Chat Q & A

In addition to the webinar recording and slide deck, below are answers to the questions posted in the Chat during the webinar.

1. **Will deck (& recording) be shared with attendees?** Yes, if you want to listen again or share with a colleague, a recording and the slide deck is available on the MACRA project website along with all materials related to this project. ([www.nationalcoalitionhpc.org/macra](http://www.nationalcoalitionhpc.org/macra))

2. **Do you see the measures incorporated into an existing survey, or implemented as a stand-alone?** The measures are intended to stand alone but also can be incorporated into an existing survey if the program desires.

3. **How do you ensure that the patient answers reflect their experience with the pallcare teams alone and not be influenced by other medical teams (e.g. their oncology teams)?** The survey includes the name of the Merit-based Incentive Payment System (MIPS)-eligible provider (from the palliative care team that saw the patient). The questions ask the patient to recall their experiences with that specific provider and team.

4. **Perhaps you’re getting to this, but I was hoping you could talk more about how the teams distributed these questions to their patients. Were these sent out as a stand-alone survey or with other questions (e.g. Press Ganey questions)?** For the Alpha and Beta tests, RAND administered the stand-alone survey using a traditional mixed mode design, which included a mailed survey with telephone follow-up. Prior to receiving the survey, patients received a letter in the mail, which explained that they would be receiving a survey and included a url that patients could use to complete the survey online. The measures are intended to stand alone but also can be incorporated into an existing survey if the program desires.

5. **Was there pediatric representation in measure development?** To support the Palliative Care Measures Project, we created a Technical Expert Clinical User Patient Panel (TECUPP), which represented a very diverse and inclusive breadth of perspectives. There were members of the TECUPP who treat pediatric palliative care patients. However, these measures will be implemented for non pediatric patients in most cases as they were developed under Medicare funding.

6. **Does this include home based palliative care?** We focused on outpatient because of the rapid growth of outpatient clinics and growing need to provide palliative care 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 has focused specifically on home-based care and ACOs, so we narrowed this project’s focus to outpatient clinics to avoid duplication and maximize harmonization across measure development efforts.

7. **Can you share your thoughts about the use of the word palliative care and serious illness care?** It seems like serious illness care is more encompassing to include primary care providers. The project team spent considerable time and energy pondering this question. Since time for measure development was limited to 3 years, and the measures are for the MIPS program, we decided it was more important for palliative care clinicians to have the
opportunity to report on measures that are meaningful to their patients and practice rather than conduct further studies on how to capture the population that needs palliative care (often referred to as the "palliative care denominator"). When we release the measures, we expect they will be used by palliative care teams, primary care providers and others who code (via billing) and indicate that the visit was a palliative care visit.

8. **What is the criteria for community based palliative care programs to participate? (e.g., program size, etc.)** For measure testing, in order to qualify for participation, palliative care programs had to provide ambulatory clinic-based care, be in operation for more than 6 months, have seen more than 20 patients in the prior six months, not be a PACE or VA program, and have MIPS-eligible practitioners who provided palliative care services to patients. These criteria were based primarily on relevance to the setting and sample size requirements for testing.

9. **The measure on pain does not differentiate between physical and non-physical pain. How would the measure accurately capture the non-physical dimensions of pain, if the questions items are not specific?** Our Technical Expert Clinical User Patient Panel (TECUPP) members discussed the “experience of pain” that includes physical, emotional and/or spiritual pain. Our discussions included how much psychosocial/spiritual distress can affect physical symptoms. The discussion also included conversations about suffering, unmet needs for various issues, and how important it is to find out “what matters most” to the patient. The TECUPP participants were reminded that the survey items will be utilized in quality measures for the Merit-based Incentive Payment System (MIPS) program which applies a payment adjustment for participating MIPS-eligible clinicians. Measures should recognize and focus on what action(s) are attributable to the MIPS-eligible provider and team. We decided to use the word "pain" and to not define it in any way so that the patient can decide what kind of pain he/she has.

10. **What did you find in your work was the understanding of what palliative care is?** Through patient interviews and cognitive testing, some patients indicated that they are unaware of palliative care despite having a serious illness; other patients had heard of palliative care and had to advocate for palliative care (some providers said it was just for end-of-life care). For our survey, we included the name of the MIPS-eligible palliative care provider and ask the patient to reference their experience with that provider and team.

11. **Are the surveys completed by caregivers or the patients themselves?** The surveys are intended for patients to complete, and we did allow for proxy response during testing. Patient vs. proxy response is something that we are looking at in our analysis of the data.

12. **What is the percentage of caregiver to patient response in the survey results?** During Beta testing, a little over 20% of surveys were completed with some level of proxy involvement. Two-thirds of proxy-involved surveys were completed without any input from patients (proxy only) whereas one-third included some patient input (proxy assisted). Most proxy-only surveys were completed by phone, and most proxy-assisted surveys were completed by mail. Among the proxy-assisted completions, the most common assistance types were that the proxy read the questions to the patient and that the proxy wrote down the answers that the patient gave.

13. **What scale was used in the survey? 1-5?** The scale depended on the question. For Heard and Understood, it was a 5-point scale from "Not at all true" to "Completely true." For Getting Help with Pain, it was a 3-point scale: "Yes, completely," "Yes, somewhat" and "No."

14. **Did survey questions include comments for the answer choices?** No, since we needed to calculate a numeric score for the measure.

15. **Is the intent to add/modify these composites to Hospice CAHPS? Or will this be a separate survey?** This will be a separate survey from CAHPS.
16. Does this only apply to a patient being managed by a specialty palliative care provider? What about a patient being managed by a primary care physician? Or supportive care? The quality measures may be used by specialty palliative care providers and teams, primary care, and any clinician who utilizes the billing codes for the patient that indicate it was a “palliative care visit.” Specifically, for our measure testing, ambulatory palliative care visits were 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.

17. Did you consider asking in the ‘Heard and Understood’ measure, something along the lines of whether patients felt that provider laid out all their treatment options so that they could fully understand the scope of their situation and empowered to make an informed decision? We tested multiple questions pertaining to the Heard and Understood measure topic that were identified via literature review and expert panel input. We further refined the questions via cognitive interviews where participants rated their response to the following items: I trusted this provider and team; I felt comfortable asking this provider and team questions; I could tell this provider and team anything, even things I might not tell anyone else; I felt this provider and team put my best interests first when making recommendations about my care; I felt this provider and team always told me the truth about my health, even if there was bad news; I felt this provider and team saw me as a person, not just someone with a medical problem; I felt this provider and team knew what worried me most about my health; I felt this provider and team understood what is important to me in my life; I felt this provider and team would know what I would want done if I was unconscious or in a coma.

18. I’m curious- for patients that have pain and say they wanted help, how many do not voice / admit to uncontrolled pain, even when asked directly? I’m thinking of the stoic patient who may privately acknowledge pain and even help with pain management, but still not voice their pain to the provider. This is a very interesting question, but it was not something that we explored during this project.

19. What was the thinking for the responses on the pain measure yes definitely / yes somewhat vs. the always, sometimes...scale used in other measures? Yes, this response scale is used in the CAHPS Hospice survey (Did your family member get as much help with pain as he or she needed: Yes, definitely; Yes, somewhat; No). We tested this response scale as well as others during cognitive interviews to evaluate comprehensibility, usability, and respondent preference.

20. I’m wondering if these measures are going to run into a ceiling effect? What is the range of performance that was found during the beta test? Analyses are still underway. However, preliminary data suggest that while patients rate their provider and team highly on both measures, there is still room for improvement. For example, if one were to set the threshold for “passing” the Feeling Heard and Understood measure at the overall average score (14.47 out of 16) across all programs who participated in our test, 68.5% of patients would be above the threshold (Yes, heard and understood), and 31.5% would be below the threshold (No, not heard and understood). Similarly, if one were to set the threshold for “passing” the Received Help for Pain Measure at the top-box response of "Yes, definitely," 80.5% would meet the measure, while 19.5% would not.

21. Does this mean five questions for the ‘Heard and Understood’ measure and at least two and possibly three for the ‘Pain’ measure? We anticipate four questions for the heard and understood measure and three questions for the pain measure.

22. For the alpha/beta tests, how many providers were standalone palliative care programs and how many were Hospice agencies with a palliative care offering? Out of the 44 programs who participated in our tests, 10 programs reported their administrative homes were hospice agencies, 24 programs reported their administrative homes were
hospitals, and 10 programs reported their administrative homes were ambulatory clinics or other administrative home types.

23. We are a home-based palliative care org that provides virtual care to our patients. I believe we would meet all the other criteria you have mentioned. Are we able to participate? For the purposes of this study, we are focused on patients receiving palliative care in ambulatory clinic-based settings. Since an in-person visit is necessary for inclusion in the measure, telephone or telehealth visits are not eligible at this time for the quality measures. However, we did collect data from asking patients if they participated in telehealth visits. Future measure refinement may include telehealth/virtual care visits as allowable for measure reporting by CMS.

24. What billing codes did you use to identify sample patients? We asked eligible palliative care programs during the testing to identify all patients who had a "palliative care visit" in the previous 6 months. Programs were given specific codes to use to aid in their identification of the appropriate population for our test. Specifically, Ambulatory palliative care visits were 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.

25. While this is outside of the scope for this project, as you are focused on ambulatory PC/SC, do you see attribution as an issue as many patients see so many different providers? Great work!!! The survey includes the name of the MIPS-eligible provider (from the palliative care team that saw the patient). The questions ask the patient to recall their experiences with that specific provider and team.

26. How will you evaluate these measurable outcomes once they are found? CMS uses quality measures in its quality improvement, public reporting, and pay-for-reporting programs for specific healthcare providers. Each participating individual or group will submit their quality measure score(s) to meet the Quality Measure Performance category for the Merit-based Incentive Payment System (MIPS). CMS will review the measure scores submitted by eligible participants. It is up to the individual participant or group to implement improvement activities based upon their measure score(s).

27. How do you assign value provided? We do not assign value as in quality/cost as cost is not being measured by these measures. A scoring methodology is applied to yield a measure score for each program/reporting entity. The individual or group receives a measure score based upon the percentage of time they successfully completed the measure(s). Their MIPS score takes into account their Quality Score along with cost, promoting interoperability and improvement activities.

28. Are you using a program like SPSS to measure your data to come up with p-value significance? All analyses were run in R Studio (https://rstudio.com/).

29. Are you aware that Press Ganey had already prepared a survey? We created a new survey for the purpose of developing these new quality measures. We are aware that there are other patient surveys, such as Press Ganey, but this was developed for this specific purpose.

30. Is feeling heard the outcome? Is there a link between being heard and other outcomes - e.g.: symptom improvement, reduced distress? Feeling heard and understood is our primary outcome of interest, as it is a direct reflection of the patient's experience while receiving palliative care services (in one domain).