, former patients, family caregivers, healthcare industry representatives, diversity experts, and others.

Members of the TECUPP have been selected from nominations received from the public and include representatives from national organizations such as AAHPM, AMDA – The Society for Post-Acute and Long-Term Care Medicine, American Association of Family Physicians (AAFP), American College of Physicians (ACP), American Geriatrics Society (AGS), American Society of Clinical Oncology (ASCO), Center to Advance Palliative Care (CAPC), Coalition to Transform Advanced Care (C-TAC), HealthCare Chaplaincy Network (HCCN), Hospice and Palliative Nurses Association (HPNA), National Hospice and Palliative Care Organization (NHPCO), National Patient Advocate Foundation (NPAF), Physician Assistants in Hospice and Palliative Medicine (PAHPM), Social Work Hospice and Palliative Network (SWHPN), Society of Pain and Palliative Care Pharmacists (SPPCP), and the Supportive Care Coalition (SCC).

In general, TECUPP members are expected to participate in the project over the course of three years and provide expertise and feedback on quality measures for patients with serious illness throughout the measure development lifecycle, as requested. In addition, from this TECUPP, a small subgroup of experts with highly technical measure development and specification expertise were selected to evaluate proposed measures for initial feasibility and review later testing results to guide decision-making regarding each measure. This subgroup is referred to as the Measures Specifications Panel (MSP).

TABLE 1 – TECUPP Composition:

<u>Name</u>	<u>Organization</u>	<u>Member of the MSP</u>	<u>Present at TECUPP meeting (4/10/2019)</u>	<u>Present at MSP Meeting (4/11/2019)</u>	<u>Additional COI disclosed during meeting</u>
Steven M. Asch, MD, MPH	Stanford University and VA Palo Alto Healthcare System, Palo Alto, CA	Yes	Yes	Yes	None
Kathleen Bickel MD, MPhil, MS	University of Colorado School of Medicine, Aurora, CO	Yes	Yes	Yes	None
Lori Bishop, MHA, BSN, RN	National Hospice and Palliative Care Organization, Alexandria, VA	Yes	Yes	Yes	None
Brenda Blunt, DHA, MSN, RN	CVP Corp, Townson, MD	No	Yes	NA	None
Amy Ciancarelli, BS, CPXP	Care Dimensions, Danvers, MA	No	Yes	NA	None
Amy Davis, DO, MS, FACP, FAAHPM	Dr. Amy Davis Palliative Care and Symptom Support, Bala Cynwyd, PA	No	Yes	NA	None
Sa’Brina Davis, family caregiver	National Patient Advocate Foundation	No	Yes	NA	None



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Sydney Dy, MD, MS, FAAHPM, *TECUPP Co - Chair	John Hopkins Bloomberg School of Public Health, Baltimore, MD	Yes	Yes	Yes	None
Mary Ersek, PhD, RN, FPCN, *TECUPP Co - Chair	Department of Veterans Affairs; University of Pennsylvania Schools of Nursing and Medicine, Philadelphia, PA	Yes	Yes	Yes	None
Torrie Fields, MPH	Blue Shield of California, San Francisco, CA	Yes	Yes	Yes	None
Elizabeth Fricklas, PA - C	Duke Health, Durham, NC	No	Yes	NA	None
Joy Goebel, RN, PhD, FPCN	California State University Long Beach, Long Beach, CA	No	Yes	NA	None
Matthew Gonzales, MD, FAAHPM	Institute for Human Caring and St. John's Health, Gardena, CA	No	Yes	NA	None
Anna Gosline, SM	Blue Cross Blue Shield of Massachusetts, Boston, MA	No	No	NA	NA
Marian Grant, DNP, CRNP, ACHPN, FPCN, RN	Consultant, Baltimore, MD	No	Yes	NA	None
George Handzo, MA, MDiv, BCC, CSSBB	HealthCare Chaplaincy Network©, New York, NY	No	Yes	NA	None
Denise Hess, MDiv, BCC - PCHAC	Supportive Care Coalition; Providence St. Joseph Health, Hillsboro, OR	No	Yes	NA	None
Sarah Hetue Hill, PhD	Ascension Health Group, St. Louis, MO	Yes	Yes	Yes	None
Faye Hollowell, BS, BM, patient advocate, family caregiver	National Patient Advocate Foundation	No	Yes	NA	None
Arif Kamal, MD, MBA, MHS, FAAHPM, FASCO	Duke University School of Medicine, Chapel Hill, NC	Yes	Yes	Yes	None
Rebecca Kirch, JD	National Patient Advocate Foundation, Washington, DC	No	Yes	NA	None
Cari Levy, MD, PhD, CMD	AMDA –The Society for Post - Acute and Long -Term Care Medicine, Denver, CO	No	Yes	NA	None
Hannah Luetke - Stahlman, MPA	Cerner Corporation, Kansas City, MO	No	Yes	NA	None
Phillip Rodgers, MD, FAAHPM	University of Michigan Medical School, Ann Arbor, MI	Yes	Yes	Yes	None
Benjamin Schalet, PhD	Northwestern University, Chicago, IL	Yes	Yes	Yes	None
Tracy Schroepfer, PhD, MSW, MA	University of Wisconsin - Madison School of Social Work, Madison, WI	No	Yes	NA	None
Cardinale B. Smith, MD, PhD	Icahn School of Medicine at Mount Sinai, New York, NY	Yes	Yes	Yes	None

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Paul E. Tatum, III, MD, MSPH, CMD, FAAHPM, AGSF	Dell Seaton Medical Center at the University of Texas, Austin, TX	No	Yes	NA	None
Martha Twaddle, MD, FACP, FAAHPM, HMDC	Northwestern Lake Forest Hospital Cancer Center, Lake Forest, IL	No	Yes	NA	None
Kathryn Walker, PharmD, BCPS, CPE	University of Maryland; MedStar Health; Society of Palliative Care Pharmacists, Baltimore, MD	No	Yes	NA	None

Preview of measures:

In alignment with CMS’s Meaningful Measures framework, which identifies high priorities for quality measurement and improvement, CMS identified gaps in the Quality Payment Program (QPP) measure set. One gap identified, by CMS, was in palliative care measures. CMS selected AAHPM, with partners the Coalition and RAND, to address this gap through the creation of new quality measures. AAHPM had done previous work to identify gaps in quality measurement for palliative care, and thus was well suited to lead this work.

TABLE 2 – Proposed Measures for Discussion during the TECUPP and MSP Meetings:

Measure Area	Description
Communication	Percent of patients age 18 years or over receiving specialist palliative care in outpatient clinics who report feeling heard and understood by their palliative care provider on the Heard & Understood data element.
Symptom	Percent of patients age 18 years and over receiving specialist palliative care in outpatient clinics who report getting the help they need for their [symptom].

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Technical Expert Clinical User Patient Panel (TECUPP) Meeting Summary

Wednesday April 10, 2019 8:30 am - 4:00 pm CT Meeting
Location: American Academy of Hospice and Palliative Medicine
8735 West Higgins Road, Suite 300
Chicago, IL 60631

8:30 Welcome Remarks:

Presenters: Steve Smith, MS, CAE, Executive Director and CEO, AAHPM
Amy Melnick, MPA, Executive Director, National Coalition for Hospice and Palliative Care

Purpose and objectives of the TECUPP:

The primary purpose of the TECUPP meeting was to solicit input from TECUPP members on specific issues facing the measure development process and team (e.g., selection of symptoms to include in data elements, wording and attribution of data elements, response scales, and timeframes), as well as general input on importance, feasibility, and expected value of the proposed measures. The TECUPP and MSP members represent a broad array of stakeholders including measure development experts, palliative care clinicians from the interdisciplinary team, specialty society representatives, patient advocates, former patients, family members, caregivers, healthcare industry representatives, diversity experts, and others. Members of the TECUPP have been selected from nominations received from the public and include representatives from national organizations. We coalesced this robust and unique combination of stakeholders to provide strategic feedback and direction to the project, which will help ensure that the new measures will be patient-centered and meaningful to seriously ill patients and their caregivers. The ultimate goal of the new measures is to improve the quality of care received by patients and families.

TECUPP Objectives:

1. Help to develop and continually refine the proposed measure concepts.
2. Assist in measure specification development.
3. Discuss and provide feedback on measure testing results.
4. Review and incorporate public comment into measure specifications.
5. Approve final measure specifications and implementation method(s).
6. Assist with developing risk adjustment methodology.
7. Defend measures during endorsement process at NQF and inclusion in the CMS QPP.
8. Help develop materials for measure dissemination and implementation.
9. Further Project Objectives overall and the additional goals of:
 - a. Ensuring dignity, respect, and autonomy in serious illness care.
 - b. Involving persons and families in the care process and demonstrate knowledge, skill, and confidence to self-manage health care, with the potential to improve person-centered care.
 - c. Helping to assure that patients feel heard and understood to improve communicating prognosis and treatment options and assuring adherence to the treatment plan.

Summary of goals for the meeting:

Presenters gave an overview of the goals for the meeting. The goal of the day was to provide input and feedback on specific issues facing the measure development process and team (e.g., selection of symptoms to include in data elements, wording and attribution of data elements, response scales, and timeframes), refine measurement concepts, and provide general input on importance, feasibility, and expected value of the proposed measures. The TECUPP meeting serves the ultimate goal of making sure that the measures are relevant and important to patients, family members, caregivers, and clinicians.

The instructions given to participants were to think holistically (incorporate biopsychosocial and spiritual perspectives), be transparent and comprehensible (especially to the public), and to be creative. TECUPP charter was approved; attendees were assured that “parking lot” items will be tracked on flip charts.

8:45 Small group breakout:

Presenters: Sydney Dy, MD, MS, FAAHPM (Co-Chair)
Mary Ersek, PhD, RN, FPCN (Co-Chair)

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Attendees broke up into small groups with the instructions to introduce themselves, share what they hope to contribute to the meeting, and provide ideas on how we can best capture the patient experience in hospice and palliative care. The two co-chairs gave instructions and expectations. This included explaining the co-chairs' role of making sure everyone's voice is heard since the TECUPP members were vetted for their unique voices, and all are of equal importance. Additional comments included: it's difficult but important to focus on the few issues we've chosen. A lot of what's important to us can't be put in a quality measure that can be endorsed by the National Quality Forum (NQF) and adopted by CMS, and it's important to be aware of this framing. As such, our focus is on what's important to patients, family members, caregivers, and clinicians, and we will try to develop the best measures that can be endorsed.

Comments from the breakout to share with broader group:

Summary/synopses of comments:

- Important to not just work on measure development and validate a tool, but to think of implementation as well. Identify gaps and how we can work with team to better educate patients and employ them to be advocates for their healthcare. It would help to understand where we are now, where we have to go, and how to advance the field.
- The two measures in this project are not the be-all, end-all, but rather are the essential starting place for what the standard of practice should be.
- All people should be conditioned to talk about their conditions.
- Public demand will change how practitioners take to this measure and in turn reinforce public demand.

9:15 - Welcome and Introduction from CMS:

Presenter: Reena Duseja, MD, MS, Chief Medical Officer, Quality Measurement and Value-Based Incentives Group, Centers for Clinical Standards and Quality, CMS

To help contextualize the project team work and the role of the TECUPP in the measure development process, Dr. Duseja provided a comprehensive overview of the QPP, MIPS, Meaningful Measures, and CMS's vision for quality reporting.

Questions/Group Discussion:

- One participant raised concerns about equity and that people who need opioids should have access to them.
- Presenter from CMS replied that they are aware that sometimes the pendulum can swing too far in the other direction. CMS wants to address patients' pain in a way that is multi-modal.

9:30 - Brief Project Overview – TECUPP Role and Tasks:

Presenter: Katherine Ast, MSW, LCSW, AAHPM

Presenter provided the following key points:

- Communication and unmet symptom needs rose to the top of the priority list for measure development because they're:
 1. Important
 2. Not duplicative of existing work
 3. Not the same as what was in other proposals
- An open public comment period will occur in year 3, quarter 2 – towards the end of the three-year project. But the process will include input throughout from the TECUPP, project advisors, and public webinars, so there are no surprises.
- The principles of patient-centered measurement are what makes this project different than others.
- Reminder to group to share their lived experiences.

Clarifying comments by other leaders:

- Lived experience includes your professional role, your research, your own family, or other experiences that brought you here. Let those experiences guide your advising and commenting, because that's one of your most important assets and will help us stay true to our mission.
- We're developing patient-reported experience measures (PREMs). Note, there is another RAND/Moore Foundation palliative care survey being developed – this project is different. Our questions are meant to be able to stand alone-should be able to use 1-2 questions by themselves, so it wouldn't be necessary to do the whole five-page survey.

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- Today, we are working on vetting the survey wording – at the project’s end, we will have performance measures.
- Most importantly, this is a “by us, for us” effort.

9:45 – Review TECUPP Notebook:

Presenter: Kanaka Shetty

Highlights from Information Gathering Work to Date were presented:

- Environmental Scan Findings
- Focus Group and Interview Findings
- Other Information Gathering Activities

To help TECUPP members consider the proposed measure concepts and provide feedback to help inform the work going forward, results of all information-gathering activities to date were presented. The purpose of these activities were to identify existing patient-centered data elements that could inform the refinement of the data elements used to assess patient experience of feeling heard and understood and of unmet symptom needs as well as to identify potentially competing quality measures to ensure that the measure development efforts are harmonized across accountability programs. These activities included a summary of results from the targeted literature review, quality measure scan, provider focus groups and patient and family interviews. We conducted four in-person focus groups in metropolitan areas across the United States for palliative care providers. We sought provider focus group participants who were:

- Frontline providers currently providing (or who have provided) palliative care services; preferably, practicing outpatient clinic-based or home-based palliative care (i.e., not inpatient palliative care or hospice care); and
- Physicians (MD/DO), advanced practice registered nurses (APRNs), physician assistants, registered nurses, social workers, chaplains, and pharmacists.

We specifically sought to identify clinicians directly involved in patient care activities rather than academic experts or administrators, to better understand the value and feasibility of implementing the proposed quality measures from their perspectives. There was a total of 35 participants across the four locations. They consisted of:

- 8 physicians (including 2 CMOs and 1 medical director)
- 6 nurse practitioners
- 6 social workers
- 3 registered nurses
- 3 pharmacists
- 5 chaplains
- 2 physician’s assistants
- 2 administrators

The patient and family and family interviews were held between February 8 and 15, 2019. Interview participants consisted of:

- 4 patients with advanced illness, not receiving/received hospice and/or palliative care (one of whom was joined by his wife during the interview)
- 2 patients receiving/received palliative care
- 1 caregiver

The literature review and measure scan identified existing data elements, surveys, and quality measures to help inform the refinement of data elements. Focus groups and interviews yielded information on the relevance and importance of our measure concepts, the feasibility of collecting patient-reported data on communication and unmet symptom need in outpatient palliative care, and potential barriers and facilitators to implementing the proposed quality measures in practice.

Questions/Group Discussion

After a review of the TECUPP Notebook, the attendees asked questions and addressed issues regarding representation of patients and caregivers relative to providers in the information gathering phase; and selection criteria including sample size, geographical regions included (e.g., rural, urban, etc.) and practice level variations (e.g., solo practice, large medical groups, or Hospice/Palliative Care programs).

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Terminology was also discussed particularly about:

- *Palliative care* - how to define and patient awareness of the terms “serious illness,” “hospice,” and/or “palliative care.”
- *Problem versus symptoms* – the group discussed how the terms used reflect medical problems (pain, symptoms, etc.) vs other “worries” (financial, family, etc.). This included discussion about what can be measured as attributable to care provided and the role of measurement in reflecting current practice vs. driving change in practice towards what best serves patients and families.
- *Palliative care provider/interdisciplinary team* – the group discussed patients’ perceptions about the role of providers and other care team members in their care and the extent to which patients perceive providers as part of a team, solo, or on the palliative care team.
- *Opioids/pain management* – addressing the opioid debate and talking about pain management was important to TECUPP members with discussion around differences and trade-offs with pain management (total pain control vs. lucidity) and satisfaction with getting the treatment they wanted.
- *Parking lot¹*: psychosocial/spiritual distress and alternative medicine was brought up in the discussion, but because it was a bigger discussion it was put in the parking lot for another time/another project.

10:15 – Review of Draft Survey Instrument:

To further contextualize the measure development work, TECUPP members were provided an overview of the survey instrument being developed to collect the necessary data for the proposed quality measures. This instrument includes patient-reported data elements assessing patient experience in the domains of communication and symptom management, including the data elements to assess feeling heard and understood and perceived help wanted for symptoms. TECUPP members were asked to consider the structure, format and wording of these data elements as the provided feedback on both the survey instrument as well as the proposed quality measures derived from these data elements.

Questions/Discussion:

Initial questions and discussions included how to convey anonymity in the survey, and was there confidence that the quality measure concepts chosen demonstrated a gap that would pass NQF endorsement. The presenters indicated that the cover letter and survey itself would assure patients that survey responses would remain anonymous, and the gap was established by both by the patient and family interviews, provider focus groups, and the literature review.

Key Design Considerations for Panelist Input:

The primary purpose of the TECUPP meeting was to solicit input from TECUPP members on specific issues facing the measure development process and team (e.g., selection of symptoms to include in data elements, wording and attribution of data elements, response scales, and timeframes), as well as general input on importance, feasibility, and expected value of the proposed measures. To obtain this input, a series of facilitated discussions were conducted with the TECUPP, whereby the key question along with relevant background and context to facilitate discussion was presented to the group, and then a focused discussion was held. Recommendations and a summary of the discussion was reviewed at the end of each facilitated discussion, with the expectation that the MSP would finalize any relevant decisions based on these facilitated discussions during their meeting on April 11th. Sydney Dy, MD, FAAHPM, and Mary Ersek, PhD, RN, FPCN, in collaboration with Sangeeta Ahluwalia, PhD from RAND facilitated the discussions.

Quality Measure Attribution – What should unit of attribution be for quality measurement in palliative care (individual provider, team, practice, etc.)?

Facilitators: Sangeeta Ahluwalia, PhD, Sydney Dy, MD, MS, FAAHPM, Mary Ersek, PhD, RN, FPCN

It was clarified that the measure testing in this project would be done in the outpatient setting, which is defined in this project as ambulatory, clinic-based care in an outpatient setting (not inpatient palliative care, and not home-based palliative care). We are focusing on outpatient because of the rapid growth of outpatient clinics and growing need to provide palliative services farther upstream; i.e., in ambulatory settings and in the primary care context. MIPS does apply to home-based care as well, and this setting is certainly important, but another RAND project focuses specifically on home-based care and ACOs, so we narrowed this project’s focus to outpatient to avoid duplication and maximize harmonization across measure development efforts.

¹ The parking lot is a productivity technique for effectively dealing with important non-agenda items that arise during the course of a meeting. Non-agenda items are recorded on a flip chart during the meeting, which is visible to all attendees. These items are able to be followed-up on later in the meeting or at future points in the project.

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There was a related discussion regarding the phrase “palliative care,” particularly since many patients may not recognize that they are being treated by a palliative care team or provider. Participants noted that the absence of a clear distinction between palliative care and other services actually positively demonstrates care coordination but acknowledged the need to consider respondent burden in attempting to answer the question. There was also discussion of the term “provider” vs “clinician” vs other labels, and one suggestion to use specific names which may be more familiar to patients (e.g., Dr. Jones and the Stanford team). Group provided input on whether a patient’s experience should be assessed on team-based service or should we only assess individual MIPS-eligible clinicians. Examples included wording on “care from [provider] with [team].” While the group saw value in mentioning both team and individual, the feasibility and purpose of capturing data would be the challenge. Challenges included how to populate the field National Provider Identifier (NPI)/Tax Identification Number (TIN), differing “team models” across settings, patients’ awareness of receiving palliative care, and that the measure is tied to physician reimbursement.

Other topics included:

- Addressing “unmet need” and “being heard and understood.”
- Assessing “what’s most important or bothersome” to the patient that they want help addressing.
- Asking how well the provider/team addressed whatever it was that the patient found most bothersome (ie, symptom or functioning or side effect or emotional need).
- Implementation and burden – would multiple MIPS providers mean multiple surveys, timing of the surveys, and point of care versus mailed surveys sometime after the appointment.
- Accountability and effect of non-MIPS providers who provide care or participate as part of the care team on overall patient rating.

The presenters discussed focus group recommendations and how they will include this discussion and concerns in testing.

11:30 – Measure Eligibility Criteria:

- How do we capture the “right” patient population?
- What is the appropriate provider population to assess?
- What are key exclusions?

The currently proposed visit eligibility criteria that TECUPP participants were asked to respond to was at least 2 visits to outpatient palliative care in the prior 6 months. Some participants felt expanding the measure beyond two visits would be valuable for ensuring adequate and appropriate exposure, particularly given that usually there is a palliative care consultation and then a follow-up with a different provider type. However, others worried that expanding to three visits would be problematic given significant variations in volume across time, patients, and sites. For example, one participant who worked in a large hospital noted they almost never see an individual three times total within 6 months; another noted using a criterion of three visits within six months would eliminate 50 percent of their patients from eligibility. Some others agreed and noted that a lot of people come only once and never come back so the proposed criteria would not include those individuals so perhaps one visit should be considered. One participant cautioned against using only one visit citing standard attribution methodology of two visits. Participants generally questioned the use of six months as a reference timeframe as being too long from a quality improvement perspective and for the potential of “loss to follow-up”; i.e., patients may have died or moved to hospice. It was also noted that a 6-month timeframe could hinder patient recall.

Presenters discussed the need to maximize the number of people eligible for the measure in order to achieve testing results that are reliable and valid, and the risk if the denominator is too specific there will not be enough patients. Additionally, the group discussed encounters that happen outside visits which may include phone calls and tele-medicine (ie, video). Patient eligibility was discussed with current exclusions being age, dying by the time the survey goes out, and those receiving hospice care. Patient proxy respondents were also discussed – specifically regarding patients with dementia. TECUPP members generally agreed that cognitive impairment (or other specific conditions) should not be an exclusion provided proxy response/assistance was allowable in order to get as robust a picture of the care experience as possible.

12:30 – Communication Measure: Provide Input on Draft Data Elements:

- Wording/Response Options
- Alternate and Additional Data Elements
- Implementation Considerations

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With the emphasis on getting at the construct of fostering healing relationships, the presenters opened the discussion about optimal item wording and response options, meaningful thresholds to evaluate performance on quality measures, and what symptoms are most clinically meaningful to measure. The group discussed how patient/respondents tend to respond to various survey options (i.e., 2-response options versus 5-response options, etc.) and the difference between “how well” and “how much.” Throughout the discussion, participants stressed translation and literacy considerations for the items and corresponding response patterns.

1:15 Unmet Symptom Need Measure: Provide Input on Draft Data Elements:

- Wording/Response Options
- Alternate and Additional Data Elements
- Implementation Considerations

The presenters discussed that they wanted a measure that reflects the patient’s goals of what they want out of treatment, not necessarily the “clinical goal.” The group discussed the “experience of pain” that includes physical, emotional and/or spiritual pain. Additionally, the point was emphasized about how much psychosocial/spiritual distress can affect physical symptoms. The discussion also included suffering and unmet needs regarding various issues and how important it is to find out “what matters most” to the patient. For example, one family caregiver spoke about the medical team focusing so much on her loved one’s physical symptoms that they failed to ask about his overall goal, which was to drive a car again. There was a recommendation to explore emotional pain. The TECUPP members made it clear that focusing just on a predefined list of physical symptoms wasn’t enough for patients, family members and caregivers – that respondents need to be able to indicate what is most important to them and focus on that. The participants were reminded that we are developing measures for the MIPS program which will affect payment and so should recognize and measure what is attributable to the MIPS-eligible provider and team. Participants discussed this concept, from their various discipline perspectives, and how it relates to what matters most to patients.

Participants were provided a list of symptoms to consider for assessment. This included:

- Pain
- Fatigue/tiredness
- Nausea/vomiting
- Anorexia
- Dyspnea/respiratory problems
- Low mood
- Anxiety

The conversation revolved around the topic that consequences of symptoms related to quality of life were more relevant than the actual symptom (i.e., having to be near a bathroom because of diarrhea). Anorexia was thought not be as necessary on the assessment because there is less that can be done about that within the context of this measure. The group discussed different ways to present the question (a check list of symptoms, open-ended questions, etc. and different checklists already available for low mood). The group also discussed different scenarios about scoring pain. The group was more in favor of an option to score pain with the following numerator and denominator.

$$\frac{\% \text{ of patients who report getting the help they want for pain}}{\% \text{ of patients who report having pain and wanting help for it}}$$

2:15 Proxy Respondents:

- When is proxy response appropriate?
- What factors should we consider when looking at proxy responses?

Proxy responses will be allowed for this measure and there will be questions about who the proxy is, how they were involved with the patient, and their ability to answer the questions. The group shared examples of why patients may need a proxy, types of proxies and level of involvement with the patient, and how that may affect the validity of the response.

“What Else”:

The presenters opened the discussion to other things that should be considered. Individuals in the group offered information on non-binary gender questions, population-based vs. QI measures, how the measures are tied to payment adjustment, and the need for family caregiver measures. The group shared information about how quickly patients can transition through various

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care settings and services (specifically palliative care and hospice), so we need to be careful not to send duplicative surveys or to exclude everyone who has died. An issue for the parking lot included the feeling of being overwhelmed and whether the team did anything to help. Coping also goes along with that. It was clarified that although we are only testing these measures in the outpatient setting, the other RAND team is testing the full patient experience of care survey in the home setting. The hope is that all these measures will be able to be used across settings, even if they're tested separately.

Summary and Next Steps:

Participants were provided a greater understanding of the project and progress to date. Participants had a robust discussion around the unit of attribution (individual provider, team, practice, etc.), eligibility criteria, wording for data elements, symptoms for the unmet symptom measure, and proxy responses. Although the point of the TECUPP discussion was not to solidify key decisions, the discussion will help inform the decision making process, and in many cases the discussion offered perspectives that better centered the conversation on the needs of patients, family members, and caregivers. The TECUPP recommended allowing proxy responses; and given the collaborative nature of palliative care, the participants recommended exploring ways to attribute the questions to both the provider/clinician and the team.

The Measure Specification Panel (MSP) was scheduled to meet the next day. TECUPP participants were assured that the robust discussion from the first day would inform the MSP meeting. The MSP would dive deeper into measure attribution, accountability, eligibility criteria, and data item construction. After the TECUPP and MSP meetings the project team will incorporate their recommendations, to the extent possible. Additionally, the TECUPP will be reconvened at strategic points throughout the project to inform critical decisions.

TABLE 3 – Key TECUPP Recommendations for Project Team and MSP Consideration:

Measure Area	Measure Description	Key TECUPP Recommendations
Communication	Percent of patients age 18 years or over receiving specialist palliative care in outpatient clinics who report feeling heard and understood by their palliative care provider on the Heard & Understood data element.	-Patient's experience should be assessed on team-based service (e.g., "care from [provider] and [team]") -A 6-month timeframe could hinder patient recall -Cognitive impairment (or other specific conditions) should not be an exclusion/ allow proxy response
Symptom	Percent of patients age 18 years and over receiving specialist palliative care in outpatient clinics who report getting the help they need for their [symptom].	-Assess "what's most important or bothersome" to the patient that they want help addressing; do not provide a list of symptoms -The "experience of pain" includes physical, emotional and/or spiritual pain; do not define pain -Address emotional pain and support

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Measure Specification Panel (MSP) Meeting Summary

Thursday April 11, 2019 8:30 am - 12:00 pm CT

Location: American Academy of Hospice and Palliative Medicine

8735 West Higgins Road, Suite 300

Chicago, IL 60631

The Measure Specification Panel (MSP) is a subgroup of the larger TECUPP (please see Table 1 above), selected for their specialized clinical measure development expertise. Throughout the course of the three-year effort, MSP participants are expected to review and provide expertise on measure specifications; provide technical feedback following the public comment period; and review measure testing methodologies and results and provide feedback, as requested.

The MSP convened in-person for a half-day meeting on Thursday, April 11, 2019 in Chicago, IL to help integrate the input of the larger TECUPP, and make recommendations for testing and measure specifications. In addition to the objectives of all TECUPP members, MSP participants have these additional objectives:

- Review and provide expertise on measure specifications including numerator, denominator, exceptions, exclusions, and other methodological considerations.
- Provide technical feedback following public comment periods and required measure specification updates through periodic conference calls.
- Review measure testing methodologies and results and provide feedback, as requested.

8:30am: Overview of Goals for MSP and panelists role:

Facilitators: TECUPP Co-Chairs, Sydney Dy, MD, MS, FAAHPM and Mary Ersek, PhD, RN, FPCN

The TECUPP Co-Chairs reviewed the topics discussed during the TECUPP, including:

- Measure attribution or accountability
- Eligibility criteria (visit, patient)
- Data item construction: e.g., wording and response options for each of the proposed data elements

The MSP were then reminded that their role is to help the project team integrate the TECUPP discussion with their personal and professional expertise.

8:45am: Review draft measure specifications based on TECUPP input:

Key reactions to the TECUPP meeting:

Before providing feedback on the identified topics, MSP participants were prompted to reflect on the previous day's discussion and share any high-level reactions:

- Participants emphasized how valuable it was to convene diverse stakeholders and capture their thoughts and perspectives on a range of relevant issues facing the field of palliative care quality measurement. They noted the importance of documenting the meeting as a resource for future work.
- Participants shared that they think it is important that all measure development projects in the field coordinate or are at least aware of each other. They also shared that it is very difficult to know how to coordinate and sequence these efforts.
- Participants remarked that team-based care is a fundamental aspect of palliative care delivery but also stressed that the provider – typically a physician, physician assistant, or advance practice nurse – is the one who is ultimately held accountable through CMS quality measurement reporting programs. While TECUPP participants disagreed on what was within the expected scope of a provider's responsibility; e.g., whether adequately addressing financial or other social needs were appropriate for quality measurement purposes, MSP participants generally agreed that such needs were beyond the responsibility of a medical provider in the context of quality and performance measurement, which underscores the importance of the team.
- Participants remarked that for the measures to have broader generalizability, utility, and longevity, they should be developed based on identified gaps in palliative care measurement and that the parameters of the Quality Payment

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Program and MIPS should not be the primary driver. However, the group agreed that passing NQF is critically important. There is a passion and commitment from the palliative care field to create measures that appropriately capture their work; however, the measures that are written must be useable, and must fill a gap within NQF. Although we are creating unique measures that fill gaps identified by CMS and the palliative care field (both patient reported outcome measures and palliative care measures), we need to also make sure that the measures are harmonized with other measures in the field and able to be implemented across various programs or settings.

- There was some confusion about the mission and objectives of the TECUPP and some concern that large decisions had not been resolved during the TECUPP meeting. However, it was explained that the project team did not expect large decisions to be made during the TECUPP meeting, but instead it was meant to be an opportunity for the expert panel to provide feedback on pre-identified topics.

Facilitated Discussion on Recommendations and Decisions:

The MSP meeting centered on a series of facilitated discussion on the three key topics outlined above. The panel was first presented with an overview of the key takeaways from previous day’s discussion for each topic, the implications of those discussions on the relevant survey item wording, and where relevant, a proposed recommendation for reactions and feedback. Specific questions were posed to the panel to stimulate discussion and consideration.

9:00am: Discussion one: is accountability at the team or individual or provider level? (Attribution and Accountability)

The first facilitated discussion focused on whether accountability should be at the team or individual provider level. Table 4 presents the summary information presented on the TECUPP discussion.

TABLE 4 – TECUPP Summary and MSP Focused Questions:

Accountability lies with everyone on the team and there should be a continued push towards team-based care. However, patients may not be able to identify/distinguish the palliative care team and not everyone has a team. For implementation, we may not be able to identify the team as it is not a TIN.	
Survey Implications	<ul style="list-style-type: none"> • Referring to a single clinician poses challenges to identification and recall for the respondent; it also does not reflect team-based palliative care and narrows eligibility. • Referring to the team poses challenges to identification for the respondent and for the data pull; this could potentially be mitigated with a list of possible clinicians but may cause confusion and/or double attribution. • Referring to both (e.g., Dr. XYZ and the ABC Care Team) would expand the potential referents and may mitigate identification/recall challenges; however, may experience additional challenges around identification for the respondent and could also cause confusion or frustration leading to non-response.
Recommendation / Question	<p>To whom should we refer the respondent when answering the survey?</p> <ul style="list-style-type: none"> • How can we help patients think of both individual clinicians and the team overall? Alternatively, how narrowly can we define the referent? • When considering single clinicians, should we limit just to specialist palliative care clinicians? If not, how should we define palliative care versus other care?

Participants reflected on the implementation considerations. They noted the challenges with using NPI or TIN to focus on a specific specialty. There is a limited range of information that can be pulled from an NPI (e.g., the provider’s name) or TIN (the legal name of the site), challenging the ability to prepopulate and tailor surveys with the name of the specific team.

Participants recommended instead using a generic “and team” to help drive the field towards co-accountability in light of the feasibility constraints of not being able to name a specific team. While some participants expressed concern about issues of ownership and accountability as well as issues of patient burden (e.g., would patients struggle with describing their experience with the single provider vs. the team) in general, the group felt this approach of using “Dr. XYZ and team” was a good solution.

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9:30am: Discussion two: Measure Eligibility Criteria

The second facilitated discussion focused on issues around eligibility – specifically the number of visits as well as the time frame for those visits. The original criteria prior to the TECUPP was set at two visits in the last six months. Per the discussion from the TECUPP, one visit in six months may be inadequate but that three or more visits could set the bar too high for “entry” into the measure. Specifying the criteria for two visits in six months might be a way to compromise between the other two options, particularly if the definition of “visit” is broadened to include encounters such as tele-video. Further, some participants felt that six months may be too long for potential respondents and could present challenges with recall or loss-to-follow-up which would make the findings less actionable. However, there were also concerns that setting the threshold to three months could limit the eligible sample. The AAHPM team presented a recommendation of requiring two visits in the last six months, with at least one visit in the last three months for the group to discuss.

Participants began the discussion focused on the number of visits. It was noted that a single visit might not be enough for the provider to address all the areas being measured; e.g., while a patient might feel “heard and understood” in a single visit, the provider may not have a chance to begin managing or addressing pain in one visit.

There was also a discussion around defining a billable visit (i.e., generated by an encounter with a qualified practitioner). This has implications on encounters such as those via telephone because while there are ways to bill, there are limitations (e.g., a certain amount of time on the phone, whether the patient is remote).

Participants noted the implications on sample size and that changing from two visits to one visit could likely double the sample. One participant liked the concept of limiting to one visit with this measure as a way to see what the impact could potentially be within one visit and that the testing data might inform future decisions around this.

Participants were concerned about the six-month time frame (despite noting its use in CAHPS surveys) due to factors such as palliative care patient characteristics (e.g., some patients may die, some may become cognitively impaired or move to another setting of care within that time frame). The group proposed instead a 3-month timeframe.

10:15am: Discussion three: Item considerations (Heard and Understood):

Summary of the TECUPP discussion:

- TECUPP participants preferred asking “how much” or “how well” you felt heard and understood verses a questions that was framed as frequency (e.g., “how often”).
- Some participants expressed concerns about the ceiling effect with four verses five response options.
- Participants also discussed what score would be considered good and what level would be acceptable to the field.
- The project team stressed the need to be careful about item wording with respect to literacy and translation and noted these would be examined in the upcoming cognitive interviews.

MSP thoughts on how to frame the item:

One participant reported that in the VA, they framed this sentiment as a statement with “My provider understood me” and then had “very true,” “somewhat true,” etc. as response options. This approach focuses more on evaluating as opposed to quantifying and can feel more personal for respondents. Other participants liked the true/not true framing (Table 5). One participant reminded the group to think about harmonization with other instruments, such as CAHPS, in case it may be integrated with that suite of surveys in the future. The group then discussed potential answer options.

TABLE 5 – Heard and Understood Suggested Wording:

I felt heard and understood by Dr. Jones and the team.

- Not at all true
 - A little bit true
 - Somewhat true
 - Mostly true
 - Very true
-

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Participants questioned the difference between “mostly” and “very” true as well as “a little bit” and “somewhat.” Substantively, many participants expected most people to respond with either “mostly true” or “very true” and that “somewhat” or “a little bit” would indicate a clear need for improvement. Participants also discussed how a lack of variation in responses is not very useful for measurement purposes.

The group also discussed other potential approaches such as using an agreement-based scale (e.g., completely agree, agree, neutral) but felt the “true-based” language may be simpler and easier to interpret. The AAHPM team noted this item wording would be a focus of the upcoming cognitive tests.

Thresholds for good/ acceptable responses were discussed and participant varied in their feedback:

- One participant felt the threshold should be towards the top and that mediocrity should not be accepted;
- However, other participants felt that setting an initial low threshold to encourage measurement and improvement was more appropriate.
- Another participant suggested data-driven thresholds with adequate variation and that these thresholds could be adjusted from year to year – the goal would be to reward approximately 20 percent to 40 percent of providers.

11 am: Continuation of discussion three: Item considerations (Unmet Symptom Need):

Summary of MSP discussion:

- Participants stated that all pain should be addressed, and we shouldn’t separate out “everyday pain”
- They stated that the term “want” is more inclusive and reflective of the patient perspective than the term “need” (e.g., did you get the help you wanted for your pain?)
- Participants began by discussing the consideration of timeframe for this measure, particularly when thinking about bothersome symptoms in that what is most bothersome to the patient at time point A may be very different than at time point B. This can also cause complications if the patient has not told his or her provider about the most bothersome symptom.

There was a discussion of different types of pain, broader concepts of suffering, and areas important to the patient beyond symptoms.

- RAND asked if we develop a symptom list, as part of this measure, which symptoms should be included?
 - Pain; trouble breathing; constipating; nausea/vomiting; others?
 - Checklist of "most bothersome" symptoms (anorexia, fatigue, anxiety, sadness, diarrhea, etc.)
 - Combination of above (e.g., top three symptoms)
- RAND also asked if this concept would be more accurately captured by two measures- one for most bothersome symptoms and another measure for response to each symptom?
- MSP participants noted there were a range of symptoms that could potentially be included.
- Some MSP participants recommended not including symptoms where there are not good associated medical treatments such as anorexia or fatigue and including symptoms such as pain, nausea and vomiting, anxiety and depression as there are good associated treatments.
- Some MSP participants felt that trying to measure “what matters most” to the patient falls outside the scope of this project and that there is work being done by others in this area.
- MSP participants suggested considering separating symptoms by domain (i.e., physical symptoms, other unmet needs).
- The group discussed options such as having separate items grouped together or scoring them separately. However, there was concern about harmonization issues with the inpatient and hospital palliative care items as well as concern that specific symptoms are not of concern to CMS. There was general consensus that this should not be four separate measures.
- Rather than consider six separate items for this measures, or a large composite measure, the group narrowed the focus to two “symptoms” but there were differing views on what those should include. In general, there was agreement that pain is an important construct to capture as part of symptoms as it is highly prevalent. However, other symptoms suggested for inclusion include dyspnea (because it is likely to lead someone to the ER) while others liked including “emotional and psychological support.” There was concern about whether the provider should be held accountable for the latter.

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By the end of the MSP discussion, there was some consensus that the three primary areas of focus for palliative care providers are 1) symptom management (pain); 2) rapport building (i.e., feeling heard and understood); and 3) social or emotional help/support; therefore, we should frame our measurement around these three areas.

Summary of MSP Recommendations and Next Steps:

The MSP’s recommendations pertaining to the key topics discussed, to guide the measure development and testing work:

- Reflect both the provider and team accountability in the survey instrument through the use of terms such as “Dr. XYZ and the team” or “this provider and the team.” This would pertain to survey instructions as well as data element wording where applicable. This attribution will be incorporated in both cognitive testing and during the Alpha test.
- Eligibility for the measure should be set at a minimum threshold to allow the greatest number of programs/providers to participate. A single visit within a 3-month timeframe could allow most programs to participate, while also ensuring adequate exposure and minimal loss to death or hospice. Additional exploration of optimal visit eligibility is needed. The project team will review this recommendation with the project advisors and determine if additional steps are necessary prior to making a final decision.
- With regard to data element wording, frequency questions may not be appropriate given a single visit eligibility criterion. In addition, MSP participants recommended serious consideration of statement-structured data elements (i.e., “how true are the following statements”) given perceived ease of use. The project team committed to testing wording during upcoming cognitive testing. Selection of thresholds should be determined primarily on distribution of data.
- Measures should be limited to “heard and understood,” “help wanted for pain,” and an additional measure of adequacy of emotional support. The project team will discuss the inclusion of this additional measure concept, will review it with the project advisors, and will discuss the feasibility with CMS.

12:15pm: Closing Comments

Input and recommendations from the TECUPP and MSP meetings will be used to inform the next phase of the project, including cognitive testing and field testing. The Alpha test and feasibility study are scheduled for summer of 2019 and a planned Beta test will begin later in the fall. There will be 12 to 15 months of planned data collection. Additional stakeholder engagement activities are planned. The MSP will be convened, as needed, to address specific measure specification questions and the full TECUPP will be convened at planned points across the 3-year project.

TABLE 7 – Revised Measures based on TECUPP and MSP Feedback:

Measure Area	Title and Description
Communication	<i>Palliative care outpatients’ experience of feeling heard and understood:</i> The percentage of patients aged 18 years and older with at least 1 outpatient palliative care visit in 3 months, answering a survey question about feeling heard and understood, who report feeling heard and understood by their palliative care provider and team.
Symptom	<i>Palliative care outpatients’ experience of receiving desired help for pain:</i> The percentage of patients aged 18 years and older with at least 1 outpatient palliative care visit in 3 months, reporting pain and wanting help for their pain, who report getting the help they wanted for their pain from their palliative care provider and team.