

# Measure Information Form

**Project Title:** MACRA Palliative Care Measure Development Project

**Date:** Information included is current on 5/24/21.

**Project Overview:**

The Centers for Medicare & Medicaid Services (CMS) has entered a cooperative agreement with the American Academy of Hospice and Palliative Medicine (AAHPM) as part of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) to develop two patient-reported measures of palliative care experience, broadly in the domains of symptoms and communication. The measures are intended to assess the extent to which patients receiving ambulatory clinic-based palliative care received the help that they wanted for their pain, and that they were heard and understood by their palliative care provider and team. The cooperative agreement name is the “Palliative Care Measures Project.” The agreement number is 1V1CMS331639-01-00. AAHPM has partnered with the National Coalition for Hospice and Palliative Care and RAND Health Care to develop the proposed measures.

**1. Measure Name/Title (NQF Submission Form De.2.)**

Ambulatory palliative care patients’ experience of feeling heard and understood

**2. Descriptive Information**

**2.1 Measure Type (NQF Submission Form De.1.)**

- process
- process: appropriate use
- outcome
- outcome: PRO/PRO-PM
- cost /resource use
- experience with care
- efficiency
- structure
- intermediate outcome
- composite

**2.2 Brief Description of Measure (NQF Submission Form De.3.)**

This is a multi-item measure consisting of 4 items: Q1: “I felt heard and understood by this provider and team”, Q2: “I felt this provider and team put my best interests first when making recommendations about my care”, Q3: “I felt this provider and team saw me as a person, not just someone with a medical problem”, Q4: “I felt this provider and team understood what is important to me in my life.”

2.3 If Paired or Grouped (NQF Submission Form De.4.)

N/A

### 3. Measure Specifications

3.1 Measure-Specific Webpage (NQF Submission Form S.1.)

To be developed if appropriate following NQF endorsement.

3.2 If this is an electronic clinical quality measure (eCQM) (NQF Submission Form S.2a.):

This is not an eMeasure.

3.3 Data Dictionary, Code Table, or Value Sets (NQF Submission Form S.2b.)

All information is provided in the Submission Form.

3.4 For an instrument-based measure (NQF Submission Form S.2c and S2.d):

A copy of the survey instrument can be found in the Appendix. The patient is the responder.

3.5 Updates since last submission (NQF Submission Form S.3.1 and S.3.2)

N/A

3.6 Numerator Statement (NQF Submission Form S.4.)

The Feeling Heard and Understood measure is calculated using top-box scoring. The top-box score refers to the percentage of patient respondents that give the most positive response. For all four questions in this measure, the top box numerator is the number of respondents who answer "Completely true." An individual's score can be considered an average of the four top-box responses and these scores are adjusted for mode of survey administration and proxy assistance. Individual scores are combined to calculate an average score for an overall palliative care program.

3.7 Numerator Details (NQF Submission Form S.5.)

Missing data in the outcome is naturally accommodated among the four response items by the modeling procedure for adjusted score estimation; thus no outcome imputation is necessary and should not be performed.

3.8 Denominator Statement (NQF Submission Form S.6.)

All patients aged 18 years and older who had an ambulatory palliative care visit.

3.9 Denominator Details (NQF Submission Form S.7.)

Denominator criteria:

All patients aged 18 years and older on date of encounter.

**AND**

Ambulatory palliative care visit 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.

**WITH**

An eligible provider type: Physicians (including doctors of medicine, osteopathy, dental surgery, dental medicine, podiatric medicine, and optometry); osteopathic practitioners; chiropractors; physician assistants; nurse practitioners; clinical nurse specialists; certified registered nurse anesthetists; physical therapists; occupational therapists; clinical psychologists; qualified speech-language pathologists; qualified audiologists; registered dietitians or nutrition professionals.<sup>1</sup>

3.10 Denominator Exclusions (NQF Includes “Exception” in the “Exclusion” Field) (NQF Submission Form S.8.)

Denominator exclusions include:

- Patients who do not complete at least one of the four items in the multi-item measure;
- Patients who do not complete the patient experience survey within six months of the eligible ambulatory palliative care visit;
- Patients who respond on the patient experience survey that they did not receive care by the listed ambulatory palliative care provider in the last six months (disavowal);
- Patients who were determined to be deceased when the survey reached them;
- Patients for whom a proxy completed the entire survey on their behalf for any reason (no patient involvement).

3.11 Denominator Exclusion Details (NQF Includes “Exception” in the “Exclusion” Field) (NQF Submission Form S.9.)

Based on technical expert clinical user and patient panel (TECUPP) and advisor feedback, we propose that for programs to be eligible to participate in this measure that they demonstrate an ability to field the survey to ambulatory palliative care patients within three-months of eligible visits. Per discussion with the TECUPP, constraining the implementation to ensure that patients are sent surveys within 3-months of their eligible visit provides a sufficiently large pool of eligible patients with visits recent enough to avoid recall bias or loss to follow-up. Surveys must be completed by patients within 6 months of the visit to avoid challenges with recall or loss-to-follow-up which would make findings less actionable. During the alpha pilot test, we confirmed the feasibility of this implementation guidance.

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<sup>1</sup> Based on 2019 Merit-Based Incentive Program (MIPS) eligible clinician types

Patients who have already completed the patient experience survey in a given reporting period will be excluded from measurement to avoid response bias due to priming effects and minimize patient burden. Patients who do not complete the item set measuring *Feeling Heard and Understood* will be excluded from the denominator as no data will be available on the proposed measure. Providers and programs will not be penalized for non-response.

Patients who have died or are unable to complete the patient experience survey due to cognitive impairment will be excluded. Proxy assistance with the survey is allowed; however, following discussion with the project advisory board, we decided to exclude surveys that were completed solely by a proxy with no patient involvement for conceptual reasons. We elected to include proxy-assisted surveys and to add an adjustment for proxy assistance to account for small differences in measure components due to the proxy involvement.

3.12 Stratification Details/Variables (NQF Submission Form S.10.)

N/A

3.13 Risk Adjustment Type (NQF Submission Form S.11.)

- no risk adjustment or risk stratification
- stratification by risk category/subgroup
- statistical risk model
- other (NQF Submission Form S.13.a.)

3.14 Type of Score (NQF Submission Form S.12.):

- count
- rate/proportion
- ratio
- categorical (e.g., yes or no)
- continuous variable (CV) (e.g., an average)
- other (specify) [Click or tap here to enter text.](#)

3.15 Interpretation of Score (NQF Submission Form S.13.)

A higher score resulting from this measure should be interpreted, relative to a lower score, as representing better quality of care.

3.16 Calculation Algorithm/Measure Logic (NQF Submission Form S.14.)

Information for the measure calculation is collected via a survey data collection instrument, which will be provided to the Centers for Medicare & Medicaid Services (CMS), to be made available to CMS-approved survey vendors and palliative care programs. The below steps should be completed by an authorized survey vendor to minimize bias and reduce workload burden on programs. The survey vendor will be responsible for identifying eligible cases using electronic/automated queries, fielding the survey in the appropriate timeframes, receiving, cleaning, and summarizing survey data for program-level quality improvement (if requested by the program), and submitting a final program-level data set to CMS for measure scoring. This last step may include the submission of both program-level data as

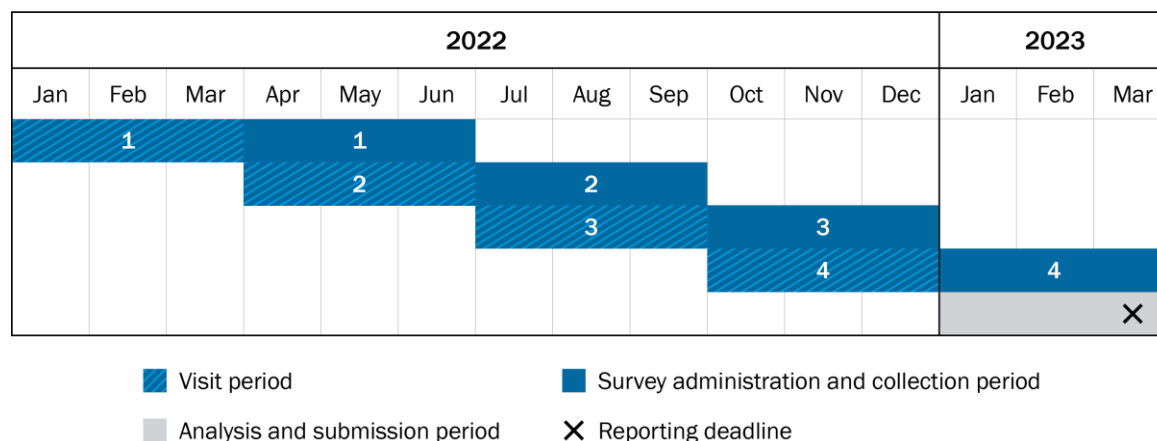
well as unadjusted program scores to CMS, for risk-adjustment once data are aggregated across programs.

1. Identify eligibility within target respondent population .
  - a. Check patient age – 18 years or older?
    - i. Yes → Eligible
    - ii. No → Not eligible
  - b. Check patient most recent disposition – alive?
    - i. Yes → Eligible
    - ii. No → Not eligible
  - c. Check whether patient received in-person ambulatory palliative care visit with a MIPS-eligible provider within the past 3 months (see Figure 1 for example fielding and data collection timeframes). The reference provider named on the survey instrument for each patient is the MIPS-eligible provider who the patient saw most often within the three-month period, with ties in numbers of visits broken by provider type, giving preference to providers holding primary responsibility for patient care outcomes (e.g., physician or physician-designee over nurse or therapist).
    - i. Yes → Eligible
    - ii. No → Not eligible
  - d. Check whether patient has already been fielded a survey in the current 12-month performance period
    - i. Yes → Not eligible
    - ii. No → Eligible
  - e. Check whether US-based contact information is available for patient
    - i. Yes → Eligible
    - ii. No → Not eligible
2. Field survey to all eligible cases using enhanced mixed-mode administration (web to mail to phone)
3. Receive all returned survey data.
4. Identify any denominator exclusions.
  - a. Survey completed (i.e., returned) within six months of the eligible ambulatory palliative care visit?
    - i. Yes → Include
    - ii. No → Exclude
  - b. Patient participated in survey completion, with or without proxy assistance?
    - i. Yes → Include
    - ii. No → Exclude
  - c. Patients responds in the patient experience survey that they received care by the listed ambulatory palliative care provider in the last six months?
    - i. Yes → Include
    - ii. No → Exclude
5. Score program-level quality measure using top-box scoring methodology

- a. For the Feeling Heard and Understood 4-item scale, “top box scoring” takes each data element and defines “Completely true” (i.e., the top-box response) as passing for that item, where 1 = passing and 0 = not passing. The number of top-box responses (up to four) can be averaged to provide an individual’s estimate for their proportion of Feeling Heard and Understood.
- 6. Eligible group, or survey vendor on behalf of the eligible group, submits clean program-level dataset (including unadjusted program score if applicable) to CMS for aggregation with other program datasets and measure scoring.
- 7. Risk adjustment calculation (to be performed by CMS or its third-party intermediary)
  - a. To estimate risk-adjusted program level measure scores, we utilize hierarchical generalized-linear models that relate the proportion of top-box patient-level outcome responses to program scores, conditioned on risk adjustment covariates (survey mode and proxy assistance).
- 8. Scores are reported at the program level aggregating results over a 12-month, or calendar year reporting period. See O’Malley et al. (2005) for an example of risk adjusted scoring.

Figure 1 shows an example data collection and reporting schedule that reflects the process used during testing: identification of all eligible visits during a 3-month or quarterly time frame, and a subsequent 3-month survey administration/data collection time frame, with data from all participating programs aggregated over a 12-month, or calendar year reporting period.

**Figure 1.** Example Data Collection and Reporting Schedule for Measure Performance Year 2022



Citations:

O’Malley, A. J., Zaslavsky, A. M., Elliott, M. N., Zaborski, L., & Cleary, P. D. (2005). Case-mix adjustment of the CAHPS Hospital Survey. *Health services research, 40*(6 Pt 2), 2162-2181.  
<https://doi.org/10.1111/j.1475-6773.2005.00470.x>

### 3.17 Sampling (NQF Submission Form S.15.)

The target population for sampling includes patients aged 18 years or older who received ambulatory palliative care services from a MIPS-eligible provider within the three months prior to the start of survey fielding. Findings from the alpha pilot test and beta field test support the feasibility of identifying eligible patients using administrative data and using a survey vendor to support survey administration and data collection. The provider or program will provide a vendor with an extract file of all patients who received care during the measurement period. To prevent gaming and to minimize administration and social desirability bias, the vendor will apply the eligibility criteria to identify the patient sample and field the survey to eligible patients. Survey administration will be mixed-mode, including web (emailed link to online survey), mail (hard-copy of the survey) followed by telephone (Computer Assisted Telephone Interviewing) survey if needed.

Assessments of measure reliability based on the intraclass correlation coefficient (ICC) suggest that programs will need a sufficient sample to have at least 37 completed responses to the *Heard and Understood* items over the 12-month reporting period.

Proxy assistance is allowed. However, the patient must be involved in survey completion. Patients for whom a proxy completed the entire survey on their behalf for any reason (i.e., with no patient involvement, including patients who are deceased by the time the survey reaches them) are excluded.

### 3.18 Survey/Patient-Reported Data (NQF Submission Form S.16.)

The measure is composed of survey data representing patient report of care over a reporting period of one calendar year (January 1st to December 31st). The data should be collected from a sample of eligible palliative care patients that is representative of the palliative care provider or program within the designated timeframe. As this measure is a multi-item measure, response rates at the program level should be calculated with respect to key items and reported to determine the sufficiency of the data to calculate the measure. Assessments of measure reliability based on the intraclass correlation coefficient (ICC) suggest that programs will need a sufficient sample to have at least approximately 37 completed responses to the *Heard and Understood* items over the 12-month reporting period.

Missing data in the outcome is naturally accommodated among the four response items by the modeling procedure for adjusted score estimation; thus no outcome imputation is necessary and should not be performed. Missing values for proxy assistance should be imputed as “No Proxy Assist.”

Within palliative care providers and/or programs with high enough response rates in the beta field test, we assessed the distribution of missing data (i.e., not responding to specific questions) and nonresponse (i.e., not responding to the survey) to assess their impact on utilizing the proposed measure. The first concern is that responders and non-responders differ in the distributions of case-mix variables, i.e., informative missingness. While we are unable to know what non-responders “would have responded” regarding their care, we can estimate the potential for bias based on observed differences in characteristics. We used available patient data to characterize the differences between respondents (n=2,804) and non-respondents (3,356) to better understand the potential for bias due to nonresponse.

Age and gender were available for all patients as they were included in the data files provided to us by participating programs; we compared mean age using a two-sample t-test and gender using a chi-squared test. Patient race was collected via self-report on the survey instrument, but a subset of participating programs provided race for at least 90% of their patients in their submitted data files. We compared patient race within this subset of programs between respondents and nonrespondents using a chi-squared test.

Survey respondents were slightly older than patients who did not complete a survey (mean age 63.4 vs 60.9;  $p < 0.01$ ). The portion of women was also higher among respondents, compared to nonrespondents (56.2% vs 54.5%); the results from a chi-squared test indicates that this difference is not statistically significant ( $p = 0.21$ ). Finally, among the subset of 12 programs who provided patient race for at least 90% of their patients, respondents were more likely to identify as White (88.1% vs 80.2%) and less likely to identify as Black (8.8% vs 11.9%) or another race (3.1% vs 8%) compared to nonrespondents. The results of a chi-squared test indicate that this difference is statistically significant ( $p < 0.01$ ).

We fielded a total of 7,595 surveys to eligible patients in the beta field test, of which 2,804 are completed surveys, or “cases,” that were used for analysis. Completed surveys are defined as any survey returned within six months of lookback start date that was not excluded due to ineligibility (e.g., surveys sent to patients who were later identified as deceased, surveys completed entirely by a proxy respondent, or surveys to patients who disavowed the receipt of care). Completed surveys may still have item-level missingness. The 2,804 completed surveys reflect a patient sample that was largely female (56%), White (88%) and non-Hispanic or Latino (95%), and very educated, with 66% having some college or more. The overall level of nonresponse to fielded surveys (after removing exclusions) was approximately 54.4%. We also examined the distribution of nonresponse across programs. There were no clear outliers in terms of program nonresponse. The distribution of non-response is clustered around the grand mean, suggesting similarity in nonresponse levels across programs. Based on this, we determined nonresponse was not systematically related to program.

A lesser concern is of missing data, such as not responding to individual items or demographic questions. To handle this, we again assessed the distributions and patterns of missing data, but here we performed an assessment to see if a missing-at-random assumption seemed plausible. Among the 2,804 completed surveys from the beta field test, the mean item-level missingness was 0.8% across the entire survey. Appropriately skipped survey items are not counted as missing. Among the four data elements that comprise the Feeling Heard and Understood measure, the data element-level missingness among responders was relatively low ranging from 1.07% (Q3: “I felt this provider and team saw me as a person, not just someone with a medical problem”) to 1.53% (Q4: “I felt this provider and team understood what is important to me in my life”). We also examined patterns in missingness among responders for each grouping of the four Feeling Heard and Understood data elements. Among responders who have any missing data across the four data elements ( $N=60$ ), approximately 43% ( $n=26$ ) skipped all of the measure data elements ( $N=26$ ), while 47% ( $n=28$ ) skipped only individual questions. This suggests there are generally low levels of missingness and no discernible patterns.

3.19 Data Source (NQF Submission Form S.17.)



- administrative data
- claims data
- patient medical records (i.e., paper-based or electronic)
- electronic clinical data
- registries
- standardized patient assessments
- patient-reported data and surveys
- non-medical data
- other—describe in 3.20 (NQF Submission Form S.18.)

3.20 Data Source or Collection Instrument (NQF Submission Form S.18.)

Patient-reported data is collected via survey instrument. The instrument was developed for this measure and can be completed via web survey, on paper or over telephone in English. Patient eligibility is determined based on coded visit information in the electronic health record.

## 3.21 Data Source or Collection Instrument (Reference) (NQF Submission Form S.19.)

Available in attached Appendix.

## 3.22 Level of Analysis (NQF Submission Form S.20.)

- individual clinician
- group/practice
- hospital/facility/agency
- health plan
- other (specify) [Click or tap here to enter text.](#)

## 3.23 Care Setting (NQF Submission Form S.21.)

- ambulatory surgery center
- clinician office/clinic
- outpatient rehabilitation
- urgent care – Ambulatory
- behavioral health: Inpatient
- behavioral health: Outpatient
- dialysis facility
- emergency medical services/ambulance
- emergency department
- home health
- hospice
- hospital
- hospital: critical care
- hospital: acute care facility
- imaging facility
- laboratory
- pharmacy
- nursing home / skilled nursing facility (SNF)
- inpatient rehabilitation facility (IRF)
- long-term acute care
- birthing center
- no applicable care setting
- other (specify) [Click or tap here to enter text.](#)

3.24 Composite Measure (NQF Submission Form S.22.)

N/A

## APPENDIX: PATIENT EXPERIENCE SURVEY

### PATIENT EXPERIENCE SURVEY

### SURVEY INSTRUCTIONS

- This survey should be completed by the patient indicated on the survey cover letter.
- You can ask a family member or friend for help with this survey or ask them to complete the survey for you.
- If you are a family member or friend helping with this survey or completing this survey for the patient indicated on the survey cover letter, please remember that all survey questions ask about the patient's experiences. Unless a question says otherwise, please do not consider your own experiences or information in the answers you provide.
- Use a dark colored pen to fill out the survey.
- Place an X directly inside the square indicating a response, like in the sample below.

Yes

No

- This survey uses the word "provider" throughout. When we say "provider", we mean a medical provider like a doctor or a nurse.

Please return the completed survey in the provided pre-paid envelope to:

**[MAILING ADDRESS HERE]**

**YOUR PROVIDER AND TEAM**

1. Our records show that you got care from the provider and team named below in the last 6 months.

[Provider] and team

Is that right?

- Yes
- No → If No, please return the completed survey in the pre-paid envelope.

The questions in this survey will refer to the provider named in Question 1 as “this provider and team.” Please think of this provider and team as you answer the survey.

**YOUR OVERALL EXPERIENCE WITH THIS PROVIDER AND TEAM**

2. Thinking about your overall experience with this provider and team in the last 6 months, how true are the following statements?

I felt heard and understood by this provider and team.

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

3. I felt this provider and team put my best interests first when making recommendations about my care.

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

4. I felt this provider and team saw me as a person, not just someone with a medical problem.

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

5. I felt this provider and team understood what is important to me in my life.

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

**ABOUT YOU (THE PATIENT)**

6. **What is the highest grade or level of school that you have completed?**
- 8th grade or less
  - Some high school but did not graduate
  - High school graduate or GED
  - Some college or 2-year degree
  - 4-year college graduate
  - More than 4-year college degree
7. **Are you of Hispanic or Latino origin or descent?**
- Yes, Hispanic or Latino
  - No, not Hispanic or Latino
8. **What is your race? Please choose one or more**
- White
  - Black or African American
  - Asian
  - Native Hawaiian or other Pacific Islander
  - American Indian or Alaska Native
  - Other

9. **What language do you mainly speak at home?**
- English
  - Spanish
  - Some other language (please print):
- 
10. **Did someone help you with this survey?**
- Yes
  - No → **If No, please return the completed survey in the pre-paid envelope.**
11. **How did that person help you complete the survey? Check all that apply.**
- Read the questions to me
  - Wrote down the answers I gave
  - Answered the questions for me
  - Translated the questions into my language

Thank you for completing this survey.

Please return the completed survey in the provided pre-paid envelope.

[MAILING ADDRESS HERE]