

# Public Comment Summary Report

## 1 OVERVIEW

### 1.1 Project Title: PALLIATIVE CARE MEASURES PROJECT

### 1.2 Dates:

- The Call for Public Comment ran from February 1, 2021 to March 2, 2021.
- The Public Comment Summary Report was finalized in July 2021.

### 1.3 Project Overview:

The Centers for Medicare & Medicaid Services (CMS) provided funding to the American Academy of Hospice and Palliative Medicine (AAHPM) as part of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) to develop patient reported outcome performance measures, in the areas of pain management and communication, for palliative care patients with serious illness. The cooperative agreement name is the Palliative Care Measures Project. The cooperative agreement number is 1V1CMS331639-03-00. As part of its measure development process, AAHPM, along with partners the National Coalition for Hospice and Palliative Care and RAND, requested interested parties to submit comments on the candidate or concept measures that may be suitable for this project. Under this cooperative agreement, AAHPM is working to advance clinical quality measure development for palliative care patients with serious illness through the engagement of stakeholders with the goal of developing and testing two (2) patient reported outcome performance measures (PRO-PMs) for patients with serious illness while incorporating the patient voice and patient preferences.

### 1.4 Project Objectives

Cooperative agreement objectives:

- Develop, test and implement two (2) patient reported outcome performance measures (PRO-PMs) for patients with serious illness while incorporating the patient voice and patient preferences.
- Develop cross-cutting measures broadly applicable to patients with serious illness and their families receiving care in palliative, primary or specialty care settings.
- Convene an innovative technical expert panel that incorporates patient, caregiver, and family input directly into the measure development, specification, testing and implementation processes.
- Submit palliative care measures for endorsement by the National Quality Forum (NQF) and inclusion into CMS's Quality Payment Program (QPP) including MIPS and APMs so that clinicians can measure and improve the quality of care that patients with serious illness receive.

### 1.5 Information About the Comments Received:

The AAHPM team solicited public comments using the following methods:

- Posting a call for public comment on the CMS public comment website and The Coalition's MACRA Palliative Care Measures Project
- Email notification to relevant stakeholders and stakeholder organizations

- These documents were posted and available for reference during the public comment period:
  - **Measure Business Cases** – included essential information relevant to thinking about implementation such as measure descriptions, justification/evidence review, approaches to implementation, costs/benefits
  - **Measure Information Forms** – included details regarding the numerator, denominator, exclusions, measure logic, sampling, and fielding the patient-reported survey
  - **Copy of survey instrument** – included full list of questions
  - **Other overview documents** – a project overview/FAQ, links to the National Consensus Project’s [Clinical Practice Guidelines for Quality Palliative Care, 4<sup>th</sup> edition](#), TECUPP summaries, Project Advisor and TECUPP rosters
- We received 12 responses for the Palliative Care Measures Project via email
- We received 195 complete responses for Palliative Care Measures Project via online survey

**Total Public Comment Individual Respondents: 207**

- Patient/Caregiver/Family Members/Advocates (combined): 71 (36% of all respondents)
- Providers/Clinicians (serious illness care): 87
- Other Healthcare Professionals: 28
- Representatives from National Organizations: 21

**Total Public Comment Responses: 1,388 unique comments**

Our public comment survey contained ten multiple-choice questions (excluding demographics), each with an opportunity for free text comment, and 2 additional open-ended questions. We responded to summarized substantive open-ended comments in this report. Verbatim comments are included as a separate report due to volume.

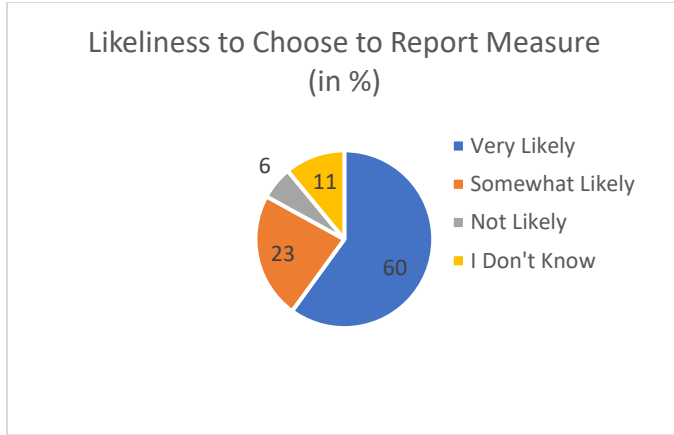
**Summary of Multiple-Choice Findings:**

**Table 1. Support of Measures**

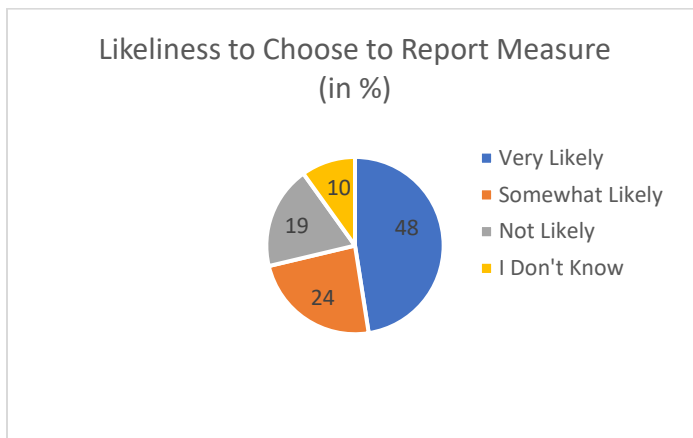
<b>Feeling Heard and Understood Measure:</b>	<b>Receiving Desired Help for Pain Measure:</b>
Support: 176 (85%)	Support: 152 (73%)
Support w/ Modifications: 17	Support w/ Modifications: 34
Did Not Support: 8	Did Not Support: 15
No answer: 6	No answer: 6

**Figure 1. Likeliness to Report Feeling Heard & Understood Measure:**

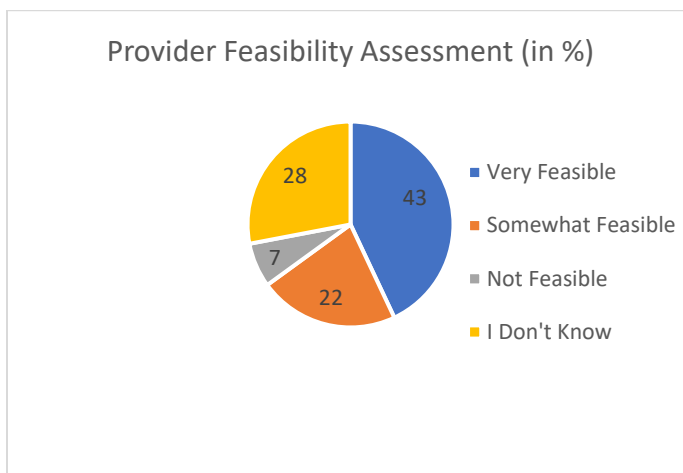
***83% of Providers Very or Somewhat Likely to Choose to Report***



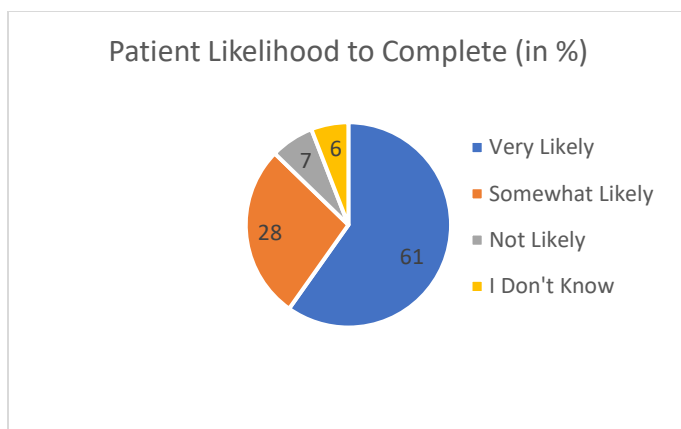
**Figure 2. Likeliness to Report Receiving Desired Help for Pain Measure:**  
**72% of Providers Very or Somewhat Likely to Choose to Report**



**Figure 3. Provider Feasibility Assessment for Both Measures**  
**65% of Providers Say Very or Somewhat Feasible to Implement**



**Figure 4. Patient Survey Likelihood of Completing Surveys**  
**87% of Patients Very or Somewhat Likely to Complete**



**Table 2. Likelihood of Using Measures for Quality Improvement**

<u>Feeling Heard &amp; Understood Measure:</u>	<u>Receiving Desired Help for Pain Measure:</u>
<b>82% Very or Somewhat Likely to Use for Quality Improvement</b>	<b>71% Very or Somewhat Likely to Use for Quality Improvement</b>
Very likely: 60%	Very likely: 47%
Somewhat Likely: 22%	Somewhat Likely: 24%
Not Likely: 6%	Not Likely: 19%
I don't know: 11%	I don't know: 10%

**Table 3. Do Measures Capture Important Information?**

<u>Feeling Heard &amp; Understood Measure:</u>	<u>Receiving Desired Help for Pain Measure:</u>
<b>79% of Patients Said Measure Captures Important Information</b>	<b>73% of Patients Said Measure Captures Important Information</b>
Yes: 79%	Yes: 73%
No: 4%	No: 7%
I don't know: 17%	I don't know: 20%

**2 General Stakeholder Comments:**

**2.1 Measure Concepts**

**2.1.1 Importance**

*Comment Summary:* Most of the comments the AAHPM team received about measure importance reflected that both proposed measures get at the heart of what palliative care should do – they align with the goals of palliative care. Many respondents also highlighted how helpful and meaningful it is that the measures are patient-driven and patient-centered. A few commenters specifically called out

how these measures could expose differences in responses due to diversity, equity and inclusion. Many others highlighted that the measures should help contribute to the value proposition for palliative care. A few commenters were concerned that focusing on pain may reinforce misunderstandings between palliative care as opposed to treatment of chronic pain. Overall, however, most organizations thanked CMS for prioritizing this work and they committed to disseminating the measures. A sampling of the comments on measure importance is captured in Table 4.

**Table 4. Examples of Comments about Measure Importance**

<p>“These questions capture the essence of specialty palliative care practice.”</p>	<p>“These measures speak to outcomes that are a matter of mission and pride for hospice clinicians.”</p>
<p>“Reflect core elements of patient and family centered care- which is an organizational priority.”</p>	<p>“The 2 measures represent information that reflects ‘what matters most’ to our patients and their families.”</p>
<p>“Palliative care providers recognize the importance of patient self-reported outcomes; [in addition,] communication and pain management are key practice areas.”</p>	<p>“These two new PRO-PMs provide a critical mechanism for demonstrating the quality that palliative care delivers, particularly as the health care system continues its transformation towards value.”</p>
<p>“Given the importance of these measures, CAPC [Center to Advance Palliative Care] is committed to disseminating them to our audience. This includes educating palliative care teams on how to use the measures by incorporating them into our tools, training, and technical assistance as appropriate. And we will continue to promote the measures through our numerous communication channels.”</p>	<p>“The COVID-19 pandemic has revealed as never before the disparities, inequities, and systemic barriers that prevent so many from accessing high quality palliative care...Thank you for prioritizing this effort and your support of this project.”</p>
<p>“Clinically relevant and important for patient-centered care. Patients and providers were highly involved in developing these measures that matter for people living with serious illness.”</p>	<p>“These measures represent the beginning of what we hope to be a robust set of measures for palliative care that encompass all settings and all palliative care services in the future.”</p>
<p><b><u>Feeling Heard &amp; Understood Measure:</u></b></p>	<p><b><u>Receiving Desired Help for Pain Measure:</u></b></p>
<p>“I love that measure. I think it measures something that is essential to the service we provide.”</p>	<p>“Pain management is also a primary palliative skill. If we aren't doing a good job with this, we aren't likely listening to the patient.”</p>
<p>“Until the story is told, no other information can be received. Being heard and understood are critical for health care yet the most underutilized. Communication still suffers in our health care systems.”</p>	

*Response:* Thank you for your comments. AAHPM agrees that these measures are critical to healthcare delivery for many reasons. We are proud that both our project and these new measures are patient-centered and patient-focused. Including patients in the work from the beginning and throughout the project has been a high priority. As far as prioritizing the pain measure, pain was found to be a priority from research, recommendations from our Technical Expert Clinical User Patient Panel (TECUPP), and our focus groups. AAHPM hopes to receive funding to develop additional measures in the near future.

**2.1.2 Actionability, Usability, and Use**

*Comment Summary:* Most providers felt strongly that the measures would help them learn how to improve the patient experience by understanding what the patient needs. A few had questions about how the measures should be used in practice, and whether lower scores would provide actionable direction for improvement. Overall, providers indicated that they would use both measures and they would result in effective quality improvement activities. Feedback received cited the opportunity provided by the measures to improve patient experience and build trust. However, some cautioned that there may be unrealistic pain relief expectations and the ideal treatment might be unattainable due to insurance, regulatory concerns, or stock issues. Providers said they would use these measures to ensure patient expectations are set, deliver provider education, advocate for resources, and develop a process for improving patient care delivery. Providers identified many ways in which the measures could be used to improve practice, such as communication training, including evidence-based tools, for providers; research with patients to examine external factors that may affect measure response; patient education about pain management to properly set expectations; provider education to ensure that they have the proper skillset to manage all types of pain (different dimensions of pain; holistic approaches); testing processes for and boundary setting with patients with opioid use disorder. Many comments referenced the need for care coordination, since patients are seen by multiple providers and sometimes fall through the cracks. A sampling of these comments is captured in Table 5.

**Table 5. Examples of Comments about Measure Actionability, Usability, and Use**

<p>“They are both critical measures to demonstrate quality care and room for improvement.”</p>	<p>“Our education and training would absolutely change based on scores.”</p>
<p>“Patient reported outcomes help guide quality improvement, and these two are impactful choices.”</p>	<p>“Scoring high on these measures would be a way to demonstrate value to patients and families.”</p>
<p>“Our patients must know that you hear their pleas. Their story. Their history. What works. What does not work. What they have tried successfully. What they have tried and failed. What they need in order to live their best life despite their limitations.”</p>	<p>“Yes, I would use this measure to improve practice and care. If scores are either too high or low, it will promote a review of the practice. Also, if demographic data is provided as feedback in relationship to the question, we may be able to identify practice inequities.”</p>
<p>“It is important that we are what the patients need. Coordination of care is juggling many doctors’ orders and educating to disease processes and medications side effects, etc.”</p>	<p>“There also needs to be oversight and a clear chain of command with care. Who do you go to when you are not receiving the care you need and who can help patients &amp; caregivers navigate that process with limited time? How patients &amp; caregivers navigate this process is not intuitive.”</p>

<b><u>Feeling Heard &amp; Understood Measure:</u></b>	<b><u>Receiving Desired Help for Pain Measure:</u></b>
<p>“The key to this is educating healthcare providers on serious illness conversations... Only providers who are skilled in having conversations and courageous enough to have such conversations are going to be truly helpful... The provider has to draw out the patient's understanding of his illness, correct misunderstandings, discuss prognosis honestly, discuss patient's and family's feelings and fears... in order for a patient to feel fully heard and understood. And there has to be follow-up so that issues that develop later can be addressed.”</p>	<p>“The approach for this measure is inclusive and sensitive to the challenges of health disparities in pain management by emphasizing relief of pain from the patient perspective and whether their goals for management are achieved – not just what the health system identifies as a goal that may not align with personal preference/priorities of patients.”</p>

*Response:* Thank you for your comments. AAHPM would love to see the Feeling Heard and Understood measure to go along with the Receiving Desired Help for Pain measure (although it's not required). The goal is not pain control but a shared decision-making process for treating pain that takes into account patient wishes and treatment feasibility. Receiving desired help for pain could come in multiple formats, not just dispensing medications. AAHPM continues to advocate for fair prescribing practices and assurances that all patients who need pain treatment will receive it. The ideas recommended during public comment will help AAHPM put together a preliminary Implementation Guide to assist providers in setting up quality improvement programs.

## 2.2 Measure Specification

### 2.2.1 Study Population and Setting (Measures Have Broader Applicability)

*Comment Summary:* Many respondents recommended that these measures be expanded and tested for other populations and settings, due to their importance and relevance to most aspects of healthcare delivery. A sampling of the comments is captured in Table 6.

**Table 6. Examples of Comments about Study Population and Setting**

<b><u>Additional Populations</u></b>	<b><u>Additional Settings of Care</u></b>
<p>“I would strongly encourage CMS to fund a similar project to develop pediatric patient-reported measures and caregiver proxy tools, which assess how well pediatric palliative care clinicians deliver palliative care to children with serious illness and their families.”</p>	<p>“We would be interested in seeing the measure revised and tested for the hospital, home care and hospice settings where we offer certification in palliative care.”</p>
<p>“While these measures are intended for use by palliative care teams, the needs of patients with serious illness go far beyond the specialty and these measures are relevant to non-palliative care specialists as well.”</p>	<p>“Expand the use of these measures to other settings, including the patient’s home, wherever they call ‘home’ (own home, assisted living facility, skilled nursing facility/long term care, etc.).”</p>

Additional Populations	Additional Settings of Care
<p>“The feeling heard and understood measure – I’ll very likely consider adoption. Would like to see data in larger cohorts/non-palliative care populations.”</p>	<p>“We would like to see further research and evaluation of the measure’s application beyond the ambulatory clinic-based palliative. We think that there is potential application in defined cancer populations as a whole, in both the inpatient and outpatient care settings.”</p>
<p>“Would like to see recognized the importance of family-centered care and defining the family as the ‘unit of care.’”</p>	<p>“As these two measures speak to the priorities of adults living with serious illness, they are relevant beyond this setting, and beyond palliative care, to all clinicians who care for adults with serious illness.”</p>

*Response:* Thank you for your comments, support, recommendations, and continued advocacy. AAHPM would welcome the opportunity to work with CMS and others on future measure development, testing and implementation projects. AAHPM would also welcome the opportunity to test the measures in additional populations and settings, and/or develop a similar measure for the pediatric population. Funding and the quality payment program this measure was developed for is for patients ages 18+. We are aware of some pediatrician researchers (Prasanna Ananth, MD at Yale; Emily Johnston, MD at UAB) who are each looking to potentially adapt the *Feeling Heard and Understood* measure questions for their respective survey work, focused on children with cancer.

**2.2.2 Considerations regarding Patient Response**

*Comment Summary:* Due to the nature of the illnesses that make up the population who receives palliative care, some commenters had concerns about the patient ability to answer due to physical or cognitive limitations. A couple other commenters noted potential difficulty in patient report of the measures due to issues related to literacy level, race, and ethnicity. Risk adjustment was recommended. The need for proxy response was mentioned by several commenters, especially in the context of adapting these measures to pediatrics. A sampling of the comments is captured in Table 7.

**Table 7. Examples of Comments about Patient Response**

<p>“There are many [potential] patient barriers including the physical and cognitive limitations of the patient...[However,] patients know when they have been heard and the knowledge transcends physical and many cognitive impairments.”</p>	<p>“Recommend to separately report the results based on self-report and report by proxy. This will allow providers to track variation (if any) over time between those individuals able to self-report and those requiring a proxy to report on their behalf.”</p>
<p>“Measuring ‘desired help’ for pain... could be good at one stage of the disease and not at another. Patients themselves may have trouble identifying what they want. If pain is excruciating, and we control it, that is easy to measure. It may be that the concept ‘desired help’ simply means that we are trying, and it would be our</p>	<p>“Create parent-reported proxy measures specific to the care of children with significant neurologic impairment.”</p>



commitment to trying that the patient is measuring us on – rather than success?”	
“Not confident all patients [could report effectively] dependent upon literacy level, race, ethnicity, etc...[to] understand enough about what they don't know as a means of articulating what they do know and understand.”	“Create patient-reported proxy measures for children with serious illness, based on the age and developmental stage of the child.”
“Between-clinic variation in scores may be attributable to the patient population, rather than the quality of the services offered.”	“Develop guidelines to assess and align parent-reported proxy and patient responses to the quality measure.”

*Response:* Thank you for your thoughtful comments. The measures have been fully vetted by our TECUPP, as well as being validated during cognitive interviews and focus groups. Additional information will be made available when the full measure specifications and testing results are released, including measure exclusions and exceptions, and risk adjustment variables. The wording was developed in collaboration with patients/caregivers, family members, clinical experts, and methodologists. The ideal would be for the Feeling Heard and Understood measure to go along with the Receiving Desired Help for Pain measure (although it's not required). The goal is not pain control but a shared decision-making process for treating pain that takes into account patient wishes and treatment feasibility. The concepts of "pain" and of "desired help" are intentionally undefined in the measure so the patient can define them for themselves. Proxy assistance on the survey is allowed for measurement purposes, but not proxy only responses. AAHPM would welcome the opportunity to test the measures in additional populations and settings, further study the effectiveness of proxy response, and/or develop similar measures for the pediatric population. Funding and the quality payment program this measure was developed for is for patients ages 18+.

## 2.3 Measure Feasibility and Implementation

### 2.3.1 Feasibility

*Comment Summary:* Those indicating that the measures would be feasible stated it would be easy to add them on to their existing processes. Positive feedback also included that the questions were simple, scientific, and easy to implement. Internal resources (time, cost) and the work involved to set up a program (establishing new processes) were the two biggest provider barriers. Those with existing processes tended to be more optimistic about implementation. The help of an outside survey vendor is also a potential relief for the resource constraint and burden. Some said that Receiving Desired Help for Pain may be more feasible because there are associated quality measures for pain, including the opioid monitoring measures. A sampling of the comments on feasibility is captured in Table 8.

**Table 8. Examples of Comments about Feasibility**

“We already report value measures so it would not be a big deal.”
“There are existing metrics that align.”
“Providers can clearly see this measure as an indicator of their work efforts.”
“Easy, pertinent.” “Measurable and quantifiable.”

*Response:* Thank you for your comments. We recommend working with a survey vendor to simplify the implementation and reporting of these patient experience of care measures. We will explore ways of defraying the cost for providers. Additional information will be made available when the full measure specifications are released. AAHPM is working on a preliminary Implementation Guide which will accompany the release of the measures.

**2.3.2 Burden of Reporting PROs**

*Comment Summary:* We received many comments citing potential burden of measure implementation. Most respondents acknowledged that patient-reported outcome measures are inherently burdensome because the data source is patient report, and automation of measure reporting is improbable. The vast majority of comments stated that despite the additional burden, having information come directly from patients is well worth the time and effort, and they plan to report on both measures. A sampling of the comments is captured in Table 9.

**Table 9. Examples of Comments about Measure Implementation**

<p>“Depends on resources available at the clinic/system. Smaller programs may find it burdensome, as the likelihood of the tasks associated with reporting would fall to someone who has another role. Larger systems/clinics, if they have an embedded/FT quality person, would likely be able to tack this onto their regular reporting process. Our organization would use a vendor, as we contract with one specifically for that purpose.”</p>	<p>“These measures represent measurable outcomes that are critical to the delivery of quality palliative care; without high marks on these two measures we are not living up to our mission. Experience measures that capture perspectives and insights of people being cared for by health teams across disciplines are vital data to evaluate and address quality improvement. People guide the measures that matter.”</p>
<p>“Current surveys (e.g., CAHPS, Press-Ganey) are not specific enough to address these issues at the level of detail needed to provide actionable data. Despite the data burden associated with the administration of patient-reported outcomes, we feel that many of our cancer centers would choose to report on these measures in the appropriate patient population. These measures also align with current internal and external quality goals for our cancer centers.”</p>	<p>“We do note that at many institutions these measures are being collected by ambulatory practices and providers are not involved in collection; this eases the burden on providers.”</p>
<p><b><u>Support for Implementation</u></b></p>	<p><b><u>Barriers to Implementation</u></b></p>
<p>“Existing infrastructure exists to report other quality measures. These can be added.”</p>	<p>“It would be up to Division Leadership whether this would be a research project the team can devote time to.”</p>
<p>“These measures were developed in a thorough, inclusive process led by AAHPM, the NCHPC, and RAND...We commit to disseminating these measures among our field.”</p>	<p>“The processes/platform exist but unsure where it falls in the priority list for IT.”</p>

<u>Support for Implementation</u>	<u>Barriers to Implementation</u>
“Patient-reported experience measures are intrinsically challenging to administer. We appreciate the testing of different modalities.”	“Would be practical if through PCQC [Palliative Care Quality Collaborative registry]; otherwise, may be more challenging to set up.”
“Recommend monitoring variation in results (if any) over time by mode of survey (phone, mail, electronic).”	“Competing priorities.”

*Response:* Thank you for your comments. We agree that patient-reported measures are inherently more difficult to collect but we believe the benefits far outweigh the costs. Providers and patients seem to agree, since the importance of the measures was stressed by almost all commenters. We recommend working with a survey vendor to simplify the implementation and reporting of these measures. We will explore ways of defraying the cost for providers. We hope that these measures are simpler to implement than much longer other surveys that are being implemented now and far less burdensome to patients. Additional information will be made available when the full measure specifications are released. AAHPM is working on a preliminary Implementation Guide which will accompany the release of the measures.

### **2.3.3 Public Reporting**

*Comment Summary:* Many comments reflected that these measures represent measurable outcomes that are critical to the delivery of quality palliative care. However, several commenters worried that the measures would not be reported unless required by CMS. A good number of respondents highlighted the importance of including the measures in the Quality Payment Program (QPP), especially in alternative payment models (APMs). A sampling of the comments is captured in Table 10.

**Table 10. Examples of Comments about Public Reporting**

<u>National Standards and Benchmarks</u>	<u>Use in the QPP, especially APMs</u>
“Establishing these measures as benchmarks in our organizations sets an expectation for the physicians and other care providers whose work they will judge.”	“Implementation likely depends on their payment arrangement (especially if APM). However, large practices with good quality programs are likely to report.”
“We want national standards and quality measures.” “Important to report in a similar way in the field.”	“I would promote the use of the measures, once fully validated, in serious illness alternate payment models or pilots being implemented by C-TAC members or partners.”
“We would like to see if these measures, if NQF endorsed and adopted into CMS quality reporting programs, could be bundled with other PROs or incorporated into existing patient surveys.”	“[Whether or not these measures are reported on] likely depends on if their reimbursement was tied to the reporting or not.”
“Data collection is essential in the value-based care environment.”	“Organizations would most likely implement if CMS was part of the equation.”

*Response:* Thank you for your comments. AAHPM is eager to continue working with CMS to test the measures in an APM for serious illness care.

**2.3.4 Advocacy**

*Comment Summary:* Several commenters emphasized the need for advocacy for new legislation to accompany implementation of the measures. A sampling of the comments is captured in Table 11.

**Table 11. Examples of Comments about Advocacy**

“Enact policy.”	“Somebody needs to hear, help, and advocate for us [patients].”
“Palliative care providers and programs are actively seeking opportunities to gather additional data to demonstrate the value of palliative care and its impact.”	“I think extensive training on bias in PC needs to be done. Especially towards younger patients who don’t ‘look sick.’ ...We are the ones who are chronically ill, we are relying on our physicians to believe us, treat us with respect and dignity, and make our lives easier not harder. Healthcare has turned into political care.”
“[We need] a clearer definition of exactly what qualifies a pain patient to be treated as a palliative care patient.”	“Engage children and adolescents with serious illness in developmentally appropriate ways, and their families, in measure development.”
“Provide a mechanism to identify beneficiaries receiving palliative care services.”	“Make sure government doesn't come between doctor and patient.”
“Standardizing definitions for eligible patients and specialty palliative physicians vs. primary palliative conversations would impact the survey process and therefore the feasibility.”	“[These measures] give legacy patients like myself a voice through advocacy groups like yours to get people in positions of making policy change to see us as real people.”

*Response:* Thank you for your comments. We appreciate the need for advocacy and will continue our work with coalitions and legislative partners to advance policy for the field. AAHPM would welcome the opportunity and funding to test the measures in additional settings. Currently, the denominator for our quality measures is all patients with an ambulatory palliative care visit. The denominator is defined as:

- ICD-10 Z51.5 (Encounter for Palliative Care), OR
- Provider Hospice and Palliative Care Specialty Code 17; AND
- CPT 99201-99205 (New Office Visit); OR CPT 99211-99215 (Established Office Visit); or Place of service (POS) Code 11 – Office.

AAHPM continues to advocate for all who need palliative care to receive it.

**2.4 Patient Involvement and Feedback**

*Comment Summary:* Most patients who responded to our public comment survey are pleased with these measures because they align with what they are seeking from providers. Patients are primarily excited about the opportunity to drive change and improve the experience for future palliative care

patients. Biggest concerns were treatment repercussions and that the survey would take time to drive action. One of the most important messages from patients to providers is to avoid making assumptions, but instead listen carefully, ask questions, and provide empathy. Patients clearly stated that they want providers to be effective listeners, empathetic communicators, and to develop a personalized plan to address their needs. Active listening was the most important thing a provider could do for both measures. Taking action and following through was more important when discussing the topic of pain relief. The vast majority of public comment responses emphasized the importance of listening, believing, and treating the patient as an individual which builds a strong relationship and helps them feel heard and understood. Patients also had a variety of suggestions for how to help them and others receive their desired help for pain. Patients expressed a lot of frustration with the health care system, noting barriers of all kinds from being rushed through appointments to uncoordinated care. Some caregivers gave a plea for more training on what might happen as their loved one becomes sicker, and better coordination of pain treatment. A sampling of the comments is captured in Table 12.

**Table 12. Examples of Comments from Patients, Family Members, Caregivers, and Patient Advocates**

<b>Patient Feedback on Measure Importance</b>	
<p>“Primary reason we go to doctors.” “It’s what palliative and hospice care is all about...making the patient comfortable.”</p>	<p>“Essential information that hits at the heart of quality care delivery from the perspective of what matters most to patients and their caregivers in the setting of serious illness and their lived experience. NPAF applauds this.”</p>
<b>Patients Emphasized Listening and Asking Questions</b>	
<p>“When I have been part of successful palliative care interactions between providers and patients (my loved ones) the provider repeats back what they heard a patient say, slowly, and that made us feel heard.”</p>	<p>“Ask questions about what matters most to the patient; what they fear most; what care they want to receive - or not receive - at the end of their lives, and so on. Similar questions for caregiver/spouse. Then listen and confirm understanding.”</p>
<p>“Ask questions to get a sense of who the patient really is before arriving at judgment, instead of being overly prescriptive.”</p>	<p>“Expand the time spent with patients, engage navigators or other support staff to find out what’s important to them and identify any barriers.”</p>
<p>“Active listening and being present to her the patient and caregiver concerns after all the patients know their bodies best.”</p>	<p>“Listen &amp; respond with appropriate interventions, ideas to assist the patient in living their best life.”</p>
<b>Patients Requested that Providers Avoid Assumptions</b>	
<p>“Start with new patients by assuming they are credible reporters. Don’t assume a patient is not reporting accurately solely because of a certain</p>	<p>“1. Make sure we have actual diagnoses that cause pain. 2. Treat our individual pain experiences, not some statistical representation of the diagnoses ‘pain levels.’”</p>

<p>diagnosis, or because of a certain medication they take.”</p>	
<p>“Listen to patients with an open mind / heart and no have preconceived options about them or their dx.”</p>	<p>“See us as human beings- individuals with loved ones, our careers, etc... we are more than checking off boxes on a pain scale- see us as individuals.”</p>
<p>“Health care teams should avoid assumptions. You can be chronically ill and look healthy. You can be chronically ill and young. You can be chronically ill and overweight, and weight not be a cause (it is often a consequence, in fact). It is possible to bear a tremendous amount of pain, fatigue, etc. when one gets used to it, so functioning is only one measure of severity. Assessing quality of life, for example, is also important.”</p>	<p>“Listen. Do not make assumptions. Believe your patients and treat the issues they raise as ‘real’, do the testing to find out the cause without thinking you know the answer in advance. Be open and willing to learn from patients, particularly chronic patients, who have typically been dealing with their complaints for an extended period and have learned some things.”</p>
<p>“Approach my visit without assumptions. Ask questions... to understand the issue. Ask questions like ‘what would you like to be able to do that you can't do now, and what would you need in order to do that?’”</p>	<p>“Be more receptive, compassionate &amp; understanding that pain &amp; the Tx thereof is a highly individualized therapy – Not a 1 size fits all equation.”</p>
<p><b>Patient Recommendations on System Improvements</b></p>	
<p>“Training on bias is extremely important in regards to pain care. Patients across the world, myself included, are experiencing biases from their doctors and we are not receiving the care we need... Pain is an individual experience that can only be measured by the individual experiencing it, that is where the focus of this topic needs to be.”</p>	<p>“Standardizing smart-phone technology to satisfy HIPAA privacy/confidentiality - by utilizing Facetime to connect family members with their loved patients around care updates and improvement plans, etc.”</p>
<p>“[Provide] recaps of visits, follow-up by team member to ask if there are any more questions. Provide more educational opportunities for caregivers, along with caregiver assessment at the beginning of treatment.”</p>	<p>“Explore other means of pain relief. Not just medication, but heat/cold/music/massage/exercise/diet etc.”</p>
<p>“I'd like it if there was less red tape, obviously. I often run into issues where miscommunications between doctors, nurses, therapists and pharmacists leaves me with no answers and no medication for a given day. Being chronically ill makes it hard to do emergency trips to the pharmacy, after already siphoning so much</p>	<p>“There also needs to be oversight and a clear chain of command with care. Who do you go to when you are not receiving the care you need and who can help patients &amp; caregivers navigate that process with limited time?” “I'm a huge proponent of palliative care, yet even with the</p>

energy out of me on the phone trying to correct everything. Better communication between health care team members, both between themselves and with me, would help.”	best care possible, my dad's pain fell through the cracks.”
“It's definitely important to have that follow-up feedback loop for whether screening has occurred, the patient knows there's a plan for management, and the management plan is actually working.”	“I'd also love if people working to care for others' health were more empathetic; if not intuitively, then trained by their employers and education systems.”
“I feel the health care team needs to make sure they have eye to eye contact and pay attention to everything the patients are saying and keep in mind that most patients don't understand most medical terms. They should provide videos or reading material if needed to patients.”	“Make more time in their appointment schedules- particularly for people who are newly diagnosed with chronic illness- to be fully available to answer questions, and not give off the impression that they need to hurry and move on to the next patient!”

*Response:* Thank you for your comments and suggestions. We agree that pain is an individual experience and treatment should be a shared decision-making process between provider and patient. We believe it's important to assess, evaluate and treat the pain (any kind), while hearing and understanding what the patient is going through. AAHPM continues to advocate for appropriate pain treatment for patients who need it, to reduce suffering as much as possible. While we cannot guarantee how the survey results would be used, the goal of these measures is to improve the communication and care that patients receive. AAHPM would welcome the opportunity and funding to develop tools and measures to assess caregiver needs and burden and provide caregiver education.

**3 Measure-Specific Stakeholder Comments:**

**3.1 Measure Wording**

*Comment Summary:* The vast majority of respondents praised the wording of both measures, noting, “These two measures are core to palliative care, which recognizes and addresses the physical, emotional, spiritual, and psychosocial pain that patients with serious illness experience.” Most of the comments about measure wording were positive regarding Feeling Heard and Understood (“Prefer this wording to other questions we use now”). A few responses displayed hesitancy, noting their belief that “Heard and Understood is a double-barreled question.” One organization liked the measure as worded and recommended additional wording for explanatory purposes: “Our member experts were supportive of the proposed measure and found it meaningful. They recommended that the measure be adjusted to include specific actions that the care team provided or didn’t provide to the patient that led them to report they were/weren’t heard or understood.” The Receiving Desired Help for Pain measure received similar mixed reactions. While many respondents praised the depth and nuance of the measure, others worried that it was trying to do too much. A sampling of the comments is captured in Table 13.

**Table 13. Examples of Comments about Receiving Desired Help for Pain Measure Wording**



<i>Support for current wording</i>	<i>Word prefer alternate wording</i>
<p>“Improvement over just getting pain relief because it includes patient engagement and pain management.”</p>	<p>“Providers must define realistic expectations for pain relief with patient. Not all pain is treated with an opioid.”</p>
<p>“We believe it is superior to the two existent measures (NQF #0383 and NQF #0384) that have been used in the cancer patient population to assess the level of pain, and if pain is present (moderate or high) that there is a plan to address this pain.”</p>	<p>“It may be better to instead explore ~ did your doctor/team talk about what is best for your pain? This question accounts for discussions around non-pharm, setting functional goals, opioid wean, etc. where appropriate.”</p>
<p>“I particularly appreciate the way this is worded. There is a difference between the expectation of resolution of pain versus the expectation of help and understanding, which includes help balancing pros and cons of different therapies (again, in the context of our goals) and help preparing for what might come next in a serious illness, or after a procedure/surgery, etc. Living well with a serious illness may not always mean complete eradication of pain, but excellent care means I can trust that my providers will be attentive to my comfort.”</p>	<p>“Worried it does not take into account pt expectations for pain control which is not always possible even with our imperfect medications, and frames satisfaction with something that may not be achievable even with best practice of Palliative Care.”</p>

*Response:* Thank you for your feedback. The Feeling Heard and Understood measure was extensively researched in focus groups and cognitive interviews to ensure it measures what it intends to measure. We are delighted that your member experts found the measure meaningful. The measures will be revisited every 2-3 years for refinements and updates, and your recommendation to include specific actions will be considered. Additional information will be made available when the full measure specifications and testing results are released. AAHPM would value continued discussions with different organizations to further refine these measures and develop new ones. Our TECUPP explicitly discussed how pain encompasses physical, mental and spiritual pain, and they decided to leave the measure wording open-ended, not specifying physical or any type of pain, so the patient could answer for themselves. The intention is for the Feeling Heard and Understood measure to go along with the Receiving Desired Help for Pain measure (although it's not required). The goal is not pain control but a shared decision-making process for treating pain that takes into account patient wishes and treatment feasibility. Receiving desired help for pain could come in multiple formats, not just medications. We appreciate your concern about substance use disorders. More specific comments regarding possible unintended consequences of the measure are summarized in the next section of this report.

**3.2 Unintended Consequences**

*Comment Summary:* We received a large volume of comments about the Receiving Desired Help for Pain measure citing concerns over either overuse of opioid medications, or the opposite – underuse of pain-relieving treatment due to fear of Drug Enforcement Administration (DEA) repercussions or substance use disorders. Because of the timeliness of this issue and the many patient testimonials we received, we



compiled a longer list of responses reflecting common themes. We also include testimonials to illustrate some very challenging experiences of patients regarding pain treatment. More comments are captured in Table 14.

**Table 14. Examples of Comments about Overuse and Underuse of Opioid Medications**

<b>Overuse Concerns</b>	<b>Underuse Concerns</b>
<p>“The measure as it stands may inadvertently give incentives to prescribe medication inappropriate for patient satisfaction.”</p>	<p>“Know me well enough to realize I’m not dependent on pain meds and that I understand the risks of over medicating.”</p>
<p>“I support with a disclaimer: palliative care does not equal a pain clinic – so I would want that to be clear; while alleviating pain is part of our job/role, we are not just a dispensary for narcotic prescriptions and we have many patients who are referred to us by their primary care providers who are not comfortable with managing this symptom. I can imagine patients/families answering this question in a negative fashion if their expectations were that we just dispense Rx, and not what we actually do (assess pain holistically and provide a variety of interventions which may or may not include narcotics).”</p>	<p>“One of the best responses I've received was from a doc who suspected I was under-reporting my pain. He gave me a book to read about pain and pain treatment that opened my awareness and furthered my understanding. I know a book isn't what everyone wants, but it was ideal for me at that moment. So that's an example of knowing what best suits the patient but it wasn't the end result. That book and the doc taught me how to more clearly represent my pain to medical pros.”</p>
<p>“Our member experts believe that this proposed measure is a reasonable addition but suggest that the measure should be used to find out what kind of pain is being treated and whether a patient has an opioid misuse disorder. It might be a good idea to ask patients if they feel they were treated fairly in their pain management.”</p>	<p>“Alternative and complementary [pain reduction] methods do not work for most. Most pain patients are very careful with their legally prescribed meds and do not need to be punished because of the few who cannot control their use. CDC estimates 0.8 - 2% of pain patients become ‘addicted’ to their meds.”</p>
<p>“We have an opioid epidemic and we are in position of telling people they need less opioids for chronic pain. This measure will not be very helpful for us and will create negative feedback that we will have to ignore if we practice good medicine and encourage non opioid Rx of chronic non malignant pain. This measure is appropriate for cancer pain but we see so much non cancer chronic pain that this measure will punish us.”</p>	<p>“The opioid crisis has caused undertreatment situations in terminally ill persons who need narcotics to relieve their symptoms; providers may be stigmatized or even censured for prescribing these medications. All clinicians have a responsibility to manage the complex symptoms of these patients. PAs [physician assistants] are licensed and regulated to prescribe controlled substances, as state law allows. MACRA will provide data for regulators to improve the ‘fit’ of medications to the patient’s needs.”</p>
<p>“I think one very important aspect that should be reported is the excessive use of pain medications and use of the wrong medications to treat</p>	<p>“The current atmosphere surrounding pain medications and their medically necessary use is very hostile towards patients and caregivers</p>

Overuse Concerns	Underuse Concerns
<p>specific types of pain. These problems are just as important as too little treatment for pain.”</p>	<p>alike. Without our voices from those who truly need these meds for restoration of function and quality of life, not to mention those of us who only seek comfort in their last days, I fear that we will be left with nothing but needless suffering.”</p>
<p>“I believe the opioid crisis has contributed to many providers not wanting to be held liable to pain management issues. I feel there are providers that are so overwhelmed in their staffing issues, Medicaid patients, they are not taking patient's seriously or just ‘passing the buck’ so to speak in referring patients to advocates instead of providers listening to the situation.”</p>	<p>“A positive acknowledgement that illicit street drugs are driving this current crisis. Emphasis must be put on not automatically classifying and assuming people who ask for pain meds are drug seekers. Truthfully, with all the negativity and fear of law enforcement retaliation, combined with the nonstop auditory programming people are bombarded with that prescription drugs are evil and must be avoided... the narrative is virtually insurmountable.”</p>
<p>“Some of our clinicians expressed concern with the phrase, ‘did you get as much help as your wanted for your pain from this provider and team.’ Their concern is that this could be problematic because it risks incentivizing higher opioid prescribing, particularly in patients with a comorbid substance abuse disorder.”</p>	<p>“I am a practicing hospital RN. My husband has scoliosis of his back &amp; has had a heart attack that I know is related to immobility from a forced tapering of pain medications due to the 2016 CDC Guidelines. The PCP did not force taper him due to fear of addiction or death or any reason other than stated fear of the DEA. Fear of losing their license, their practice &amp; their livelihoods. Many Drs have been imprisoned for simply caring for their patients with knowledge, education, empathy, compassion &amp; humane treatments that they absolutely know that the patient actually does need. It is gut wrenching for the Dr, the patient, the caregiver &amp; those who love them. Under no circumstances should humans or animals be allowed to suffer without dignity &amp; reasonable care &amp; relief.”</p>

There were also commenters that found the nuanced wording of the measure to be “just right” in terms of balance, such as one commenter who said, “Our member experts indicated that they would use this measure and find it helpful. It provides specific actionable focus of a palliative program that can be easily addressed through standards of practice and approaches of care. It would also be a useful prompt to review a practice if the score is too high or too low. A 100 percent satisfaction rating should prompt a program to review for inappropriate prescribing. Less than 50 percent should cause a practice to review competence in managing complex pain. If demographic data is given as well then it may show inequity in prescribing and pain management practices.” Several providers also noted, “Perhaps what is shared in the survey, in aggregate, will become helpful to further relationship-centered care practices and priorities.” Patient suggestions included, “Address pain control concerns with all involved, insurance, pharmacy, caregiver- all on the same page for the patient to have access to pain control without delays.”

Another response described additional challenges: “We note that practices who have support and who are more affluent may have better outcomes than practices who are more limited and serve population where managing pain is more challenging (for example, lack of opioid treatment in the community, lack of provider support, lack of access to alternative/complementary/interventional management for pain).”

*Response:* Thank you for your comments. Feedback at TECUPP meetings pointed out that “We know some people may say the measure could cause overuse, but that’s precisely why this is patient report rather than simply ‘pain control.’” The concept of "pain" in the measure was left intentionally undefined and could include physical, emotional, existential or other kinds of pain. The intention is for the Feeling Heard and Understood measure to go along with the Receiving Desired Help for Pain measure (although it's not required). The goal is not pain control but a shared decision-making process for treating pain that takes into account patient wishes and treatment feasibility. AAHPM acknowledges that it is a difficult balance. While we cannot guarantee how the survey results would be used, the goal of this measure is to find a way to improve the communication and care that patients receive. We appreciate the concern about substance use disorders. Desired help for pain could come in multiple formats, not just medications. We received many stories from patients that reported uncontrolled pain, dismissive attitudes, and feeling stigmatized for wanting an opioid. The story above from one patient’s wife is typical of what we hear and reflects great distress. AAHPM believes it is important to assess, evaluate and treat the pain (any kind), while hearing and understanding what the patient is going through. AAHPM continues to advocate for appropriate pain treatment for patients who need it, to reduce suffering as much as possible. Thank you for bringing attention to the gender/cultural differences around admitting that one has pain and confirming that help is wanted. We are eager to conduct further studies on a more culturally diverse sample.

#### 4 Overall Analysis of the Comments and Recommendations

##### 4.1 Preliminary Recommendations

Overall, providers are likely to use both measures; there is just a slightly lower likelihood for the pain measure. Providers feel that both measures get at the heart of what palliative care should do – they align with the goals of palliative care. One commenter said, “The second measure rests on the first. If we aren't listening in order to understand, we cannot hear the needs our patients are sharing. Feeling heard and understood is critical to relieve of suffering at end of life. Even if the patient is symptom free, we are failing to meet their needs if we are not listening and responding to what we hear. Patients want two things from their professional caregivers – they want **high tech** in terms of skill sets, but more importantly they want **high touch**...I think pairing these measures is an excellent way to measure the quality of our work – they go hand in hand.” Another common overall message we saw in the comments was, “The two measures proposed are a great starting point to future development of robust measures. We thank CMS for prioritizing this work and pledge to continue dissemination of these measures to our members and stakeholders.” The next few tables further summarize thoughtful comments and helpful recommendations from both providers and patients alike.

**Table 15. Provider Report of Actions they would take Based on Measure Results**

<b>Top 3 overall actions are overarching, not dependent on one specific measure: setting patient expectations, delivering provider education, and using data to advocate for additional resources.</b>	<b>Both measures can be used to advocate for resources; use data to support additional resources to support patient care.</b>
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<u>Feeling Heard &amp; Understood</u>	<u>Receiving Desired Help for Pain</u>
<ul style="list-style-type: none"> <li>• <b>Provider Communication Training:</b> Provide communication training including evidence-based tools for providers</li> <li>• <b>Perform Root Cause Analyses:</b> Conduct research with patients and examine external factors that affect process flow                             <ul style="list-style-type: none"> <li>• Look closely at aspects of care that influence feeling heard and understood (e.g., conduct focus groups)</li> <li>• Examine potential external factors that influence the score (e.g., scheduling, delays in appointments, miscommunication around referrals, etc.)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <b>Patient Pain Mgmt. Education:</b> Provide education about pain management to patients to properly set expectations</li> <li>• <b>Provider Pain Education:</b> Provide education for providers to ensure that they have the proper skillset to manage all types of pain (addressing different dimensions and considering holistic approaches)</li> <li>• <b>Opioid-Specific Processes:</b> Set boundaries and establish testing processes for patients with opioid use disorder</li> </ul>

**Table 16. Summary of Patient Recommendations for Providers**

<p><b>Most importantly and most mentioned, patients want providers to be 1) effective listeners, 2) empathetic communicators, and 3) to develop a personalized plan to address their needs.</b></p>	<p><b>Active Listening (MOST IMPORTANT FOR BOTH MEASURES)</b></p> <p>Using an active listening approach, where providers iteratively listen and reflect back what was heard from the patient</p> <p>Establishing the expectation that communication is important between patients and providers</p> <p>Providers giving their undivided attention during conversations with patients</p>
<p><b>Empathy &amp; Tone</b></p> <p>Patients feel respected based on interactions with the provider (Patients feel the provider as taking his or her concerns seriously, believes them)</p> <p>Providers demonstrate empathy in discussions with patients</p> <p>Providers communicate with a positive tone</p> <p>Providers do not act superior to the patient</p> <p>Believe the patient</p>	<p><b>Confirm Patient Understanding</b></p> <p>Understand information provided, educate patient and provide accurate information</p> <p>Ending conversations with patients by asking, “What other questions do you have?”</p> <p>Employing the teach-back method to make sure that the patient understands what he or she needs to do after a visit</p>

<b>Treat/Take Action for Patient (MORE IMPORTANT FOR PAIN RELIEF)</b>	<b>Partner with Patient to Take Their Input, Personalize Care</b>
Patients feel the provider is taking his or her concerns seriously	Personalize care based on the patient, engage patient as a partner in care
Providers following through on promises	Care matches goals and priorities, concerns are addressed
Help facilitate coordinated care	Encouraging patients to share their stories or journeys (early and often)
Remove medication barriers	Providers are willing to take the time to get to know and develop a relationship with patients to establish a comfort level when it comes time to discuss the more challenging topics such as prognosis or surgery
Patient education	

#### 4.2 Overall Analysis of the Comments and Recommendations

CMS and the AAHPM team appreciate the comments received for the Palliative Care patient-reported outcome performance measures. We thank all commenters for sharing their support, concerns, questions, and recommendations. We will consider these and continued comments in future measure development and evaluation efforts. AAHPM has begun work on a preliminary Implementation Guide, to help palliative care programs implement the new measures. In summary:

##### For the Feeling Heard and Understood Measure –

- Providers feel the positives far outweigh the small negatives with the feeling heard and understood measure
- Most importantly, the measure is a good measure that aligns with what palliative care does
- Providers also feel strongly that the measure will help them learn how to improve the patient experience by understanding what the patient needs
- Will help providers understand patient satisfaction; will demonstrate the value of palliative care
- Only small concerns with implementation burden and wanting to learn more about the measure

##### For the Receiving Desired Help for Pain Measure –

- Some raised concerns about capturing the complexity of pain with the measure, the potential impact on prescribing, and implementation
- There was a slightly lower likelihood of using this measure, but the positives of the measure still do outweigh the negatives
- Also, most important for the pain measure, it too is a good measure that aligns with what palliative care does
- Improvement over just getting pain relief, includes patient engagement in managing pain

- Providers also feel this measure will help them learn how to improve the patient experience

**Table 17. Key Insights on Both Measures from Public Comment**

<p><u>Feeling Heard &amp; Understood</u></p> <p>The public comment survey emphasized the importance of listening, believing, and treating the patient which builds a strong relationship and helps them feel heard and understood.</p>	<p><u>Receiving Desired Help for Pain</u></p> <p>The public comment survey emphasized the importance of listening and treating the patient’s pain – taking action to treat has a higher level of importance for the pain measure.</p>
<p><b>Key Insights</b></p> <ul style="list-style-type: none"> <li>• Active listening and really hearing the patient describe their experiences and needs is the single most important thing a provider can do to ensure a patient feels heard and understood.</li> <li>• Communication style is the next most important factor – being empathetic, believing the patient, and building a good relationship.</li> <li>• Taking action to treat the patient in the manner discussed closes the loop and confirms to the patient that they have been heard and understood.</li> <li>• Finally, slowing down helps ensure a patient receives a personalized experience and allows time to confirm the patient understands everything discussed.</li> </ul>	<p><b>Key Insights</b></p> <ul style="list-style-type: none"> <li>• Active listening and really hearing the patient describe their experiences and needs is also the most important thing a provider can do to help a patient get their desired help for pain.</li> <li>• Taking action to treat the patient is of greater importance when focused specifically on pain – removing barriers to treatment, improving independence, and coordinating the patient care experience.</li> <li>• Additionally, slowing down helps ensure a patient receives a personalized experience and allows time to confirm the patient understands everything discussed.</li> <li>• Relationships and communication style are still impactful, but not as important as they were to feel heard and understood.</li> </ul>

**Feedback from our TECUPP**

We shared a preliminary summary of the public comments with members of our TECUPP. They posed some clarifying questions, which led to some changes in the document, as noted below.

- Which questions were asked of providers, representatives and professionals only versus patients, family members, caregivers and advocates? We clarified which questions were asked of which group of respondents.
- The potential of creating a pediatric version of each question is incredibly important; could we make a plan for how to help create pediatric measures or list other projects that are addressing pediatric measures? We added a note about two pediatrician researchers (Prasanna Ananth, MD at Yale; Emily Johnston, MD at UAB) who may be adapting the *Feeling Heard and Understood* measure for children with cancer.
- How can we help address the measure feasibility/burden of implementation issue? Could the Project team (and TECUPP members) share best practices re: implementation with providers

AND reasons why patients care deeply about these measures to reassure them the gain of using patient/family reported data outweighs the work / burden? We noted where applicable in the report how we are collating all the feedback we've received from the public comment survey, patient and provider interviews, TECUPP meetings, webinars, etc. about implementation and how providers can help patients. This feedback will go into an Implementation Guide which will be available to providers on the AAHPM website.

- What are the other measures some commenters are referring to when they say there is competition to use these new measures? Although other PRO-PMs exist, the vast majority are embedded in a much longer CAHPS or other survey where certain questions cannot be used alone. We noted that our measures have far fewer questions (PROMs) than CAHPS and can be used separately or together as a set. As for other pain performance measures, there are some which ask about pain screening and assessment, as well as pain control within 48 hours. Pain control is very subjective so we sought the more nuanced patient experience of help wanted for pain instead of a pain score in an electronic health record (EHR).
- How will we handle commenters who worry that our pain measure will lead to overuse of opioid medication? The issue of medication overuse is brought up many times in the public comment survey, as is medication underuse; we have patient testimonials of being treated as an addict and left alone in pain. We addressed the issue by presenting examples of each point of view and pointing to our advocacy efforts to ensure all patients with serious illness have access to pain relief. TECUPP comments included, "We know some people may say the measure could cause overuse, but that's precisely why this is patient report rather than simply 'pain control.'"
- Can we acknowledge that pain encompasses physical, mental and spiritual pain? We noted in our summary that the TECUPP explicitly discussed this issue at the in-person meeting, and decided to leave the word "pain" open-ended, not specifying physical or any type of pain, so the patient could answer for themselves. The TECUPP also recommended work on developing an Emotional Support measure, which AAHPM hopes to pursue in the near future.

This additional TECUPP guidance assisted the AAHPM team in improving the Public Comment Summary and preparing the preliminary Implementation Guide which will accompany the rollout of the measures. As the measures are reviewed by the Measures Application Partnership (MAP) and the National Quality Forum (NQF), AAHPM will continue to call on our TECUPP clinician experts, methodologists, measure implementers, members of the interdisciplinary team, patients, caregivers, and family members, as well as our champion administrators from the Beta Test to support the measures, provide comments, suggest future changes or new measures to develop, and especially to use the measures for the QPP and quality improvement. AAHPM hopes to receive funding to design and run an implementation project in the near future to further refine the measures and add to the Implementation Guide.

### **Recommendations and Next Steps**

Finally, we present our recommendations and next steps for measure users to help facilitate putting the measures into practice:

#### ***Benefits of Using the Measures to the Patient –***

- ✓ Ability to focus on what really matters in the multidimensional world of palliative care
- ✓ Support measures that matter most to patients by guiding organization to focus on them as the definition of quality



- ✓ Learn about and improve care delivery to patients

***Benefits of Using the Measures to the Organization –***

- ✓ Collects data to advocate for more resources for the team
- ✓ Benefits entire organization and raises visibility of the palliative care department
- ✓ Fosters collaboration with other key groups inside and outside of the organization (quality, value-based payment, state Dept. of Public Health, etc.)

***Next Steps for Providers to Remember –***

- ✓ Familiarize yourself with the details on the measures to help to build comfort and trust in the measures, addressing any questions about them and how they were developed
- ✓ Use these measures to drive action ensuring patient expectations are set, delivering provider education, advocating for resources, and developing new processes for improving patient care
- ✓ Patients are pleased with these measures because they align with what they are seeking from providers; many have spoken in favor of filling out the survey

***Next Steps to Overcome Implementation Barriers –***

- ✓ Use Implementation Guides to generate ideas for how to overcome lack of internal resources (time, budget); make the case for senior leadership using PowerPoint template provided
- ✓ To navigate infrastructure and process – use Implementation Guides to lay out how to begin a new PRO-PM reporting program and how to successfully adjust an existing program
- ✓ Set expectations for sites regarding the types of capabilities (staff, process) that will be required can help with resource planning
- ✓ Ensure consistent implementation with step-by-step Instructions, simplified checklists, and timelines (examples included in many Implementation Guides)
- ✓ Consider using the measures for MIPS reporting, Maintenance of Certification (MOC) Part IV activities, and for quality improvement
- ✓ Use the data from the measures to help both internal and external customers see the value of palliative care

For more information, please review the [Palliative Care Measures Project website](#), which includes many helpful resources, additional background information, and FAQs.



## Public Comment Verbatim Report

*You may attach this table as a separate file. This template contains optional fields that can be deleted at the request of the Contracting Officer's Representative (COR).*

Comment Number*	Date Posted/ Received	Name, Credentials, and Organization of Commenter	Type of Organization*	Email Address*	Measure Set or Measure	Text of Comments	Response*

\*Optional

*Note: Measure developers may enter the text of comments verbatim without edits for spelling, punctuation, grammar, or any other reason and should ask their COR for specific guidance.*