NATIONAL QUALITY FORUM
Driving measurable health improvements together

Measure Worksheet

This document summarizes the evaluation of the measure as it progresses through NQF's Consensus Development Process (CDP). The information submitted by measure developers/stewards is included after the Brief Measure Information, Preliminary Analysis, and Pre-meeting Public and Member Comments sections.
To navigate the links in the worksheet: Ctrl + click link to go to the link; ALT + LEFT ARROW to return

Brief Measure Information

NQF #: 3666
Corresponding Measures:
Measure Title: Ambulatory Palliative Care Patients’ Experience of Receiving Desired Help for Pain
Measure Steward: American Academy of Hospice and Palliative Medicine
sp.02. Brief Description of Measure:
The percentage of patients aged 18 years and older who had an ambulatory palliative care visit and report getting the help they wanted for their pain from their palliative care provider and team within 6 months of the ambulatory palliative care visit.

1. Per the recommendation of our technical expert clinical user and patient panel (TECUPP), survey items refer to “this provider and team” which reflects the interdisciplinary team structure of care delivery in ambulatory palliative care. Providers can be one of many MIPS-eligible provider types, ranging from Doctor of Medicine to clinical nurse specialists. Providers serve as the lead of the palliative care team and are therefore referenced (i.e., named) at the start of the survey instrument. To identify the reference provider named on the survey instrument for each patient, the data set was first filtered to include only visits with MIPS-eligible provider types that occurred in the three months prior to the anticipated start date of survey fielding. We then selected the MIPS-eligible provider whom 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). If patients had multiple visits, we selected the most recent visit for each patient with the reference provider. We did not conduct testing to specifically evaluate how patients differentiated between team members in their responses to the survey items.
2. We will consult with our TECUPP and advisors about potential revisions to the measure description prior to full submission. The proposed measure is intended to have a broad timeframe, as pain interventions and time frames for improvement may vary based on patient preferences and goals, and individual patients with serious illness make important tradeoffs (e.g., patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects). Furthermore, our TECUPP, particularly members with lived experiences of palliative care, emphasized the many different kinds of pain, from physical to emotional to spiritual to existential, and recommended that “pain” not be defined in the measure but be left to the interpretation of the patient. Therefore, this measure is asking about the patient’s holistic experience of their pain during the course of treatment and whether the provider and team provided the help they wanted.
3. We were unable to specifically test accuracy of recall of subjective experiences of pain among ambulatory palliative care patients who completed the survey. Ambulatory palliative care is often started earlier in the disease trajectory to promote quality of life over the course of serious illness. We selected the time frame parameters based on discussion with palliative care experts from our technical expert clinical user and patient panel (TECUPP) and advisory board and confirmed the feasibility of these time frame parameters in testing. In addition, prior to field testing, we conducted cognitive testing of the *Receiving Help for Pain* data elements through 25 interviews with ambulatory palliative care patients and their family members to establish the comprehensibility, readability, and adaptability of survey instructions and data elements, including response options.

1b.01. Developer Rationale: Palliative care has expanded rapidly in recent years, and consensus has been growing within the palliative care community regarding the need for measuring the quality of end-of-life care. Yet little is known about the quality of palliative care delivered, particularly among patients who receive their palliative care early in their disease trajectory, in the ambulatory setting. The patterns of palliative care received in ambulatory clinics differ substantially from palliative care received in other settings. Ambulatory palliative care typically supplements a primary treating service such as oncology, as needed. Patients may have several visits with different members of the palliative care team, or they may only have a single visit. This variability in the patient experience of palliative care raises important measurement challenges (Chen et al., 2020), which this project seeks to address.

Although palliative care is growing rapidly, the quality of care delivered by palliative care providers (and by other clinicians responsible for seriously ill patients) is unknown, particularly in ambulatory settings. As a result, stakeholders – including patients and their advocates, as well as providers and health systems – lack actionable measures to guide improvement efforts, as noted by NQF and the CMS Measures Application Partnership (MAP) as well as the 2017 CMS Environmental Scan and Gap Analysis Report (CMS Health Services Advisory Group, 2017). Measures of palliative care quality are also underrepresented in the CMS QPP, with current measures addressing small populations that are often limited to patients with cancer or hospice patients. Furthermore, palliative care quality assessment that incorporates patient preferences (i.e., patient "voice") is noticeably absent despite the patient-centered nature of palliative care (Anhang Price & Elliott, 2018; Anhang Price et al., 2014; Anhang Price et al., 2018; Teno et al., 2017). Patient-centered measures, and especially patient-reported outcome measures, are an important complement to clinician-reported measurement data.

It is important to note that the palliative care field is unique in that palliative care patients are seriously ill, and death is not always a negative outcome, though the quality of that death is important. Accordingly, palliative care requires measures that examine whether patients are receiving care that aligns with their goals, rather than meeting clinical outcomes that may be more appropriate to other conditions, such as mortality (Chen et al., 2020).

As noted above, managing patient symptoms and psychosocial needs is a key goal of palliative care. Pain is one of the most common and distressing symptoms among the seriously ill (Bernabei et al., 1998; Cleeland et al., 1994; Conill et al., 1997; Portenoy et al., 1994; Spiegel et al., 1994; Strang, 1992; Turner et al., 1996). Pain is highly prevalent among ambulatory palliative care patients and is one of the most common reasons for referral to palliative care (Johnson et al., 2008; Perry et al., 2013; Potter et al., 2003). While many existing QMs assess standardized clinical outcomes and processes of care (e.g., pain reduced to a comfortable level within 48 hours [NQF 0209]), the subjective experience of symptoms does not lend itself to a "one size fits all" evaluation approach. Individual patients with serious illness make important tradeoffs (e.g., patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects) and hold different preferences for their care that may only be reflected via patient experience measures, that is, from a measure based on patient or proxy report rather than an evaluation conducted by the provider (Chen et al., 2020).

The proposed measure is also valuable for implementation of innovative payment models for palliative care delivery that impacts emerging models of community-based palliative care (e.g., embedded clinic models). Interdisciplinary palliative care team services are often unbillable under a fee-for-service model, and value-based payment models may be an alternative for reimbursement (Center to Advance Palliative Care, 2017). However, innovative financial models require quality metrics to ensure accountability for patients as well as payers and providers (Anhang Price et al., 2018; California Health Care Foundation, 2018). Many emerging models of community-based palliative care are delivered in community settings and may not utilize the same interdisciplinary team nor have the same level of training as programs evaluated in the literature (Teno et al., 2017). Palliative care quality measures would hold programs accountable for quality and would allow providers to demonstrate the value of their services (California Health Care Foundation, 2018). Currently available measures are generally limited to end-of-life utilization and process measures and are not consistently used across programs, thus patient reported quality metrics are needed to assess the impact of community-based palliative care and ensure transparency and accountability for these vulnerable patients (California Health Care Foundation, 2018; Teno et al., 2017).

Citations:

Anhang Price, R., & Elliott, M. N. (2018). Measuring Patient-Centeredness of Care for Seriously Ill Individuals: Challenges and Opportunities for Accountability Initiatives. *J Palliat Med*, *21*(Suppl 2), S-28-S-35.

Anhang Price, R., Elliott, M. N., Zaslavsky, A. M., Hays, R. D., Lehrman, W. G., Rybowski, L., Edgman-Levitan, S., & Cleary, P. D. (2014). Examining the role of patient experience surveys in measuring health care quality. *Med Care Res Rev*, *71*(5), 522-554.

Anhang Price, R., Stucky, B., Parast, L., Elliott, M. N., Haas, A., Bradley, M., & Teno, J. M. (2018). Development of Valid and Reliable Measures of Patient and Family Experiences of Hospice Care for Public Reporting. *J Palliat Med*, *21*(7), 924-932.

Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., Lipsitz, L., Steel, K., & Mor, V. (1998). Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *Jama*, *279*(23), 1877-1882.

California Health Care Foundation. (2018). *Lessons Learned from Payer-Provider Partnerships for Community-Based Palliative Care*.

Center to Advance Palliative Care. (2017). *Payment Primer: What to Know about Payment for Palliative Care Delivery*.

Cleeland, C. S., Gonin, R., Hatfield, A. K., Edmonson, J. H., Blum, R. H., Stewart, J. A., & Pandya, K. J. (1994). Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med*, *330*(9), 592-596.

CMS Health Services Advisory Group. (2017). *CMS Quality Measure Development Plan Environmental Scan and Gap Analysis Report (MACRA, Section 102)*. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/ValueBased-Programs/MACRA-MIPS-and-APMs/MACRA-MIPS-and-APMs.html.

Conill, C., Verger, E., Henriquez, I., Saiz, N., Espier, M., Lugo, F., & Garrigos, A. (1997). Symptom prevalence in the last week of life. *J Pain Symptom Manage*, *14*(6), 328-331.

Johnson, C. E., Girgis, A., Paul, C. L., & Currow, D. C. (2008). Cancer specialists' palliative care referral practices and perceptions: results of a national survey. *Palliat Med*, *22*(1), 51-57.

Perry, B. A., Westfall, A. O., Molony, E., Tucker, R., Ritchie, C., Saag, M. S., Mugavero, M. J., & Merlin, J. S. (2013). Characteristics of an ambulatory palliative care clinic for HIV-infected patients. *J Palliat Med*, *16*(8), 934-937.

Portenoy, R. K., Thaler, H. T., Kornblith, A. B., Lepore, J. M., Friedlander-Klar, H., Coyle, N., Smart-Curley, T., Kemeny, N., Norton, L., Hoskins, W., & et al. (1994). Symptom prevalence, characteristics and distress in a cancer population. *Qual Life Res*, *3*(3), 183-189.

Potter, J., Hami, F., Bryan, T., & Quigley, C. (2003). Symptoms in 400 patients referred to palliative care services: prevalence and patterns. *Palliat Med*, *17*(4), 310-314.

Spiegel, D., Sands, S., & Koopman, C. (1994). Pain and depression in patients with cancer. *Cancer*, *74*(9), 2570-2578.

Strang, P. (1992). Emotional and social aspects of cancer pain. *Acta Oncol*, *31*(3), 323-326.

Teno, J. M., Price, R. A., & Makaroun, L. K. (2017). Challenges Of Measuring Quality Of Community-Based Programs For Seriously Ill Individuals And Their Families. *Health Affairs*, *36*(7), 1227-1233.

Turner, K., Chye, R., Aggarwal, G., Philip, J., Skeels, A., & Lickiss, J. N. (1996). Dignity in dying: a preliminary study of patients in the last three days of life. *J Palliat Care*, *12*(2), 7-13.

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sp.12. Numerator Statement: The number of patients aged 18 years and older who report getting the help they wanted for their pain from their palliative care provider and team within 6 months of an ambulatory palliative care visit.

sp.14. Denominator Statement: All patients aged 18 years and older who had an ambulatory palliative care visit.

sp.16. Denominator Exclusions: Denominator exclusions include:

- Patients who do not complete and return the patient experience survey within 6 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 deceased when the survey reached them;
- Patients for whom a proxy completed the entire survey on their behalf for any reason (no patient involvement);
- Patients who respond “No” to the questions “In the last 6 months, have you ever had pain?” OR “In the last 6 months, did you want help from this provider and team for this pain?”

It is possible that ambulatory palliative care patients may receive pain management from other services in addition to palliative care. However, it is unlikely that the ambulatory palliative care team would not be involved in pain management, as pain is one of the most common reasons for referral to palliative care. Our 30-member TECUPP felt strongly that while other providers might be concurrently involved in the patient’s care, pain management, and attention to the person’s physical and existential distress, is very much a core responsibility of palliative care, and they would want to be held accountable for this very basic care process. Moreover, this measure goes beyond pain management and addresses the patient’s perspective on feeling satisfied with the care and attention they received by the palliative care provider (which as the TECUPP emphasized, could be achieved even if the patient’s pain was not fully resolved).

Measure Type: Outcome: PRO-PM

sp.28. Data Source: Instrument-Based Data

sp.07. Level of Analysis: Clinician: Group/Practice

IF Endorsement Maintenance – Original Endorsement Date:
Most Recent Endorsement Date:

IF this measure is included in a composite, NQF Composite#/title:
IF this measure is paired/grouped, NQF#/title:
sp.03. IF PAIRED/GROUPED, what is the reason this measure must be reported with other measures to appropriately interpret results?

Preliminary Analysis: New Measure

Criteria 1: Importance to Measure and Report

1a. Evidence

1a. Evidence. The evidence requirements for a health outcome measure include providing empirical data that demonstrate a relationship between the outcome and at least one healthcare structure, process, intervention, or service; if these data not available, data demonstrating wide variation in performance, assuming the data are from a robust number of providers and results are not subject to systematic bias. For measures derived from patient report, evidence also should demonstrate that the target population values the measured outcome, process, or structure and finds it meaningful.

Evidence Summary

- This is a patient-reported outcome performance measure (PRO-PM) using instrument-based data at the group/practice clinician level to calculates the percentage of patients aged 18 years and older who had an ambulatory palliative care visit and reported getting the help they wanted for their pain from their palliative care provider and team within 6 months of the ambulatory palliative care visit.
- The logic model depicts that the availability of systemic and routine assessment of pain in the ambulatory palliative care setting will lead to routine pain assessment and follow-up and discussion about patient preferences and goals for pain management, which will ultimately lead to low levels of unmet needs for pain and patients receiving preferred level of help for pain.
- The developer assessed the meaningfulness of the measure via 30-to 60-minute phone interviews with patients, caregivers, and family members. All patients, caregivers, and family members who participated in interviews mentioned pain as a specific symptom or concern.
- Developer cites the Integrative Framework of Appraisal and Adaptation in Serious Medical Illness as an aid towards the description of the proposed process by which palliative care improves experiences of care for patients with serious illness.
  - Developer includes that the framework posits that palliative care's focus on symptom management, coping with illness, goals of care, and treatment decisions may be associated with improved patient quality of life in part by increasing patients' use of active and approach-oriented (vs. avoidant) coping strategies.

Question for the Committee:

- Is there at least one thing that the provider can do to achieve a change in the measure results?
- Does the target population value the measured outcome and finds it meaningful?

Guidance from the Evidence Algorithm

Measure assesses outcome (box 1) YES -> relationship between outcome and at least one healthcare action (box 2) YES -> PASS

Preliminary rating for evidence: ☒ **Pass** ☐ **No Pass**

1b. Gap in Care/Opportunity for Improvement and 1b. Disparities

1b. Performance Gap. The performance gap requirements include demonstrating quality problems and opportunity for improvement.

- The developer gathered performance data from 44 ambulatory palliative care programs (i.e., the accountable clinical groups) that participated in the beta field test, including 10 hospice sites, 24 hospitals, 10 ambulatory or other administrative sites.
- Within the sample of 44 programs, the developer oversampled larger programs (i.e., those with more patients), stratifying recruitment efforts for ambulatory palliative care programs by administrative home type (i.e., hospice, hospital, ambulatory, and other administration) and by geographic location to ensure representation across Census Regions. Patient sampling was conducted each month between November 2019 and February 2021, with a pause between March and September 2020 due to the COVID-19 pandemic.
- The developer fielded 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.
  - Average adjusted measure score/mean score is 80.2
  - Min score = 66.1%
  - Max score = 89.4%
  - 25th percentile = 76.8%
  - 75th percentile = 84.7%
  - IQR = 7.9%
  - Confidence intervals for the highest and lowest program scores do not overlap:
  - Lowest Program CI: (48.6, 79.6)
  - Highest Program CI: (78.9, 96.2)
  - Standard deviation in average program scores is 5.25
- The developer states that the proposed measure will fill identified measure gaps and posits that analyses from the beta field test further demonstrate room for improvement and observed variability across programs (adjusted ICC point estimate = 0.079) supports the potential of the measure to distinguish among programs with high, medium, and low performance.
- The developer adds that when programs are ranked by their measure performance, program calculations at the median of measure performance would need a large increase of 5.29 points in their measure score to improve to the 20th top-ranked program while a program at the bottom of the ranking (e.g., the 10th lowest ranked program) would need a 6-point increase measure score to improve to the median.

Disparities

- The developer evaluated the relationship of various social risk factors to the measure score and the programs and found no variables to be significant in their relationship with the measure after adjustment for multiple factors. The various social risk factors included (see sections 2b.23 and 2b.24 for additional details): race/ethnicity, education, primary language, urbanicity, median household income, public insurance use, unemployment, and gender.
- Developer cites systematic reviews that have identified longstanding disparities in pain management across various health care settings, including underdiagnosis and undertreatment of pain in Black patients, and reporting on disparities by race/ethnicity and socioeconomic status in the prevalence of unmet needs for symptom management among patients with serious illness.

Questions for the Committee:

- Is there a gap in care that warrants a national performance measure?

Preliminary rating for opportunity for improvement: ☐ High ☒ Moderate ☐ Low ☐ Insufficient

Committee Pre-evaluation Comments:

Criteria 1: Importance to Measure and Report (including 1a, 1b, 1c)

1a. Evidence to Support Measure Focus: For all measures (structure, process, outcome, patient-reported structure/process), empirical data are required. How does the evidence relate to the specific structure, process, or outcome being measured? Does it apply directly or is it tangential? How does the structure, process, or outcome relate to desired outcomes? For maintenance measures –are you aware of any new studies/information that changes the evidence base for this measure that has not been cited in the submission? For measures derived from a patient report: Measures derived from a patient report must demonstrate that the target population values the measured outcome, process, or structure.

- Patient reported outcome, indirect
- Supported by evidence and patient interviews
- The evidence relates to the outcome being measured
- It is still unclear how this information will be pulled
- Developer provides good rational and evidence for the measure. Notes the measure (a PRO) was ass with patients, caregivers, and family members via phone interviews.
- The developer provides a comprehensive summary of studies that demonstrate how pain is one of the most common and distressing symptoms of serious illness.
- Evidence provided to support the measure
- The measure looks at pain, which is not just physical, which may be difficult to measure. In the interviews the developers conducted all those interviewed mentioned pain as specific symptom or concern.

1b. Performance Gap: Was current performance data on the measure provided? How does it demonstrate a gap in care (variability or overall less than optimal performance) to warrant a national performance measure? Disparities: Was data on the measure by population subgroups provided? How does it demonstrate disparities in the care?

- Large gap, large observed variability among programs, disparities known
- Yes, gap is present, room for improvement
- Yes, there is a performance gap, and this is an important clinical care issue
- There is a need and yet this seems very vague
- Measured in 44 programs. 2804/7595 surveys completed (note low number). Score range from 66.1% to 89.4%. The developer evaluated the relationship of various social risk factors to the measure score and the programs and found no variables to be significant in their relationship with the measure after adjustment for multiple factors. But developer cites systematic reviews that have identified disparities in pain management across settings and groups.
- The perception and therefore management of pain is highly individual and there is demonstrated variability across programs.
- Possible gap in care related to adequate pain management for palliative care patients in the ambulatory care setting
- They cited differences between various ambulatory settings, including the number of patients seen. They also evaluated various systematic reviews that identified disparities in pain management.

Criteria 2: Scientific Acceptability of Measure Properties

2a. Reliability: Specifications and Testing

2b. Validity: Testing; Exclusions; Risk-Adjustment; Meaningful Differences; Comparability; Missing Data

Reliability

2a1. Specifications requires the measure, as specified, to produce consistent (reliable) and credible (valid) results about the quality of care when implemented. For maintenance measures – no change in emphasis – specifications should be evaluated the same as with new measures.

2a2. Reliability testing demonstrates if the measure data elements are repeatable, producing the same results a high proportion of the time when assessed in the same population in the same time period and/or that the measure score is precise enough to distinguish differences in performance across providers. For maintenance measures – less emphasis if no new testing data provided.

Validity

2b2. Validity testing should demonstrate the measure data elements are correct and/or the measure score correctly reflects the quality of care provided, adequately identifying differences in quality. For maintenance measures – less emphasis if no new testing data provided.

2b2-2b6. Potential threats to validity should be assessed/addressed.

Complex measure evaluated by Scientific Methods Panel? ☒ **Yes** ☐ **No**

Evaluators: Alex Sox-Harris, Sam Simon, Zhenqiu Lin, Larry Glance, Matt Austin, Terri Warholak, Jeffrey Geppert, Christie Teigland, Eugene Nuccio, Lacy Fabian, Marybeth Farquhar, Joseph Kunisch

Methods Panel Review (Combined)

Methods Panel Evaluation Summary:
This measure was reviewed by the Scientific Methods Panel (SMP) and passed both reliability and validity evaluations by the SMP Subgroup. It was not discussed during the SMP measure evaluation meeting. A summary of the measure and the Panel subgroup evaluation is provided below.

Specifications

- SMP subgroup members requested additional clarification around the specifications, specifically on the target population, age range, survey questions, time periods.

Reliability

- Reliability testing conducted at the Patient or Encounter level:
  - Developers used a test-retest reliability coefficient and percent agreement to test the survey data element Receiving Desired Help for Pain. Although a mixed response modes are used for data collection (i.e., web (emailed link to online survey), mail (hard copy of the survey) followed by telephone (Computer Assisted Telephone Interviewing) survey), only phone survey test respondents were eligible for CATI retest. The result from the polychoric correlation coefficient was 0.90 with 88% agreement for the CATI data collection method.
- Reliability testing conducted at the Accountable Entity level:
  - Using a signal-to-noise analysis, accountable entity testing was conducted to assess between- (i.e., signal) and within- (i.e., noise) subject variability to discriminate provider performance.

    - Developers used hierarchical generalized-linear regressions to decompose variability of binomial outcomes to programs and to covariates with the data hierarchy as patient observations. The variance of the model can be decomposed using the (adjusted) ICC, which provides a summary of the reliability of the measure as tested, with higher values implying more variability between programs. Using Bayesian generalized mixed-effects models obtained a posterior distribution of the adjusted ICC with estimates of approximately 0.079 (95 percent CI: 0.02, 0.175) is "extremely low and is concerning."
    - For projected to observed variance from within each program, Spearman-Brown prophecy formula was used to determine reliability results to future samples. To obtain a result of 0.7 or higher, an average of 49 eligible and complete responses were required. Results across all programs r=0.482 and across programs with a minimum of 33 respondents (considering 68 percent response rates) were r=0.735. The SMP acknowledges that testing during the COVID-19 pandemic may have affected changes in palliative care services and experiences.
    - To assess the average adjusted reliability of individual programs, developers estimated a posterior distribution for the overall variability using an Adams-like (2009) approach, which resulted in an average reliability across programs of approximately r = 0.752.

Validity

- Validity testing conducted at the Patient or Encounter level:
    - Convergent validity testing was used for patient- encounter-level validity testing hypothesizing the relationship so similar constructs, including data elements from other instruments: 1) Consumer Assessment of Healthcare Providers and Systems [CAHPS] Hospice, from the four-item CAHPS Communication composite measure, and 2) Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood.
    - Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood is a new measure developed by the same developer that is currently being reviewed by NQF. Developers hypothesized that pain management would link with feeling heard and understood by that same palliative care provider and team.
    - Interpretation of the bivariate correlation followed standard conventions for small, medium, and large associations (i.e., 0.10, 0.30, 0.50) (Rosnow & Rosenthal, 1989). Both showed moderate correlations. Experience of Receiving Desired Help for Pain scale were associated with higher CAHPS communication scores (r = 0.57, p<.001) and Feeling Heard and Understood, the correlations were weak/low (r = 0.61, p< .001).
- Validity testing conducted at the Accountable Entity level:
    - To assess accountable entity level validity, measure scores examined the association of the measure scores to 1) the current NQF-submitted #3665 Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood, 2) the CAHPS communication measure score, and 3) the individual's overall rating of their palliative care provider and team. The developer hypothesized these scores would be positively associated to Feeling Heard and Understood.
    - The measure showed low/weak positively associated with the CAHPS communication quality measure (r = 0.386, p =0.014) and the Experience of Feeling Heard and Understood quality measure (r = 0.41, p<.009). It also showed moderate low linkage to overall rating of the palliative care provider and team (r= 0.56, p=<.001) with associated to other similar measures (r = 0.5 – 0.8).
    - Face validity was assessed with a panel of seven palliative care communication experts who assessed the final measure specifications and testing results and rate the measure's ability to distinguish quality palliative care. Face validity ratings were from 1 (lowest rating) to 9 (highest rating); numeric ratings corresponded with descriptive ratings of low (1-3), moderate (4-6), or

high (7-9). The average face validity ratings of the measure score were 7.7 which corresponds to a developer defined average rating of “high.”

Questions for the Committee regarding reliability:

- Do you have any concerns that the measure can be consistently implemented (i.e., are measure specifications adequate)?
- The Scientific Methods Panel is satisfied with the reliability testing for the measure. Does the Committee think there is a need to discuss and/or vote on reliability?

Questions for the Committee regarding validity:

- Do you have any concerns regarding the validity of the measure (e.g., exclusions, risk-adjustment approach, etc.)?
- The Scientific Methods Panel is satisfied with the validity analyses for the measure. Does the Committee think there is a need to discuss and/or vote on validity?

Preliminary rating for reliability: ☐ **High** ☒ **Moderate** ☐ **Low** ☐ **Insufficient**

Preliminary rating for validity: ☐ **High** ☒ **Moderate** ☐ **Low** ☐ **Insufficient**

Committee Pre-evaluation Comments:

Criteria 2: Scientific Acceptability of Measure Properties (including all 2a, 2b, and 2c)

2a1. Reliability-Specifications: Which data elements, if any, are not clearly defined? Which codes with descriptors, if any, are not provided? Which steps, if any, in the logic or calculation algorithm or other specifications (e.g., risk/case-mix adjustment, survey/sampling instructions) are not clear? What concerns do you have about the likelihood that this measure can be consistently implemented?

- Passed scientific methods panel
- No concerns
- This is a new measure and some of the reviewer’s concerns suggest it will need to be implemented to learn more about its reliability
- It will be inconsistent but will begin a standard
- Test retest done for phone survey results - with correlation coefficient of 0.9 and 88% agreement. Using Bayesian generalized mixed-effects models obtained a posterior distribution of the adjusted ICC with estimates of approximately 0.079 (95 percent CI: 0.02, 0.175) is “extremely low and is concerning.” Reliability data were mixed.
- I have no concerns.
- Data elements defined
- None

2a2. Reliability - Testing: Do you have any concerns about the reliability of the measure?

- Passed scientific methods panel, only phone evals used in cati retest
- No concerns
- No, although some reviewers raise good concerns about this new measure in that regard
- Yes
- Reliability data were mixed.
- No.
- Provides reliability data. Have concern as to how to include patients who have cognitive impairment as they are currently excluded
- No

2b1. Validity -Testing: Do you have any concerns with the testing results?

- Indirect testing of other measure used
- No concern

- No but appreciate some of the reviewers' concern in this area
- No
- Some mixed results - "showed low/weak positively associated with the CAHPS communication quality measure (r = 0.386, p =0.014) and the Experience of Feeling Heard and Understood quality measure (r = 0.41, p<.009). It also showed moderate low linkage to overall rating of the palliative care provider and team (r= 0.56, p=<.001) with associated to other similar measures (r = 0.5 – 0.8)." face validity measured with 7 PC communication experts-- found to be "high" face validity
- No.
- Reasonable validity
- No

2b2-3. Other Threats to Validity (Exclusions, Risk Adjustment) 2b2. Exclusions: Are the exclusions consistent with the evidence? Are any patients or patient groups inappropriately excluded from the measure? 2b3. Risk Adjustment: If outcome (intermediate, health, or PRO-based) or resource use performance measure: Is there a conceptual relationship between potential social risk factor variables and the measure focus? How well do social risk factor variables that were available and analyzed align with the conceptual description provided? Are all of the risk-adjustment variables present at the start of care (if not, do you agree with the rationale provided)? Was the risk adjustment (case-mix adjustment) appropriately developed and tested? Do analyses indicate acceptable results? Is an appropriate risk-adjustment strategy included in the measure?

- Was substance abuse risk adjusted
- No risk adjustment with this measure.
- Again, it's a new measure so lack operational information on these areas
- Unknown
- Unclear if risk adjustment is adequate. Excludes pediatric patients.
- The exclusions appear appropriate. The risk adjustment does not include social risk factors.
- Some risk adjustment concerns and exclusion concerns for those patients with cognitive impairment
- No exclusions are apparent. Yes, everything appears to be present.

2b4-7. Threats to Validity (Statistically Significant Differences, Multiple Data Sources, Missing Data) 2b4. Meaningful Differences: How do analyses indicate this measure identifies meaningful differences about quality? 2b5. Comparability of performance scores: If multiple sets of specifications: Do analyses indicate they produce comparable results? 2b6. Missing data/no response: Does missing data constitute a threat to the validity of this measure?

- Concern for meaningful difference because so much variability in interdisciplinary ambulatory teams
- Could have non-response bias. Negative responders might be more likely to complete the survey
- I do not have concerns in these areas
- It will be inconsistent
- Mixed results
- None.
- Missing data, need to have provider defined
- I agree with the SMP and do not feel that the measure needs to be discussed. The measure seems to be valid and repeatable, there does not appear to be any missing data.

Criterion 3. Feasibility

3. Feasibility is the extent to which the specifications including measure logic, require data that are readily available or could be captured without undue burden and can be implemented for performance measurement.

- The developer explains that patient-reported data is collected via a survey instrument that 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.
- Developer adds that the information for the measure calculation will be provided to CMS and made available to CMS-approved survey vendors and palliative care programs.
- Developer addressed how it would aid in the administration of the data collection, specifically the minimization of bias and workload burden on programs. Developer explains that 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.
- The developer provided additional context on the proven feasibility of the measures. The developer tested the feasibility of identifying eligible patients using administrative data and using a survey vendor to support survey administration and data collection and indicated that the findings from the alpha pilot test and beta field test support the feasibility of identifying eligible patients Interviews with programs. The developer shares data, from a 2021 comment period, on the supported feasibility of the proposed measure and the majority of comments indicated support for feasibility of the proposed measure,
    - 21.8% of respondents indicated that the measure is "very feasible"
    - 42.7% respondents indicated that the measure "somewhat feasible."
    - The developer added that some commenters raised concerns about the cost of hiring a survey vendor and implementation burden (e.g., staffing and support limitations).

Questions for the Committee:

- Are the required data elements routinely generated and used during care delivery?
- Is the data collection strategy ready to be put into operational use?
- Are potential feasibility issues assessed?

Preliminary rating for feasibility: ☒ High ☐ Moderate ☐ Low ☐ Insufficient

Committee Pre-evaluation Comments:

Criteria 3: Feasibility

3. Feasibility: Which of the required data elements are not routinely generated and used during care delivery? Which of the required data elements are not available in electronic form (e.g., EHR or other electronic sources)? What are your concerns about how the data collection strategy can be put into operational use?

- Concern for vendor cost and implementation
- No concerns.
- No concerns.
- Are they the correct measures?
- PRO data collected via web, on paper of over telephone in English, Survey data shows ~64% respondent indicate the measure is "somewhat" or "very" feasible. Some need for developer to address how it would aid in administration of the data collection.
- The use of a survey vendor makes using the measure feasible.
- Reasonable feasibility noted
- Everything seems to be in place, the developer tested the feasibility and the issue of the cost of survey vendor was brought up.

Criterion 4: Usability and Use

4a. Use (4a1. Accountability and Transparency; 4a2. Feedback on measure)

4a. Use evaluates the extent to which audiences (e.g., consumers, purchasers, providers, policymakers) use or could use performance results for both accountability and performance improvement activities.

4a.1. Accountability and Transparency. Performance results are used in at least one accountability application within three years after initial endorsement and are publicly reported within six years after initial endorsement (or the data on performance results are available). If not in use at the time of initial endorsement, then a credible plan for implementation within the specified timeframes is provided.

Current uses of the measure

Publicly reported? ☐ **Yes** ☒ **No**

Current use in an accountability program? ☐ **Yes** ☒ **No** ☐ **UNCLEAR**

OR

Planned use in an accountability program? ☒ **Yes** ☐ **No**

Accountability program details

- This is a newly developed measure that is not currently in use in an accountability program or public reporting mechanism. The developer explains that the measure is intended to be used by providers eligible for CMS' Merit-Based Incentive Payment System (MIPS) who provide palliative care services to their patients.
- The developer add that the measure was submitted to the 2021 MUC list for inclusion into CMS' Quality Payment Programs, including MIPS and APMs, and will be reviewed by the MAP in December 2021.

4a.2. Feedback on the measure by those being measured or others. Three criteria demonstrate feedback: 1) those being measured have been given performance results or data, as well as assistance with interpreting the measure results and data; 2) those being measured, and other users have been given an opportunity to provide feedback on the measure performance or implementation; 3) this feedback has been considered when changes are incorporated into the measure

Feedback on the measure by those being measured or others

- Developer obtained feedback, from 25 palliative care programs that participated in pilot testing, on potential implementation challenges and usefulness of the proposed palliative care measures for quality improvement during the 2021 public comment period. Respondents included patients, family caregivers, and advocates living with serious illness; providers/clinicians caring for those living with serious illness; representatives from national organizations; and other professionals.
- The developer received feedback on the following concerns related to factors that influence measure implementation
  - Survey fatigue
  - Appropriate and comprehensible question for a broad range of patient populations, including those with low literacy levels.
  - Potential for bias with proxy responses might introduce bias, particularly if family member perceptions were not aligned with patient perceptions (e.g., thinking that pain was undertreated).
  - Attribution in context to patients who experience multiple providers

    - Selection of survey modalities (i.e., email, mail, in-person) that will yield high response rates and thoughtful responses (i.e., after patients have had a chance to think about their experience)
    - Financial and administrative burden for implementation
- The developer found that most programs had previously worked with a vendor to administer patient surveys. The following concerns related to resources required for measure implementation were still cited:
    - Cost, sensitivity and tracking issues (i.e., concerns about sending surveys to deceased patients),
    - Patient survey fatigue
    - Ability to compare measure performance with other programs
    - Unstable patient mailing addresses
    - Cost of quality improvement associated with the measure

Additional Feedback:

- The developer collected additional feedback from administrators, including program managers and data specialists, regarding measure implementation. Details are contained in section 4a.08 of developer submission.

Questions for the Committee:

- How have (or can) the performance results be used to further the goal of high-quality, efficient healthcare?
- How has the measure been vetted in real-world settings by those being measured or others?

Preliminary rating for Use: ☒ **Pass** ☐ **No Pass**

4b. Usability (4a1. Improvement; 4a2. Benefits of measure)

4b. Usability evaluates the extent to which audiences (e.g., consumers, purchasers, providers, policymakers) use or could use performance results for both accountability and performance improvement activities.

4b.1 Improvement. Progress toward achieving the goal of high-quality, efficient healthcare for individuals or populations is demonstrated.

Improvement results

- This is a new measure and not currently in use in any quality improvement programs.

4b2. Benefits vs. harms. Benefits of the performance measure in facilitating progress toward achieving high-quality, efficient healthcare for individuals or populations outweigh evidence of unintended negative consequences to individuals or populations (if such evidence exists).

Unexpected findings (positive or negative) during implementation

- The measure is newly developed and not currently in use. Developer notes no encounter with unintended adverse consequences from measuring the extent to which patients received desired help for pain.

Potential harms

- Developer states that continued assessment of measure benefits as well as negative consequences is needed, but still obtained valuable feedback from providers on perceive benefits of the measure.
- Noted benefits included but were not limited to usefulness for palliative care quality improvement programs and movement towards a more comprehensive and multidisciplinary approach to pain management.

Additional Feedback:

None

Questions for the Committee*:*

- How can the performance results be used to further the goal of high-quality, efficient healthcare?
- Do the benefits of the measure outweigh any potential unintended consequences?

Preliminary rating for Usability and use: ☐ High ☒ Moderate ☐ Low ☐ Insufficient

Committee Pre-evaluation Comments:

Criteria 4: Usability and Use

4a1. Use - Accountability and Transparency: How is the measure being publicly reported? Are the performance results disclosed and available outside of the organizations or practices whose performance is measured? For maintenance measures - which accountability applications is the measure being used for? For new measures - if not in use at the time of initial endorsement, is a credible plan for implementation provided? 4a2. Use - Feedback on the measure: Have those being measured been given performance results or data, as well as assistance with interpreting the measure results and data? Have those being measured or other users been given an opportunity to provide feedback on the measure performance or implementation? Has this feedback has been considered when changes are incorporated into the measure?

- New measure, plan not credible
- Obtained feedback from small patient sample
- NA, new measure not yet reported
- It will be good to discuss and hear from others
- This is a newly developed measure that is not currently in use in an accountability program or public reporting mechanism. Feedback from pilot study - survey fatigue, potential for bias with proxy responses, attribution in context to patients who experience multiple providers, some financial admin burdens. Section of survey modalities could yield high response rates.
- My concerns are misattribution in the case of patients who see multiple providers and survey fatigue.
- Currently not publicly reported. Plans to include as part of CMS Quality Payment Program
- This measure is not being publicly reported but will be in the future. The developer has utilized input from programs that participated in pilot testing including patients and caregivers.

4b1. Usability – Improvement: How can the performance results be used to further the goal of high-quality, efficient healthcare? If not in use for performance improvement at the time of initial endorsement, is a credible rationale provided that describes how the performance results could be used to further the goal of high-quality, efficient healthcare for individuals or populations? 4b2. Usability – Benefits vs. harms: Describe any actual unintended consequences and note how you think the benefits of the measure outweigh them.

- Worried for potential unintended consequences especially if tied to reimbursement
- No concerns
- No concerns here
- It is one measure
- New measure. Not currently in use. Did get feedback from providers on perceived benefits--included useful to PC QI programs and movement toward more comprehensive multi-disciplinary approach to pain management.
- The management of pain in serious illness is very important. The only unintended consequence might be social desirability--patients feeling they need to report positive results.

- Not currently in use. Some questions as to how this measure will be considered as part of the CMS Quality Payment Model since both provider and team included in the care.
- No harms were identified

Criterion 5: Related and Competing Measures

Related or competing measures

The following measure is identified as related, though not necessarily competing:

- NQF 2651 – CAHPS Hospice Survey (experience with care)

Harmonization

- Developer indicates that the measure is harmonized to the extent possible but does not provide any information detailing elements of the harmonization.

Committee Pre-evaluation Comments: Criterion 5: Related and Competing Measures

5. Related and Competing: Are there any related and competing measures? If so, are any specifications that are not harmonized? Are there any additional steps needed for the measures to be harmonized?

- Yes, but different population
- CAHPS - Hospice survey; developers feel harmonized
- No, this fills an important existing gap
- No
- NQF 2651 – CAHPS Hospice Survey (experience with care) + Harmonized
- 2651-CAHPS but the developer indicates that the measures have been harmonized.
- CAHPS There was mention of harmonization of this measure
- No

Public and Member Comments

Comments and Member Support/Non-Support Submitted as of: 01/19/22

- **Of the one NQF member who has submitted a support/non-support choice:**
    - One supports the measure
    - Zero do not support the measure
- Comment by: **American Academy of Hospice and Palliative Medicine**

This comment is in response to SMP review.

- **Issue 3: Risk Adjustment**

  R3: Risk adjustment approach seem incomplete. While there are data availability issues, important factors such as disease status could have been captured and included. R4: Lack of meaningful risk adjustment.

- **Developer Response 3:**

  Using the data available to us (which was limited in terms of what programs were able to provide to us, and how much we could reliably capture via survey-based self-report), we did explore some potential program- and patient-level risk adjustment factors.

  None of the potential risk adjustment variables were significant in their relationship with the pain measure after adjustment for multiple comparisons. However, our TECUPP emphasized the importance of considering inclusion of some variables, such as survey mode and proxy assistance, to increase the face validity of our modeling.

At the patient level, the *Receiving Desired Help for Pain* data element was significantly associated with diagnosis group (p<0.01). The quality measure score was also significantly associated with diagnosis group. These results held after multiple comparison adjustments. Because of challenges with data quality, we were unable to conduct further analyses within the scope of this effort, but these findings provide preliminary indication that diagnosis might affect responses to the performance measure data elements and overall measure performance**. We acknowledge the importance of further research in this area before the measure is used for high-stakes decisions.**

- Comment by: **American Academy of Hospice and Palliative Medicine**

This comment is in response to SMP review.

- **Issue 3: Measure Score Reliability**

  R6: Measure score - The adjusted ICC (0.079 with CI 0.02-0.175) is extremely low and is concerning. However, the individual program reliability (especially when taking into account the programs that met the minimum number of respondents is 0.735 which is good. R6: I rated low based solely on the ICC results. R9: This is a benefit of the doubt rating, measure score reliability was low.

- **Developer Response 3:**

  Since reliability is a function of both sample size and ICC, we believe the adjusted ICC on its own is not concerning. Various patient experience surveys have very low ICCs for item responses. For example, from “Psychometric Properties of the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Clinician and Group Adult Visit Survey” it was reported that the item ICCs for Access to Care were an average of 0.08, ranging from 0.07 to 0.11, all above the set 0.05 criterion (see section on “Multilevel Analyses”). Similarly, for CAHPS Hospice, ICCs for both their composite and single item measures range from 0.010 to 0.021 (see “Development of Valid and Reliable Measures of Patient and Family Experiences of Hospice Care for Public Reporting”). Considering *both* sample size and ICC, our measure test suggests that to achieve a reliability around 0.7, providers must have at least 33 respondents. We acknowledge that only 30% of programs *in our test* met this threshold (in implementation, this number could be higher, as we describe in our response to the comment below).

  Dyer, Naomi, Joann S. Sorra, Scott A. Smith, Paul Cleary, and Ron Hays. "Psychometric properties of the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) clinician and group adult visit survey." *Medical care* 50, no. Suppl (2012): S28.

  Anhang Price, Rebecca, Brian Stucky, Layla Parast, Marc N. Elliott, Ann Haas, Melissa Bradley, and Joan M. Teno. "Development of valid and reliable measures of patient and family experiences of hospice care for public reporting." Journal of palliative medicine 21, no. 7 (2018): 924-932.

- **Issue 4: Minimum Patient Volume**

  R9: The average reliability for all group/programs for the measure score was 0.482 with a wide range of values. However, when the requirement of n=33 was imposed, reliability jumped to 0.735 with a narrow range of values. However, this reduced the reportability of these results to only 30% of the beta (field) test sample groups/programs. Will reportability be an issue when the measure is scaled to a national roll-out? R3: Average reliability was around 0.48. After imposing 33 volume restriction, average reliability was around 0.73 but it would remove many programs.

- **Developer Response 4:** As noted by the reviewer, only 13 of 43 programs (30%) had sufficient patient volume to meet the minimum required respondents for a reliability measure score. Although our sample of outpatient palliative care programs did not include all programs in the United States who might have been able to participate, this drop-off in the number of programs does raise concerns about reportability and participation upon national implementation. It is possible that more programs would participate if the measures were implemented. It is also possible that the data submitted by participating programs to us for the test was limited (e.g.: by lack of dedicated resources to prepare data files, by the onset of the pandemic) and that once implemented, more of these programs would meet the minimum numbers of respondents. Further work will be important to address this, and other issues related to implementation, that can only be accomplished once these measures are rolled out more widely.

- Comment by: **American Academy of Hospice and Palliative Medicine**

This comment is in response to a concern raised by one of the Scientific Methods Panel reviewers. Reliability

- **Issue 1: Attribution**

  R3: My main concern is with the potential misalignment of provider attribution and patient-reported outcome attribution. Provider was identified based on a three-month period, MIPS-eligible provider who the patient saw most often during the three-month period. However, the attached survey form refers to "the last 6 months". Given that provider who the patient saw most often in the 3-month period may not be the same one in the 6-month period, and it is quite likely that patient might have seen multiple providers during the 6-month period. Therefore, this may potentially cause provider misattribution. To further complicate things, the survey form does not identify the eligible ambulatory palliative care visit, so there is no explicit anchor visit for the patient to refer to even though the developer referred to the eligible ambulatory palliative visit repeatedly in this application, for example, the developer mentioned that patients who had transitioned to hospice could still answer the survey by reflecting on their experience with the visits.

- **Developer Response 1:** Our eligibility and sampling procedures, informed by input from our TECUPP, was designed to reduce the potential for misattribution as much as possible, while enhancing patient recall and their evaluation of the care they received from the palliative care provider and team.

  From the data files outpatient palliative care programs sent us, we first filtered to include only visits with Merit-based Incentive Payment System (MIPS)-eligible provider types that occurred in the three months prior to the anticipated start date of survey fielding (i.e., the planned date for mailing the prenotification letter to patients). We limited to 2019 MIPS-eligible providers so that these measures could be used for MIPS reporting). We limited eligible visits to a three-month period to ensure the recency of the visit patients should consider when responding about their experience. Setting this time frame also allowed each program's "clock" to start at the same time.

  We then identified a reference provider to be named on the survey instrument for each patient by selecting the MIPS-eligible provider whom 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). If patients had multiple visits, we selected the most recent visit for each patient with the reference provider.

  The survey instrument included additional protections against misattribution. In both the survey cover letter as well as the instrument itself, we name the provider and team (e.g.: "Dr. Jones and team"). We included mention of the "team" because palliative care is an interdisciplinary team effort, and we anticipated that many patients would have seen the primary provider as well as other palliative care team members across and within visits that they had in the 3-month period. By naming the specific palliative care provider seen most often during the 3-month period, we hoped to avoid confusion with other providers outside palliative care that the patient might have seen.

  The survey instrument refers to a 6-month timeframe rather than the 3-month visit eligibility timeframe to cover potential lags in timing between when the palliative care program sent their data files, and when the survey was fielded and ultimately reached the patient.

  As an example, a program might have submitted a data file to us on September 1st, 2019, covering visits from March 1st through August 31st, 2019. We would sample visits June through August 2019 (the most recent 3 months of data), and field the survey September 25th (once all data files had been cleaned and prepared). The patient might then receive/open the survey on October 1st, 2019. Referring to a 6-month timeframe (rather than a 3-month timeframe) thus covers the full sampling timeframe of June-August 2019.

  Guided by input from our TECUPP, we did not anchor the survey instrument to a specific single visit. Rather, we intentionally wanted patients to reflect on their experience of palliative care as a whole, rather than segmented into what happens in just a single visit, because palliative care as a discipline is intended to be holistic and comprehensive, with a longer-term care relationship. As such, the proposed measures reflect the experience of care over time and cannot be justifiably assessed after a single visit. For example, ensuring that a patient receives the help that they desire for their pain necessarily takes place over time rather than in a single visit.

- Comment by: **American Academy of Hospice and Palliative Medicine**

This comment is in response to an SMP member's concerns.

- **Issue 2: Proxy Response**

  R6: Also, it is stated throughout the application that responses completed by a proxy with our assistance from the patient will be excluded. I'm assuming (perhaps wrongly) that question 10 of the survey (option 3 - Answered the questions for me) will be used to determine this. If that is the case, I have an issue with this as I would not understand that response to indicate no patient involvement. Thus, I feel like this question needs to be re-worked. Also, it is indicated through the application that <u>surveys that were completely filled out by a proxy are excluded</u>. However, it is unclear to me how this would be identified. I'm assuming (perhaps wrongly) that survey question 11 is used for this purpose and that option "answered the questions for me" is used to signify that the patient was not involved. However, I find this option unclear, and I would not have understood it to indicate that the patient was not involved. Thus, I think this item needed to be re-worked to increase clarity before use.

- **Developer Response 2:**

  We excluded from the denominator patients for whom a proxy completed the entire survey on their behalf for any reason i.e., with no patient involvement, (proxy-only responses), but retained proxy-assistance responses, adjusting slightly upward for the latter in our measure scoring procedure, as indicated by our risk adjustment analysis.

  We defined “proxy-only” as the response option “answered the questions for me” to the question “How did that person help you complete the survey?”. This was the only response that indicated that the proxy actually provided the answers to the questions. Based on cognitive interviews and TECUPP input, we felt comfortable that this response option was indicative of <u>no</u> patient involvement. In contrast, we defined “proxy-assistance” as any or all of these responses: “read the questions to me”, “wrote down the answer I gave”, “translated the questions into my language; “helped in some other way”. Further work could reinforce these distinctions and identify slight revisions to increase clarity; the work done to date provides general support for the language currently used.

- Comment by: **American Academy of Hospice and Palliative Medicine**

This comment is in response to SMP review.

- **Issue 6: Sampling**

  R6: Also, on page 35 it is indicated that data should be collected from "eligible palliative care patients that are representative of the palliative care provider program." This indicates to me that some sampling technique is used but up to this point in the application I thought the practice would send data on all of the patients who met the criteria - not sample. This is an easy fix and just needs a clarification.

- **Developer Response 6:** Depending on the volume of patients and to support feasibility for programs, palliative care practices may survey all eligible patients or a *random* sample of eligible patients. 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.

- Comment by: **American Academy of Hospice and Palliative Medicine**

These comments are in response to SMP review.

Validity

- **Issue 1: Non-Response**

  R1, R3:am concerned about survey non-response. Although not very large, there is variation in non-response between programs and demographic differences between responders and non-responders. I'm curious is the former is related to the latter. Are there better methods to account for survey non-response than just ignoring it? Nonresponse bias needs to be addressed with known differences between respondents and non-respondents.

- **Developer Response 1:**

  Of the 7,595 surveys we fielded, 2,804 were included as cases for analysis. Another 1,435 were deemed to be ineligible for the measure (e.g.: patient had died or disavowed the reference program or provider) and are thus not considered non-responders.

  Of the remaining 3,356 non-responders (i.e., surveys sent to presumably eligible patients but not returned to us), the majority (80%) were not reachable: 63% were not reachable after the maximum 8 phone call attempts and 17% had non-working phone numbers). Of note, another 14% were reachable but refused to complete the survey.

  As prior survey research has established, it is likely that people who do not return or respond to surveys are systematically different than those who do. This is particularly likely among respondents who explicitly decline or refuse to answer the survey. Our data suggest that survey respondents were slightly older than nonrespondents (mean age 63.4 versus 60.9; p < 0.01). The proportion of women was also higher among respondents as compared with nonrespondents (56.2 percent versus 54.5 percent), but the difference was not statistically significant (p = 0.21). Although information on patient race was self-reported via the survey instrument, a subset of 12 participating palliative care programs provided patient race for at least 90 percent of their patients in their submitted data files. Among this subset, there was a greater proportion of White patients (88.1 percent versus 80.2 percent) and a lower proportion of Black patients (8.8 percent versus 11.9 percent) in the respondent group compared with the nonrespondent group. The results of a chi-squared test indicate that this difference is statistically significant (p < 0.01).

  Because the non-responders did not return a survey, we were unable to compare differences in measure scores between them and responders. Although outside the scope of this initial testing effort, future work could attempt to explore other differences between these two groups, for example, to qualitatively understand whether their care experiences differed, in order to shed light on potential response bias.

- **Issue 2: Telehealth**

  R6: I think Telehealth visits should be considered for inclusion in the future. R6, others: Concern about the exclusion of telehealth visits, should be included in the future

- **Developer Response 2:** We strongly agree that telehealth visits should be considered for inclusion in the future. Although we explored the inclusion of telephone and video visits as eligible visits at the outset of our alpha test, we decided not to include those visits because of their low frequency and difficulty identifying these visits. Thus, our initial performance measure eligibility criteria relied on coding in-person office visits. However, because of the COVID-19 pandemic, we were faced with an unexpected situation when participating palliative care programs shifted rapidly to providing telehealth services for their patients. With the input of our TECUPP and project advisory group, as well as input from participating programs, we decided to continue to disallow telehealth visits as eligible for the performance measure when we restarted data collection from September 2020 to February 2021. This ensured consistency in our results (i.e., we were measuring patient experiences with only in-person visits throughout the national beta field test) and avoided any potential confounding effects of the pandemic and telehealth use. However, it is likely that telehealth visits will continue in greater frequency than before the pandemic and should be included in measurement programs in the future. In interviews we conducted with palliative care programs during our testing phase, though most programs had little to no experience with telehealth prior to the pandemic, all programs converted to telehealth after March 2020 and continue to sustain telehealth services in some form. Closer attention to the development and testing of these and other patient experience measures within a telehealth context is warranted prior to widespread use in accountability programs.

- **Issue 3: Risk Adjustment**

  R3, R4: The risk model seems overly simplified, there are many factors that should have been looked into and potentially included, for example, administrative home type, disease status and others; Considered only a small number of patient level risk factors; lack of risk adjustment for patient level factors. Although I understand that this is because of lack of patient-level data on risk factors, this is not an "excuse" for the lack of risk adjustment.

- **Developer Response 3:**

  Using the data available to us (which was limited in terms of what programs were able to provide to us, and how much we could reliably capture via survey-based self-report), we did explore some potential program- and patient-level risk adjustment factors.

  Only survey mode was significant in its relationship with the HU performance measure (p = 0.013) and with programs (p = 0.001) after adjustment for multiple comparisons.

  At the patient-level, a single data element ("I felt this provider and team understood what is important to me out of life") of the four Feeling Heard and Understood data elements was significantly associated with diagnosis group (p < 0.01), and the raw measure score was significantly associated with diagnosis group. These results held after multiple comparison adjustments. Because of challenges with data quality, we were unable to conduct further analyses within the scope of this effort, but these findings provide preliminary indication that diagnosis might affect responses to the performance measure data elements and overall measure performance. **We acknowledge the importance of further research in this area before the measure is used for high-stakes decisions.**

- Comment by: **American Academy of Hospice and Palliative Medicine**

These comments are in response to SMP review.

Validity

- **Issue 1: Non- Response**

  R1, R3:am concerned about survey non-response. Although not very large, there is variation in non-response between programs and demographic differences between responders and non-responders. I'm curious is the former is related to the latter. Are there better methods to account for survey non-response than just ignoring it? Nonresponse bias needs to be addressed with known differences between respondents and non-respondents.

- **Developer Response 1:**

  Of the 7,595 surveys we fielded, 2,804 were included as cases for analysis. Another 1,435 were deemed to be ineligible for the measure (e.g.: patient had died or disavowed the reference program or provider) and are thus not considered non-responders.

  Of the remaining 3,356 non-responders (i.e., surveys sent to presumably eligible patients but not returned to us), the majority (80%) were not reachable: 63% were not reachable after the maximum 8 phone call attempts and 17% had non-working phone numbers). Of note, another 14% were reachable but refused to complete the survey.

  As prior survey research has established, it is likely that people who do not return or respond to surveys are systematically different than those who do. This is particularly likely among respondents who explicitly decline or refuse to answer the survey. Our data suggest that survey respondents were slightly older than nonrespondents (mean age 63.4 versus 60.9; p < 0.01). The proportion of women was also higher among respondents as compared with nonrespondents (56.2 percent versus 54.5 percent), but the difference was not statistically significant (p = 0.21). Although information on patient race was self-reported via the survey instrument, a subset of 12 participating palliative care programs provided patient race for at least 90 percent of their patients in their submitted data files. Among this subset, there was a greater proportion of White patients (88.1 percent versus 80.2 percent) and a lower proportion of Black patients (8.8 percent versus 11.9 percent) in the respondent group compared with the nonrespondent group. The results of a chi-squared test indicate that this difference is statistically significant ($p < 0.01$).

Because the non-responders did not return a survey, we were unable to compare differences in measure scores between them and responders. Although outside the scope of this initial testing effort, future work could attempt to explore other differences between these two groups, for example, to qualitatively understand whether their care experiences differed, in order to shed light on potential response bias.

- **Issue 2: Telehealth**

  R6: I think Telehealth visits should be considered for inclusion in the future. R6, others: Concern about the exclusion of telehealth visits, should be included in the future

- **Developer Response 2:** We strongly agree that telehealth visits should be considered for inclusion in the future. Although we explored the inclusion of telephone and video visits as eligible visits at the outset of our alpha test, we decided not to include those visits because of their low frequency and difficulty identifying these visits. Thus, our initial performance measure eligibility criteria relied on coding in-person office visits. However, because of the COVID-19 pandemic, we were faced with an unexpected situation when participating palliative care programs shifted rapidly to providing telehealth services for their patients. With the input of our TECUPP and project advisory group, as well as input from participating programs, we decided to continue to disallow telehealth visits as eligible for the performance measure when we restarted data collection from September 2020 to February 2021. This ensured consistency in our results (i.e., we were measuring patient experiences with only in-person visits throughout the national beta field test) and avoided any potential confounding effects of the pandemic and telehealth use. However, it is likely that telehealth visits will continue in greater frequency than before the pandemic and should be included in measurement programs in the future. In interviews we conducted with palliative care programs during our testing phase, though most programs had little to no experience with telehealth prior to the pandemic, all programs converted to telehealth after March 2020 and continue to sustain telehealth services in some form. Closer attention to the development and testing of these and other patient experience measures within a telehealth context is warranted prior to widespread use in accountability programs.

Combined Methods Panel Scientific Acceptability Evaluation

RELIABILITY: SPECIFICATIONS

1. **Are submitted specifications precise, unambiguous, and complete so that they can be consistently implemented?** ☒ **Yes** ☐ **No**

   Submission document: Items sp.01-sp.30

   NOTE*: NQF staff will conduct a separate, more technical, check of eCQM specifications, value sets, logic, and feasibility, so no need to consider these in your evaluation.*

2. **Briefly summarize any concerns about the measure specifications.**

   ○ For example: Which data elements, if any, are not clearly defined? Which codes with descriptors, if any, are not provided? Which steps, if any, in the logic or calculation algorithm or other specifications (e.g., risk/case-mix adjustment, survey/sampling instructions) are not clear? What concerns do you have about the likelihood that this measure can be consistently implemented?

   ○

   ○ **Reviewer 3:** My main concern is with the potential misalignment of provider attribution and patient-reported outcome attribution. Provider was identified based on a three-month period, MIPS-eligible provider who the patient saw most often during the three-month period. However, the attached survey form refers to "the last 6 months". Given that provider who the patient saw most often in the

3-month period may not be the same one in the 6-month period, and it is quite likely that patient might have seen multiple providers during the 6-month period. Therefore, this may potentially cause provider misattribution. To further complicate things, the survey form does not identify the eligible ambulatory palliative care visit, so there is no explicit anchor visit for the patient to refer to even though the developer referred to the eligible ambulatory palliative visit repeatedly in this application, for example, the developer mentioned that patients who had transitioned to hospice could still answer the survey by reflecting on their experience with the visits.

Reviewer 5: Shouldn't the denominator be: "All patients aged 18 years and older who had an ambulatory palliative care visit [who provided a response to the question]"?

Reviewer 6: The issue (and it is easily fixable) is that it is unclear how a rate measure gets covered to a 1-100 scale. I think an example calculation would be helpful for the reader.

Reviewer 9: Three-question survey about presence of pain and whether the patient received "… as much help as you wanted for your pain …" from the provider. Several demographic questions surround these three questions. The submission form is 99 pages in length! The measure was developed using a TEP that recommended that they NOT focus on the type or amount of treatment for the pain. The focus was wholistic and idiosyncratic to the patient, taking into consideration that QOL may be a balance for the drugs received to manage the patient's pain in an ambulatory palliative care setting. Used a Top Box approach (i.e., only "yes, definitely" received pain care desired counts in numerator). Developer provides an algorithm for how the measure is calculated from the individual patient data to aggregating to group level and applying risk adjustment (pp. 30 – 33). Minimum sample size for measure at the group/program level is 33 (n who answered the single key question). To achieve this n, the measured entity will have a much higher number of patients who are receiving ambulatory palliative care (n = 106 – 132) and receive the questionnaire but are filtered out prior to key question based on lack of presence of pain or desire to have pain treated.

Reviewer 11: No concerns

Reviewer 12: no concerns

RELIABILITY: TESTING

Submission document: Questions 2a.01-09

3. **Reliability testing level**

○ *For example: for some types of measures, if patient/encounter level validity is demonstrated, additional reliability testing is not required. Please review table above.*

☒ **Accountable-Entity Level** ☒ **Patient/Encounter Level** ☐ **Neither**

4. **Reliability testing was conducted with the data source and level of analysis indicated for this measure**

NOTE: "level of analysis" reflects which entity is being assessed or held accountable by the measure.
For example: If a measure is specified for a clinician level of analysis, but facility-level testing is provided, then testing does NOT match level of analysis. Or, if two levels of analysis are specified (e.g., clinician and facility) but testing is conducted for only one, then testing does NOT match level of analysis. Or, if claims data are selected as a data source, but testing data doesn't include claims data, then testing does NOT match data source.
Also, check "NO" if only descriptive statistics are provided or submitter only describes process for data management/cleaning/computer programming.

○ ☒ **Yes** ☐ **No**

5. If accountable-entity level and/or patient/encounter level reliability testing was NOT conducted or if the methods used were NOT appropriate, was **empirical VALIDITY testing** of patient-level data conducted?

- ○ *According to current guidance patient/encounter level validity testing can be used for patient/encounter level reliability testing. Answer ONLY if you responded "Neither" on question #3 and/or "No" to question #4. Note that for some types of measures, additional reliability testing is not required IF patient/encounter level validity is demonstrated.*

  ☒ **Yes** ☒ **No**

6. **Assess the method(s) used for reliability testing**

   Submission document: Question 2a.10

   For example: Is the method(s) appropriate? If not, please explain (and offer potential alternatives if possible). Does the testing conform to NQF criteria and guidance? Was testing was conducted with the data source and level of analysis indicated for this measure? Address each level of testing provided, and each analysis under each method.

Reviewer 1: methods were good
Reviewer 3: The developer tested the data element reliability by test-retest reliability to ascertain the key item reliability. For measure score reliability, the developer employed a hierarchical logistic regression model to obtain intra class correlation coefficient and then converted it to reliability. Both are appropriate.
Reviewer 4: Data element reliability was tested using Cronbach's alpha = 0.95 and test-retest reliability (0.85) SNR = 0.48.
Reviewer 5: Data element: Appropriate methods. Evaluated using a test-retest reliability coefficient and percent agreement. Measure score: Appropriate methods. Completed a 'signal to noise' analysis.
Reviewer 6: Yes. Methods are appropriate. However, I don't think that 2 days for the second measure on the test-retest is long enough.
Reviewer 8: Reliability of data elements was evaluated using a measure of internal consistency based on data from a subset of respondents at two timepoints to conduct test-retest reliability. A final subsample of 197 respondents was used for the test-retest analysis. Only patient respondents who completed the original survey without proxy assistance were invited to participate in the retest.
Reliability of the quality measure score at the program level was evaluated using "signal-to-noise" analysis. Hierarchical generalized-linear regression models with binomial outcomes to decompose the variability were used to relate outcome measures to programs and covariates, where the hierarchy of data is patient observations within the program.
The reliability from the measure test was then projected out based on observed variances and sample sizes from each program, using the Spearman-Brown prophecy formula to estimate a required within-program sample size to achieve a desired reliability for the measure.
Reviewer 9: The developer indicates that t-tests and chi-square tests were used, but the results are not presented clearly (e.g., in tabular format). Additionally, while the developer attempted to sample a diverse group based on race, this proved to be impossible given the data were collected during the Covid period and the strong homogeneity of patients (white, not Hispanic) in the palliative care sites that agreed to participate in the beta testing. The data collection instrument is new (developed by Rand?). The Cronbach's alpha tests methodology was presented. Similarly, the developer described the methodology (S-t-N) for the measure score was described as well as the computational method for applying the risk adjustment to the measure score. Table 2 (pg. 46) shows that there were approximately 2800 completed and usable surveys in their beta (field) test and approximately 4800 unusable surveys due to lack of response or ineligibility. Is there the possibility of a response bias that is either positive or negative in the

usable data? Demographic data in tables that follow suggest that those completing the survey were likely to be white (~88%) and college educated (~65%).

Reviewer 10: Correlation, Signal to noise

Reviewer 11: Methods are appropriate. Should test for difference between modes of administration if any.

Reviewer 12: Yes, similar to other survey measure

7. **Assess the results of reliability testing**

Submission document: Question 2a.11

For example: Is the test sample adequate to generalize for widespread implementation? Is there high or moderate confidence that the measure results and/or the data used in the measure are reliable? Address each level of testing provided, and each analysis under each method.

Reviewer 1: patient level reliability was high. Entity-level reliability was low for the entire sample but good for entities with at least 33 responses.

Reviewer 3: Test-retest correlation was 0.90 and agreement between two rounds of test was 88%, indicating acceptable reliability of the data element reliability. For measure score, model ICC was around 0.08, also indicating reasonable variation among groups. With 33 responses, 0.7 reliability can be achieved. The developer also calculated the reliability using beta-binomial approach and found the average reliability across programs to be around 0.48. With volume restriction of 33, the average reliability would be 0.73. However, this would remove 70% programs.

Reviewer 4: Data element reliability was tested using Cronbach's alpha = 0.95 and test-retest reliability (0.85) SNR = 0.48.

Reviewer 5: Data element: Results were excellent (test-retest correlation (r) between Time 1 and Time 2 scores was 0.90 and there was 88 percent agreement in responses from Time 1 to Time 2). Measure score: When restricted to higher-response programs (min sample size of 35 respondents), avg. reliability is 0.735

Reviewer 6: Data element - Test-retest = 0.9 - which is good reliability. Measure score - The adjusted ICC (0.079 with CI 0.02-0.175) is extremely low and is concerning. However, the individual program reliability (especially when taking into account the programs that met the minimum number of respondents is 0.735 which is good.

Reviewer 8: Data Element Reliability: Test-retest reliability score was 0.90 indicating that scores can be reliably used in the quality measure.

Quality Measure Score Reliability: The estimate of the Bayesian adjusted ICC was 0.079 (95% CI: 0.02 to 0.175) indicating a low level of between-program variability as compared to the within-program variability. However, using the S-B prophecy formula they estimate that to obtain a nominal reliability of 0.7, an average sample size of 33 respondents would be required.

Reviewer 9: The data element reliability results based on test-retest correlation was 0.90; an acceptable value. The measure score reliability using a Bayesian generalized mixed effects models using the ICC distribution was 0.079 (95% CI: 0.02 – 0.175). The average reliability for all group/programs for the measure score was 0.482 with a wide range of values. However, when the requirement of n=33 was imposed, reliability jumped to 0.735 with a narrow range of values. However, this reduced the reportability of these results to only 30% of the beta (field) test sample groups/programs. Will reportability be an issue when the measure is scaled to a national roll-out?

Reviewer 10: .90; 88 percent ICC .079

Reviewer 11: Appropriate.

Reviewer 12: Yes, similar to other survey measure

8. Was the method described and appropriate for assessing the proportion of variability due to real differences among measured entities? **NOTE:** If multiple methods used, at least one must be appropriate.
   - ○ Submission document: Question 2a.10-12
   - ○ For example: Appropriate signal-to-noise analysis; random split-half correlation; other accepted method with description of how it assesses reliability of the performance score.

   ☒ **Yes**

   ☐ **No**

   ☐ **Not applicable**

9. Was the method described and appropriate for assessing the reliability of ALL critical data elements?

○ **Submission document:** Question 2a.10-12
For example: inter-abstractor agreement (ICC, Kappa); other accepted method with description of how it assesses reliability of the data elements

○ *Answer NO if: only assessed percent agreement; did not assess separately for all critical data elements (or at minimum, for numerator, denominator, exclusions)*

☒ **Yes**

☐ **No**

☐ **Not applicable** (patient/encounter level testing was not performed)

10. **OVERALL RATING OF RELIABILITY** (taking into account precision of specifications and **all** testing results):

☒ **High** (NOTE: Can be HIGH **only if** accountable-entity level testing has been conducted)

☒ **Moderate** (NOTE: Moderate is the highest eligible rating if accountable-entity level testing has **not** been conducted)

☒ **Low** (NOTE: Should rate **LOW** if you believe specifications are NOT precise, unambiguous, and complete or if testing methods/results are not adequate)

☐ **Insufficient** (NOTE: Should rate **INSUFFICIENT** if you believe you do not have the information you need to make a rating decision)

11. **Briefly explain rationale for the rating of *OVERALL RATING OF RELIABILITY* and any concerns you may have with the approach to demonstrating reliability.**

Reviewer 1: My rating of 'high' is contingent on the minimum sample of 33/entity.

Reviewer 3: Average reliability was around 0.48. After imposing 33 volume restriction, average reliability was around 0.73 but it would remove many programs.

Reviewer 4: low reliability at the measure level. Reliability is especially low given near absence of risk adjustment (i.e., SNR will be higher when risk adjustment is inadequate to account for differences in provider case mix)

Reviewer 5: Used appropriate testing methods; demonstrated strong results.

Reviewer 6: I rated low based solely on the ICC results. The other results are acceptable.

Reviewer 8: Reliability results were generally very strong.

Reviewer 9: This is a “benefit of the doubt” rating. The measure score reliability was low. However, given that this is a new measure and has a small, restricted sample due to Covid, the measure score does have potential to assess the patient's experience with palliative care. Response bias and reportability are issues that need to be monitored and reported on in the next review of this measure.

Reviewer 10: Reasonable approach and findings

Reviewer 11: Based on test results

Reviewer 12: No concerns

VALIDITY: TESTING

12. **Validity testing level (check all that apply):**

- ○ ☒ **Accountable-Entity Level** ☒ **Patient or Encounter-Level** ☐ **Both**

13. **Was the method described and appropriate for assessing the accuracy of ALL** critical data elements**?**
NOTE that data element validation from the literature is acceptable.
Submission document*:* Questions 2b.01-02.
For example: Data validity/accuracy as compared to authoritative source- sensitivity, specificity, PPV, NPV; other accepted method with description of how it assesses validity of the data elements.
Answer NO if: only assessed percent agreement; did not assess separately for all critical data elements (or at minimum, for numerator, denominator, exclusions)

☒ **Yes**

☐ **No**

- ○ ☒ **Not applicable** (patient/encounter level testing was not performed)

14. **Method of establishing validity at the *accountable-entity level:***

- ○ **NOTE:** Empirical validity testing is expected at time of maintenance review; if not possible, justification is required.
- ○ **Submission document:** Questions 2b.01-02
- ○ ☒ **Face validity**
- ○ ☒ **Empirical validity testing at the accountable-entity level**
- ○ ☐ **N/A (accountable-entity level testing not conducted)**

15. **Was the method described and appropriate for assessing conceptually and theoretically sound hypothesized relationships?**

- ○ **Submission document:** Question 2b.02
- ○ *For example: Correlation of the accountable-entity level on this measure and other performance measures; differences in performance scores between groups known to differ on quality; other accepted method with description of how it assesses validity of the performance score*

☒ **Yes**

- ○ ☐ **No**
- ○ ☐ **Not applicable** (accountable-entity level testing was not performed)

16. **Assess the method(s) for establishing validity**

Submission document: Question 2b.02

For example:

- *If face validity the only testing conducted: Was it accomplished through a systematic and transparent process, by identified experts, explicitly addresses whether performance scores resulting from the measure as specified can be used to distinguish good from poor quality, and the degree of consensus and any areas of disagreement provided/discussed?*
- *If a maintenance measure, but no empirical testing conducted, was justification provided?*

- *If construct validation conducted, was the hypothesized relationship (including strength and direction) described and does it seem reasonable?*

Reviewer 1: reasonable methods for validity testing
Reviewer 3: To assess data element reliability, the developer compared the key item to other relevant survey items to assess convergent validity. The developer also examined the association between this measure and other related measures. However, using "Feeling heard and understood" for this testing is questionable as this is currently being evaluated at NQF now. The developer also surveyed seven experts for face validity.
Reviewer 4: data element validity – assessed convergent validity with survey data elements that are currently in use (r values 0.48-0.54) quality measure level – associated with other similar measures (r = 0.5 – 0.8)
Reviewer 5: Data element: Included items from other "like" surveys to look at agreement in responses. Measure score: Used both convergent validity testing and formal face validity testing.
Reviewer 6: Convergent validity was used for both data element and Measure score validity assessment. These methods seem appropriate. However, my question is how does the measure score differ from the data element for a 1 item measure operationally? This part is unclear to me (perhaps I missed the explanation).
Reviewer 8: Data element validity was assessed by including additional survey data elements from other instruments with expected relationship to the Feeling Heard and Understood items. These included CAHPS item “in the last 3 months, how often did this provider and team listen carefully to you?”.
Quality measure score validity was assessed by examining the relationship of score with the “feeling heard and understood” and CAHPS communication measure scores. Face validity was determined using panel of experts. Advisors were asked to consider how well the measure scoring approach distinguishes between programs with high, medium, and low performance and how useful it is to quality improvement efforts. Advisors rated face validity on a scale of 1 (lowest rating) to 9 (highest rating); numeric ratings corresponded with descriptive ratings of low (1-3), moderate (4-6), or high (7-9).
Reviewer 9: The presentation of the methodologies for both data element and measure score were clear."
Reviewer 10: Correlation, TEP
Reviewer 11: Face validity and correlation with CAHPS composites.
Reviewer 12: Yes, similar to other survey measure

17. **Assess the results(s) for establishing validity**

Submission document: Questions 2b.03-04

For example: Is the test sample adequate to generalize for widespread implementation? Do the results demonstrate sufficient validity so that conclusions about quality can be made? Do you agree that the score from this measure as specified is an indicator of quality?

Reviewer 1: Supported the hypothesized relationships.
Reviewer 3: Without considering the results based on 'feeling heard and understood", the results based on CAHPS were somewhat supportive. Face validity ratings were very good.
Reviewer 4: data element validity – assessed convergent validity with survey data elements that are currently in use (r values 0.48-0.54) quality measure level – associated with other similar measures (r = 0.5 – 0.8)

Reviewer 5: Data element: supportive of convergent validity. Receiving desired help for pain was positively associated with a higher CAHPS communication composite score (r = 0.57, p<.001). Also as expected, receiving desired help for pain was positively associated with feeling heard and understood (r =0.61, p<.001). Measure score: supportive of convergent validity. Measure was significantly associated with the CAHPS communication quality measure (r = 0.386, p =.014), the Feeling Heard and Understood quality measure (r = 0.410, p =.009), and the overall rating of the palliative care provider and team (r = 0.56, p=<.001).

Reviewer 6: Measure score - correlation with CAHPS = 0.57 and with feeling heard = 0.61. Both seem executable. Data element - Correlation with CAHPS communication = 0.386, feeling heard = 0.410, and overall rating or the team = 0.56. The first two are fairly low correlations. Face validity is acceptable.

Reviewer 8: Data Element level: Higher scores on the Receiving Desired Help for Pain data element were associated with higher CAHPS communication scores (r = 0.57, p<.001) as well as with feeling heard or understood (r = 0.61, p< .001).

Quality Measure level: The measure scores were significantly and positively associated with the CAHPS communication quality measure (r = 0.386, p=0.014), the Feeling Heard and Understood quality measure (r = 0.410, p<.009) and the overall rating of the palliative care provider and team (r= 0.56, p=<.001). Seven expert advisors rated face validity of ~~of~~ the measure score a mean of 7.7 on a scale of 1-9, corresponding with an average rating of "high." These ratings reflect fairly strong support for face validity of the proposed quality measure from experts in palliative care and quality measurement.

Reviewer 9: Note: Proxy assistance is limited to reading the questions to the patient and/or translating the questions into the patient's primary language. The responses must be the patient's and questions to this effect are embedded in the instrument. The results for both data element and measure score were comparisons (correlation) to the existing CAHPS scores for these facilities. The results were positive (r=0.57, p<0.001) for data element. For measure score the results were compared with communication quality, the "Feeling Heard and Understood" measure, and the overall rating of the palliative care provider and team. The results were consistent and positive (r=0.386, p=0.14; r=0.410, p=0.009; r=0.56, p<0.001, respectively).

Reviewer 10: Reasonable findings given available options

Reviewer 11: Adequate.

Reviewer 12: Adequate, similar to other survey measure

VALIDITY: ASSESSMENT OF THREATS TO VALIDITY

18. **Please describe any concerns you have with measure exclusions.**

Submission document: Questions 2b.15-18.

For example: Are there exclusions? If so, are the exclusions/exceptions of sufficient frequency and variation across providers to be needed (and outweigh the data collection burden)? Are any patients or patient groups inappropriately excluded from the measure? If patient preference (e.g., informed decision-making) is a basis for exclusion, does it impact performance and if yes, is the measure specified so that the information about patient preference and the effect on the measure is transparent? If you have concerns based on a clinical rationale, please note here as well as in question #29.

Reviewer 3: Potential misalignment of provider attribution and patient-reported outcome attribution is a real threat.

Reviewer 5: none

Reviewer 6: I have similar issues with the exclusions for this measure as I had with measure 3665. Specifically, I think Telehealth visits should be considered for inclusion in the future. Also, it is stated throughout the application that responses completed by a proxy with our assistance from the patient will be excluded. I'm assuming (perhaps wrongly) that question 10 of the survey (option 3 - Answered the questions for me) will be used to determine this. If that is the case, I have an issue with this as I would not understand that response to indicate no patient involvement. Thus, I feel like this question needs to be re-worked.

Reviewer 9: The exclusions were explained clearly and are reasonable.

Reviewer 11: No concerns.

Reviewer 12: no concerns

19. **Risk Adjustment**

○ **Submission Document:** Questions 2b.19-32

○ *Applies to all outcome, cost, and resource use measures. Please answer all checkbox questions (19a -19d), then elaborate on your answers in your response to 19e.*

19a. **Risk-adjustment method**

☐ None ☒ Statistical model ☐ Stratification

☐ Other method assessing risk factors (please specify)

19b. **If not risk-adjusted, is this supported by either a conceptual rationale or empirical analyses?**

☐ Yes ☐ No ☐ Not applicable

19c. **Social risk adjustment:**

19c.1 Are social risk factors included in risk model? ☒ Yes ☒ No ☒ Not applicable

19c.2 Conceptual rationale for social risk factors included? ☒ Yes ☒ No

19c.3 Is there a conceptual relationship between potential social risk factor variables and the measure focus? ☒ Yes ☒ No

19d.**Risk adjustment summary:**

19d.1 All of the risk-adjustment variables present at the start of care? ☒ Yes ☒ No

19d.2 If factors not present at the start of care, do you agree with the rationale provided for inclusion?

☒ Yes ☒ No

19d.3 Is the risk adjustment approach appropriately developed and assessed? ☒ Yes ☒ No

19d.4 Do analyses indicate acceptable results (e.g., acceptable discrimination and calibration)

☒ Yes ☒ No

19d.5.Appropriate risk-adjustment strategy included in the measure? ☒ Yes ☒ No

19e**. Assess the risk-adjustment approach**

For example: If measure is risk adjusted*:*

- *If the developer asserts there is no conceptual basis for adjusting this measure for social risk factors, do you agree with the rationale?*
- *How well do social risk factor variables that were available and analyzed align with the conceptual description provided?*
- *Are the candidate and final variables included in the risk adjustment model adequately described for the measure to be implemented?*
- *Are all of the risk adjustment variables present at the start of care (if not, do you agree with the rationale)?*

- *If social risk factors are not included in the risk-adjustment approach, do you agree with the developer's decision?*
- *Is an appropriate risk-adjustment strategy included in the measure (e.g., adequate model discrimination and calibration)?*
- *Are all statistical model specifications included, including a "clinical model only" if social risk factors are included in the final model?*

***If measure is NOT risk-adjusted**:*

- *Is a justification for not risk adjusting provided (conceptual and/or empirical)?*
- *Is there any evidence that contradicts the developer's rationale and analysis for not risk-adjusting?*

Reviewer 3: Risk adjustment approach seem incomplete. While there are data availability issues, important factors such as disease status could have been captured and included.

Reviewer 4: There is no adjustment for patient-level risk factors.

Reviewer 5: Risk adjustment approach was appropriate. Adjusts for mode of administration and whether a proxy helped complete the question.

Reviewer 6: No concerns.

Reviewer 9: The risk adjustment used a 12-month period for data collection collected during four three-month periods of Provider-Patient interaction.

Reviewer 11: re-test for social risk factors in the future.

Reviewer 12: Justification to not include social risk factors

20. **Please describe any concerns you have regarding the ability to identify meaningful differences in performance.**

Submission document: Questions 2b.05-07

For cost/resource use measures, does this measure identify meaningful differences about cost and resource use between the measured entities?

Reviewer 3: The range of measure scores seem to be reasonable, scores on both ends are statistically different.

Reviewer 5: None. See variation across programs.

Reviewer 6: I am not convinced that meaningful differences can be identified with a 1 item measure based on Figure 6 on page 169.

Reviewer 9: Because this is a new measure data, meaningful difference comparisons are difficult to assess empirically. The developer used preliminary data to extrapolate to create a larger hypothetical data set. The results of this hypothetical data set suggest that meaningful differences among palliative care facilities can be identified.   There is some evidence in the narrative provided by the developer (2b.09 on pg. 72) that there may be unaccounted for biases were not controlled in the risk adjustment model—notably racial differences and response bias (i.e., 7595 sampled patients but only 2804 could be used to complete the measure score, and the patients completing usable survey information were largely female (56%), white (88%), non-Hispanic (95%), and college educated (66%).

Reviewer 10: None

Reviewer 11: No concerns

21. **Please describe any concerns you have regarding comparability of results if multiple data sources or methods are specified.**

Submission document: Questions 2b.11-14.

***Note**: This item is directed to measures that are risk-adjusted (with or without social risk factors) **OR** to measures **with more than one set of specifications/instructions**. It does **not apply** to measures that use more than one source of data in one set of specifications/instructions (e.g., claims data to identify the denominator and medical record abstraction for the numerator). Comparability is not required when comparing performance scores with and without social risk factors in the risk adjustment model. However, if comparability is not demonstrated for measures with more than one set of specifications/instructions, the different specifications (e.g., for medical records vs. claims) should be submitted as separate measures.*

Note if not applicable. Note if applicable but not addressed. If multiple sets of specification (e.g., due to different data sources or methods of data collection): Do analyses indicate they produce comparable results?

Reviewer 3: One potential factor should be looked into is "administrative home type" where ambulatory palliative visit occurred.

Reviewer 5: Not applicable.

Reviewer 10: None

Reviewer 11: No concerns.

22. **Please describe any concerns you have regarding missing data.**

Submission document: Questions 2b.08-10.

For example: Are there any sources of missing data not considered? Is it clear how missing data are handled? Is missing data more of a problem for some providers or patients than others? Does the extent of missing data impact the validity of the measure?

Reviewer 1: I'm concerned that the response rate may vary across entities and that it may be related to the outcome?

Reviewer 3: Potential nonresponse bias should be addressed. For example, age difference between respondents and non-respondents.

Reviewer 5: None.

Reviewer 6: No concerns.

Reviewer 9: Measure score suffers from lack of response to the survey that provides the source data.

Reviewer 10: None

Reviewer 11: No concerns.

Reviewer 12: No concerns

For cost/resource use measures ONLY:

If not cost/resource use measure, please skip to question 25.

23. **Are the specifications in alignment with the stated measure intent?**

○ *Consider these specific aspects of the measure specifications: attribution, cost categories, target population.*

○ **☐ Yes ☐ Somewhat ☐ No (If "Somewhat" or "No", please explain)**

24. **Describe any concerns of threats to validity related to attribution, the costing approach, carve outs, or truncation (approach to outliers):**

Attribution: Does the accountable entity have reasonable control over the costs/resources measured? Is this approach aspirational (intending to drive change) or was it developed based on current state?
Costing Approach: Do the cost categories selected align with the measure intent, target population and care settings? Is the approach for assigning dollars to resources
Carve Outs: Has the developer addressed how carve outs in the data source are handled (or should be handled for other users)? For example, if pharmacy data is carved out (missing) from the data set, can a measure that focuses on cost of care for asthmatics still be valid?
Truncation (approach to outliers): What is the threshold for outliers (i.e., extremely high cost or low-cost cases) and how are they handled?

25. **OVERALL RATING OF VALIDITY taking into account the results and scope of all testing and analysis of potential threats.**

☒ **High** (NOTE: Can be HIGH only if accountable-entity level testing has been conducted)

☒ **Moderate** (NOTE: Moderate is the highest eligible rating if accountable-entity level testing has NOT been conducted)

☒ **Low** (NOTE: Should rate LOW if you believe that there are threats to validity and/or relevant threats to validity were **not assessed OR** if testing methods/results are not adequate)

☐ **Insufficient** (NOTE: For instrument-based measures and some composite measures, testing at both the accountable-entity level and the patient/encounter level **is required;** if not conducted, should rate as INSUFFICIENT.)

26. **Briefly explain rationale for rating of *OVERALL RATING OF VALIDITY* and any concerns you may have with the developers' approach to demonstrating validity.**

Reviewer 1: For responders, the measure appears to be valid. Since non-response is ~50%, it is hard to know how well the data represent the population of interest.
Reviewer 3: Three concerns for validity: Attribution problem, inadequate risk adjustment, and non-response bias.
Reviewer 4: lack of meaningful risk adjustment
Reviewer 5: Used strong methods for testing and saw strong results.
Reviewer 6: I selected low because I am not convinced difference can be identified.
Reviewer 8: Validity tests consistently showed moderate validity of the data elements and measure score.
Reviewer 9: As stated previously, this rating is based on the fact that this is a new measure with reasonable potential to be useful in assessing a patient's experience with palliative care. The issues of response bias and sociodemographic variable impact on risk adjustment and overall response rate to source data survey should be monitored throughout the initial period of use. Additionally, the use of the measure score limited. While the ~~the~~ results related to meaningful differences show a clear pattern, there appears to be limited evidence of meaningful differences except for extreme values based on CI values. Note: The discussion and presentation of results for their risk adjustment model was extensive and showed limited interactions between specific risk factors and either the outcome or at the program/group level. Clearly, there was an attempt, albeit unsuccessful, to address the issue of how to risk adjust this measure. More analytic efforts in this area are warranted.
Reviewer 10: Reasonable, given available data
Reviewer 11: Based on testing and technical panel review results.
Reviewer 12: Results similar to other survey measure

For composite measures ONLY

If not composite, please skip this section.
Submission documents: Questions 2c.01-08
Examples of analyses:
1) If components are correlated - analyses based on shared variance (e.g., factor analysis, Cronbach's alpha, item-total correlation, mean inter-item correlation).
2) If components are not correlated - analyses demonstrating the contribution of each component to the composite score (e.g., change in a reliability statistic such as ICC, with and without the component measure; change in validity analyses with and without the component measure; magnitude of regression coefficient in multiple regression with composite score as dependent variable, or clinical justification (e.g., correlation of the individual component measures to a common outcome measure).
3) Ideally, sensitivity analyses of the effect of various considered aggregation and weighting rules and the rationale for the selected rules; at a minimum, a discussion of the pros and cons of the considered approaches and rationale for the selected rules.
4) Overall frequency of missing data and distribution across providers. Ideally, sensitivity analysis of the effect of various rules for handling missing data and the rationale for the selected rules; at a minimum, a discussion of the pros and cons of the considered approaches and rationale for the selected rules.

27. **What is the level of certainty or confidence that the empirical analysis demonstrates that the component measures add value to the composite and that the aggregation and weighting rules are consistent with the quality construct?**

For example: Do the component measures fit the quality construct and add value? Are the objectives of parsimony and simplicity achieved while supporting the quality construct? Do analyses demonstrate the aggregation and weighting rules fit the quality construct and rationale?

☐ **High**

☐ **Moderate**

☐ **Low**

☐ **Insufficient**

28. **Briefly explain rationale for rating of EMPIRICAL ANALYSES TO SUPPORT COMPOSITE CONSTRUCTION**

ADDITIONAL RECOMMENDATIONS

29. **If you have listed any concerns in this form, do you believe these concerns warrant further discussion by the multi-stakeholder Standing Committee? If so, please list those concerns below.**

Reviewer 12: As noted in the other survey measure, the homogeneity of the population

Developer Submission

1. Importance to Measure and Report

Extent to which the specific measure focus is evidence-based, important to making significant gains in healthcare quality, and improving health outcomes for a specific high-priority (high-impact) aspect of healthcare where there is variation in or overall less-than-optimal performance. Measures must be judged to meet all sub criteria to pass this criterion and be evaluated against the remaining criteria

Please separate added or updated information from the most recent measure evaluation within each question response in the Importance to Measure and Report: Evidence section. For example:

2021 Submission:
Updated evidence information here.

2018 Submission:
Evidence from the previous submission here.

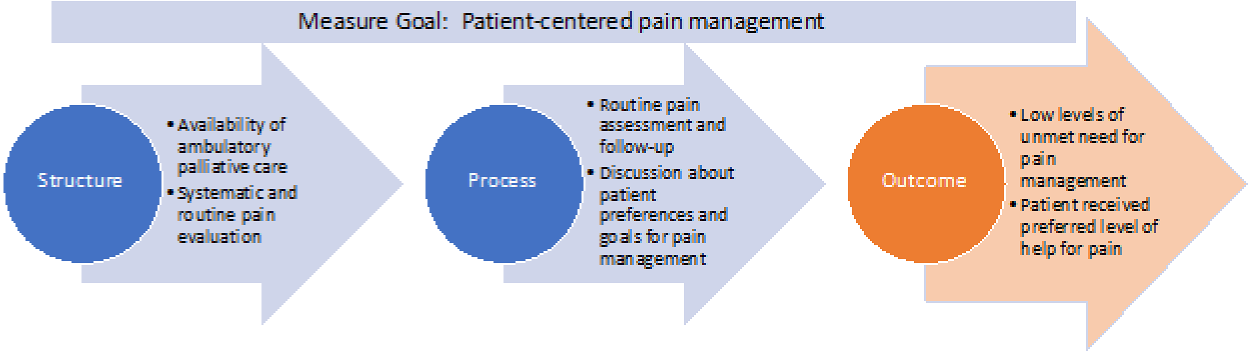
1a.01. Provide a logic model.

Briefly describe the steps between the healthcare structures and processes (e.g., interventions, or services) and the patient's health outcome(s). The relationships in the diagram should be easily understood by general, non-technical audiences. Indicate the structure, process or outcome being measured.

[Response Begins]
The importance of the proposed measure for receiving desired help for pain is predicated on existing guidelines and conceptual models of the quality of palliative care, including the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (2018) supported by a systematic review (Ahluwalia et al., 2018), the National Quality Forum Preferred Practices of Palliative and Hospice Care (National Quality Forum, 2006) (i.e. Preferred Practice 12 and 13), a consensus building process from the National Coalition for Hospice and Palliative Care, and input from qualitative inquiry of patients and providers.

The Integrative Framework of Appraisal and Adaptation in Serious Medical Illness describes the proposed process by which palliative care improves experiences of care for patients with serious illness (Bickel et al., 2020). The framework posits that palliative care's focus on symptom management, coping with illness, goals of care, and treatment decisions may be associated with improved patient quality of life in part by increasing patients' use of active (vs. passive) and approach-oriented (vs. avoidant) coping strategies. For example, palliative care providers can recommend strategies to treat or improve pain, a direct problem-solving coping strategy (Bickel et al., 2020). In addition, helping patients set short-term, incremental goals for improvement, such as a goal of being able to manage the pain enough to get some chores done, can improve perceived control and reduce patient feelings of hopelessness or powerlessness (Bickel et al., 2020). Patients are constantly appraising and adapting to serious illness, and the one of the roles of palliative care is to assess and respond to patient needs for symptom management. Symptom management is a core competency for palliative care providers, and the patient's experience in this domain is central to the overall quality of palliative care (American Academy of Hospice and Palliative Care Medicine, 2009; National Quality Forum, 2006).

The logic model that describes the relevant healthcare and structures to the patient's health care outcome is described below. The goal of the proposed measure is to improve pain management that is tailored to patient preferences and goals in ambulatory palliative care settings. The outcome that is the focus of the proposed quality measure is to ensure that the patient received their preferred level of help for their pain from their ambulatory palliative care provider and team, resulting in low level of unmet need for their pain. The proposed measure is related to two NQF Preferred Practices for Palliative and Hospice Care Quality (National Quality Forum, 2006): #12 – Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales; and #13 - Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.


Measure Goal: Patient-centered pain management
Structure
Availability of ambulatory palliative care
Systematic and routine pain evaluation
Process
Routine pain assessment and follow-up
Discussion about patient preferences and goals for pain management
Outcome
Low levels of unmet need for pain management
Patient received preferred level of help for pain

Citations:

Ahluwalia, S. C., Chen, C., Raaen, L., Motala, A., Walling, A. M., Chamberlin, M., O'Hanlon, C., Larkin, J., Lorenz, K., Akinniranye, O., & Hempel, S. (2018). A Systematic Review in Support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition. *J Pain Symptom Manage*, *56*(6), 831-870.

American Academy of Hospice and Palliative Care Medicine. (2009). *Hospice and Palliative Care Medicine Core Competencies Version 2.3*.

Bickel, K. E., Levy, C., Macphee, E., Brenner, K. O., Temel, J. S., Arch, J. J., & Greer, J. A. (2020). An Integrative Framework of Appraisal and Adaptation in Serious Medical Illness. *J Pain Symptom Manage*, *60*(3), 657-677.e656.

National Consensus Project for Quality Palliative Care (2018). Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care. https://www.nationalcoalitionhpc.org/ncp

National Quality Forum. (2006). *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*. NQF.

[Response Ends]

1a.02. Provide evidence that the target population values the measured outcome, process, or structure and finds it meaningful.

Describe how and from whom input was obtained.

[Response Begins]
The meaningfulness of the measured outcome to the target population was assessed via 30- to 60-minute phone interviews with patients, caregivers, and family members. For these interviews, we sought patients who were currently receiving palliative care and/or hospice or who had received these services in the past, patients with advanced illness who were not currently receiving hospice and/or palliative care services, informal caregivers of patients receiving hospice and/or palliative care services, and patient advocates. The National Coalition for Hospice and Palliative Care sent outreach emails with information on this research to partners at the National Patient Advocate Foundation (NPAF), American Cancer Society, Family Caregiver Alliance, and National Alliance for Caregiving, and solicited nomination forms. NPAF also identified and provided the contact information of individual patients, caregivers, and family members, whom RAND directly contacted via phone. Our final sample of interview participants consisted of 4 patients with advanced illness who had never received hospice and/or palliative care (one of whom was joined by his wife during the interview), 8 patients who were receiving or had previously received palliative care, and 1 caregiver.

The interview protocols included the following topics: what it is like to receive palliative care, what information sharing between patients and providers would look like in an ideal situation, unmet symptom need and communication, and preferences for responding to mail versus in-person surveys. When discussing unmet symptom needs, patients most

frequently mentioned pain as an example of a symptom. All patients, caregivers, and family members who participated in interviews mentioned pain as a specific symptom or concern.
[Response Ends]

1a.03. Provide empirical data demonstrating the relationship between the outcome (or PRO) and at least one healthcare structure, process, intervention, or service.

[Response Begins]
Existing evidence and expert consensus have highlighted significant unmet need among seriously ill persons and gaps in symptom management, despite the noted importance of symptom management to seriously ill patients and their families (CMS Health Services Advisory Group, 2017). These gaps may be particularly pronounced in ambulatory settings, where patients and families have limited access to palliative care services and may struggle to manage their illness and accept their trajectory. Pain is one of the most serious and prevalent symptoms among the seriously ill (Bernabei et al., 1998; Cleeland et al., 1994; Conill et al., 1997; Portenoy et al., 1994; Spiegel et al., 1994; Strang, 1992; Turner et al., 1996). Pain is highly prevalent among ambulatory palliative care patients and is one of the most common reasons for referral to palliative care (Johnson et al., 2008; Perry et al., 2013; Potter et al., 2003). While many existing quality measures assess standardized clinical outcomes and processes of care (e.g., pain reduced to a comfortable level within 48 hours [NQF 0209]), the subjective experience of symptoms does not lend itself to a "one size fits all" evaluation approach. Individual patients with serious illness make important tradeoffs (e.g., patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects) and hold different preferences for their care that may only be reflected via patient experience measures, that is, from a measure based on patient or proxy report rather than an evaluation conducted by the provider.

Available evidence supports that the proposed patient-reported, patient experience measure can improve quality of care processes in palliative care settings. The "Help Wanted" data element has been tested and used in inpatient palliative care and non-palliative care (e.g., oncology) populations in different formats (Anhang Price et al., 2018; Walling et al., 2016; Yoon et al., 2008). A specific example of this outcome being associated with a process is demonstrated in a 2016 study by Walling et al., who found that lower ratings of physician communication were associated with greater unmet need for symptom management in patients with lung and colorectal cancer. The authors examined prevalence of unmet needs for symptom management among a nationally representative sample of patients with lung and colorectal cancer, with unmet needs defined as patients who reported that they wanted help for at least one common symptom (pain, fatigue, depression, nausea/vomiting, cough, dyspnea, diarrhea) in the previous four weeks but did not receive it. Overall, 15% (791 of 5,422) of patients had one or more unmet needs for symptom management. Patients who rated their physician's communication score less than 80 (on a 0 to 100 scale) had adjusted rates of unmet need for symptom management more than twice as high as patients who rated their physicians with a perfect communication score (Walling et al., 2016).

While no randomized controlled trials (RCTs) have assessed the newly developed *Receiving Desired Help for Pain* measure as an outcome, multiple RCTs demonstrate that interventions implemented in ambulatory palliative care settings can reduce pain severity (Lovell et al., 2010; Oldenmenger et al., 2011; Oliver et al., 2001; Syrjala et al., 2008) and improve patient-provider communication regarding pain and other symptoms (Berry et al., 2011; Detmar et al., 2002; Taenzer et al., 2000; Takeuchi et al., 2011; Velikova et al., 2004). A systematic review of palliative care interventions (Dy et al., 2012) identified four RCTs in ambulatory palliative care settings demonstrating that patient and caregiver educational interventions for self-management of pain led to reduced pain severity (Lovell et al., 2010; Oldenmenger et al., 2011; Oliver et al., 2001; Syrjala et al., 2008). Another systematic review found strong evidence that routine symptom assessment in ambulatory oncology settings with feedback to providers can improve patient-provider communication about pain and other symptoms and improve patient satisfaction (Chen et al., 2013). Several large RCTs demonstrated that routine collection of patient-reported symptom and quality of life measures with timely provider feedback led to increased discussion of symptoms and quality of life issues during oncology clinic visits (Berry et al., 2011; Detmar et al., 2002; Taenzer et al., 2000; Takeuchi et al., 2011; Velikova et al., 2004). Successful interventions occurred in the context of sufficient intensity of feedback (multiple times over a sustained period of time) targeting multiple stakeholders (doctors, nurses, interdisciplinary team members, and patients) (Chen et al., 2013). This evidence suggests that interventions implemented in ambulatory palliative care settings can lead to improved patient report of pain needs being met.

Palliative care itself is associated with improved outcomes including improved communication and symptom management. Managing patient symptoms and psychosocial needs is a central goal of palliative care (National Consensus Project for Quality Palliative Care, 2018). High quality serious illness communication is necessary to ensure patients receive help wanted for their symptoms (Sanders et al., 2018).

Citations:

Anhang Price, R., Stucky, B., Parast, L., Elliott, M. N., Haas, A., Bradley, M., & Teno, J. M. (2018). Development of Valid and Reliable Measures of Patient and Family Experiences of Hospice Care for Public Reporting. J Palliat Med, 21(7), 924-932.

Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., Lipsitz, L., Steel, K., & Mor, V. (1998). Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *Jama*, *279*(23), 1877-1882.

Berry, D. L., Blumenstein, B. A., Halpenny, B., Wolpin, S., Fann, J. R., Austin-Seymour, M., Bush, N., Karras, B. T., Lober, W. B., & McCorkle, R. (2011). Enhancing patient-provider communication with the electronic self-report assessment for cancer: a randomized trial. *J Clin Oncol*, *29*(8), 1029-1035.

Chen, J., Ou, L., & Hollis, S. J. (2013). A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers, and health organisations in an oncologic setting. *BMC Health Serv Res*, *13*, 211.

Cleeland, C. S., Gonin, R., Hatfield, A. K., Edmonson, J. H., Blum, R. H., Stewart, J. A., & Pandya, K. J. (1994). Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med*, *330*(9), 592-596.

CMS Health Services Advisory Group. (2017). *CMS Quality Measure Development Plan Environmental Scan and Gap Analysis Report (MACRA, Section 102)*. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/ValueBased-Programs/MACRA-MIPS-and-APMs/MACRA-MIPS-and-APMs.html.

Conill, C., Verger, E., Henriquez, I., Saiz, N., Espier, M., Lugo, F., & Garrigos, A. (1997). Symptom prevalence in the last week of life. *J Pain Symptom Manage*, *14*(6), 328-331.

Detmar, S. B., Muller, M. J., Schornagel, J. H., Wever, L. D., & Aaronson, N. K. (2002). Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *Jama*, *288*(23), 3027-3034.

Dy, S. M., Aslakson, R., Wilson, R. F., Fawole, O. A., Lau, B. D., Martinez, K. A., Vollenweider, D., Apostol, C., & Bass, E. B. (2012). Closing the quality gap: revisiting the state of the science (vol. 8: improving health care and palliative care for advanced and serious illness). *Evid Rep Technol Assess (Full Rep)*(208.8), 1-249.

Johnson, C. E., Girgis, A., Paul, C. L., & Currow, D. C. (2008). Cancer specialists' palliative care referral practices and perceptions: results of a national survey. *Palliat Med*, *22*(1), 51-57.

Lovell, M. R., Forder, P. M., Stockler, M. R., Butow, P., Briganti, E. M., Chye, R., Goldstein, D., & Boyle, F. M. (2010). A randomized controlled trial of a standardized educational intervention for patients with cancer pain. *J Pain Symptom Manage*, *40*(1), 49-59.

National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. https://www.nationalcoalitionhpc.org/ncp

Oldenmenger, W. H., Sillevis Smitt, P. A., van Montfort, C. A., de Raaf, P. J., & van der Rijt, C. C. (2011). A combined pain consultation and pain education program decreases average and current pain and decreases interference in daily life by pain in oncology outpatients: a randomized controlled trial. *Pain*, *152*(11), 2632-2639.

Oliver, J. W., Kravitz, R. L., Kaplan, S. H., & Meyers, F. J. (2001). Individualized patient education and coaching to improve pain control among cancer outpatients. *J Clin Oncol*, *19*(8), 2206-2212.

Perry, B. A., Westfall, A. O., Molony, E., Tucker, R., Ritchie, C., Saag, M. S., Mugavero, M. J., & Merlin, J. S. (2013). Characteristics of an ambulatory palliative care clinic for HIV-infected patients. *J Palliat Med*, *16*(8), 934-937.

Portenoy, R. K., Thaler, H. T., Kornblith, A. B., Lepore, J. M., Friedlander-Klar, H., Coyle, N., Smart-Curley, T., Kemeny, N., Norton, L., Hoskins, W., & et al. (1994). Symptom prevalence, characteristics, and distress in a cancer population. *Qual Life Res*, *3*(3), 183-189.

Potter, J., Hami, F., Bryan, T., & Quigley, C. (2003). Symptoms in 400 patients referred to palliative care services: prevalence and patterns. *Palliat Med*, *17*(4), 310-314.

Sanders, J. J., Curtis, J. R., & Tulsky, J. A. (2018). Achieving Goal-Concordant Care: A Conceptual Model and Approach to Measuring Serious Illness Communication and Its Impact. *J Palliat Med*, *21*(S2), S17-s27.

Spiegel, D., Sands, S., & Koopman, C. (1994). Pain and depression in patients with cancer. *Cancer*, *74*(9), 2570-2578.

Strang, P. (1992). Emotional and social aspects of cancer pain. *Acta Oncol*, *31*(3), 323-326.

Syrjala, K. L., Abrams, J. R., Polissar, N. L., Hansberry, J., Robison, J., DuPen, S., Stillman, M., Fredrickson, M., Rivkin, S., Feldman, E., Gralow, J., Rieke, J. W., Raish, R. J., Lee, D. J., Cleeland, C. S., & DuPen, A. (2008). Patient training in cancer pain management using integrated print and video materials: a multisite randomized controlled trial. *Pain*, *135*(1-2), 175-186.

Taenzer, P., Bultz, B. D., Carlson, L. E., Speca, M., DeGagne, T., Olson, K., Doll, R., & Rosberger, Z. (2000). Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients. *Psychooncology*, *9*(3), 203-213.

Takeuchi, E. E., Keding, A., Awad, N., Hofmann, U., Campbell, L. J., Selby, P. J., Brown, J. M., & Velikova, G. (2011). Impact of patient-reported outcomes in oncology: a longitudinal analysis of patient-physician communication. *J Clin Oncol*, *29*(21), 2910-2917.

Turner, K., Chye, R., Aggarwal, G., Philip, J., Skeels, A., & Lickiss, J. N. (1996). Dignity in dying: a preliminary study of patients in the last three days of life. *J Palliat Care*, *12*(2), 7-13.

Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P., Brown, J. M., & Selby, P. J. (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol*, *22*(4), 714-724.

Walling, A. M., Keating, N. L., Kahn, K. L., Dy, S., Mack, J. W., Malin, J., Arora, N. K., Adams, J. L., Antonio, A. L., & Tisnado, D. (2016). Lower Patient Ratings of Physician Communication Are Associated With Unmet Need for Symptom Management in Patients With Lung and Colorectal Cancer. *J Oncol Pract*, *12*(6), e654-669.

Yoon, J., Malin, J. L., Tisnado, D. M., Tao, M. L., Adams, J. L., Timmer, M. J., Ganz, P. A., & Kahn, K. L. (2008). Symptom management after breast cancer treatment: is it influenced by patient characteristics? Breast Cancer Res Treat, 108(1), 69-77.

[Response Ends]

1b.01. Briefly explain the rationale for this measure.

Explain how the measure will improve the quality of care, and list the benefits or improvements in quality envisioned by use of this measure.

[Response Begins]

Palliative care has expanded rapidly in recent years, and consensus has been growing within the palliative care community regarding the need for measuring the quality of end-of-life care. Yet little is known about the quality of palliative care delivered, particularly among patients who receive their palliative care early in their disease trajectory, in the ambulatory setting. The patterns of palliative care received in ambulatory clinics differ substantially from palliative care received in other settings. Ambulatory palliative care typically supplements a primary treating service such as oncology, as needed. Patients may have several visits with different members of the palliative care team, or they may only have a single visit. This variability in the patient experience of palliative care raises important measurement challenges (Chen et al., 2020), which this project seeks to address.

Although palliative care is growing rapidly, the quality of care delivered by palliative care providers (and by other clinicians responsible for seriously ill patients) is unknown, particularly in ambulatory settings. As a result, stakeholders – including patients and their advocates, as well as providers and health systems – lack actionable measures to guide improvement efforts, as noted by NQF and the CMS Measures Application Partnership (MAP) as well as the 2017 CMS Environmental Scan and Gap Analysis Report (CMS Health Services Advisory Group, 2017). Measures of palliative care quality are also underrepresented in the CMS QPP, with current measures addressing small populations that are often limited to patients with cancer or hospice patients. Furthermore, palliative care quality assessment that incorporates patient preferences (i.e., patient "voice") is noticeably absent despite the patient-centered nature of palliative care (Anhang Price & Elliott, 2018; Anhang Price et al., 2014; Anhang Price et al., 2018; Teno et al., 2017). Patient-centered measures, and especially patient-reported outcome measures, are an important complement to clinician-reported measurement data.

It is important to note that the palliative care field is unique in that palliative care patients are seriously ill, and death is not always a negative outcome, though the quality of that death is important. Accordingly, palliative care requires measures that examine whether patients are receiving care that aligns with their goals, rather than meeting clinical outcomes that may be more appropriate to other conditions, such as mortality (Chen et al., 2020).

As noted above, managing patient symptoms and psychosocial needs is a key goal of palliative care. Pain is one of the most common and distressing symptoms among the seriously ill (Bernabei et al., 1998; Cleeland et al., 1994; Conill et al., 1997; Portenoy et al., 1994; Spiegel et al., 1994; Strang, 1992; Turner et al., 1996). Pain is highly prevalent among ambulatory palliative care patients and is one of the most common reasons for referral to palliative care (Johnson et al., 2008; Perry et al., 2013; Potter et al., 2003). While many existing QMs assess standardized clinical outcomes and processes of care (e.g., pain reduced to a comfortable level within 48 hours [NQF 0209]), the subjective experience of symptoms does not lend itself to a "one size fits all" evaluation approach. Individual patients with serious illness make important tradeoffs (e.g., patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects) and hold different preferences for their care that may only be reflected via patient experience measures, that is, from a measure based on patient or proxy report rather than an evaluation conducted by the provider (Chen et al., 2020).

The proposed measure is also valuable for implementation of innovative payment models for palliative care delivery that impacts emerging models of community-based palliative care (e.g., embedded clinic models). Interdisciplinary palliative care team services are often unbillable under a fee-for-service model, and value-based payment models may be an alternative for reimbursement (Center to Advance Palliative Care, 2017). However, innovative financial models require quality metrics to ensure accountability for patients as well as payers and providers (Anhang Price et al., 2018; California Health Care Foundation, 2018). Many emerging models of community-based palliative care are delivered in community settings and may not utilize the same interdisciplinary team nor have the same level of training as programs evaluated in the literature (Teno et al., 2017). Palliative care quality measures would hold programs accountable for quality and would allow providers to demonstrate the value of their services (California Health Care Foundation, 2018). Currently available measures are generally limited to end-of-life utilization and process measures and are not consistently used across programs, thus patient reported quality metrics are needed to assess the impact of community-based palliative care and ensure transparency and accountability for these vulnerable patients (California Health Care Foundation, 2018; Teno et al., 2017).

Citations:

Anhang Price, R., & Elliott, M. N. (2018). Measuring Patient-Centeredness of Care for Seriously Ill Individuals: Challenges and Opportunities for Accountability Initiatives. *J Palliat Med*, *21*(Suppl 2), S-28-S-35.

Anhang Price, R., Elliott, M. N., Zaslavsky, A. M., Hays, R. D., Lehrman, W. G., Rybowski, L., Edgman-Levitan, S., & Cleary, P. D. (2014). Examining the role of patient experience surveys in measuring health care quality. *Med Care Res Rev*, *71*(5), 522-554.

Anhang Price, R., Stucky, B., Parast, L., Elliott, M. N., Haas, A., Bradley, M., & Teno, J. M. (2018). Development of Valid and Reliable Measures of Patient and Family Experiences of Hospice Care for Public Reporting. *J Palliat Med*, *21*(7), 924-932.

Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., Lipsitz, L., Steel, K., & Mor, V. (1998). Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *Jama*, *279*(23), 1877-1882.

California Health Care Foundation. (2018). *Lessons Learned from Payer-Provider Partnerships for Community-Based Palliative Care*.

Center to Advance Palliative Care. (2017). *Payment Primer: What to Know about Payment for Palliative Care Delivery*.

Cleeland, C. S., Gonin, R., Hatfield, A. K., Edmonson, J. H., Blum, R. H., Stewart, J. A., & Pandya, K. J. (1994). Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med*, *330*(9), 592-596.

CMS Health Services Advisory Group. (2017). *CMS Quality Measure Development Plan Environmental Scan and Gap Analysis Report (MACRA, Section 102)*. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/ValueBased-Programs/MACRA-MIPS-and-APMs/MACRA-MIPS-and-APMs.html.

Conill, C., Verger, E., Henriquez, I., Saiz, N., Espier, M., Lugo, F., & Garrigos, A. (1997). Symptom prevalence in the last week of life. *J Pain Symptom Manage*, *14*(6), 328-331.

Johnson, C. E., Girgis, A., Paul, C. L., & Currow, D. C. (2008). Cancer specialists' palliative care referral practices and perceptions: results of a national survey. *Palliat Med*, *22*(1), 51-57.
Perry, B. A., Westfall, A. O., Molony, E., Tucker, R., Ritchie, C., Saag, M. S., Mugavero, M. J., & Merlin, J. S. (2013). Characteristics of an ambulatory palliative care clinic for HIV-infected patients. *J Palliat Med*, *16*(8), 934-937.
Portenoy, R. K., Thaler, H. T., Kornblith, A. B., Lepore, J. M., Friedlander-Klar, H., Coyle, N., Smart-Curley, T., Kemeny, N., Norton, L., Hoskins, W., & et al. (1994). Symptom prevalence, characteristics, and distress in a cancer population. *Qual Life Res*, *3*(3), 183-189.
Potter, J., Hami, F., Bryan, T., & Quigley, C. (2003). Symptoms in 400 patients referred to palliative care services: prevalence and patterns. *Palliat Med*, *17*(4), 310-314.
Spiegel, D., Sands, S., & Koopman, C. (1994). Pain and depression in patients with cancer. *Cancer*, *74*(9), 2570-2578.
Strang, P. (1992). Emotional and social aspects of cancer pain. *Acta Oncol*, *31*(3), 323-326.
Teno, J. M., Price, R. A., & Makaroun, L. K. (2017). Challenges Of Measuring Quality Of Community-Based Programs For Seriously Ill Individuals And Their Families. *Health Affairs*, *36*(7), 1227-1233.
Turner, K., Chye, R., Aggarwal, G., Philip, J., Skeels, A., & Lickiss, J. N. (1996). Dignity in dying: a preliminary study of patients in the last three days of life. *J Palliat Care*, *12*(2), 7-13.

[Response Ends]

1b.02. Provide performance scores on the measure as specified (current and over time) at the specified level of analysis.

Include mean, std dev, min, max, interquartile range, and scores by decile. Describe the data source including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities include. This information also will be used to address the sub-criterion on improvement (4b) under Usability and Use.

[Response Begins]
A total of 44 ambulatory palliative care programs (i.e., the accountable clinical groups) participated in the beta field test (defined as providing at least one sample file during the field-testing period). A detailed description of palliative care program characteristics is provided in section 2a.05. We sought national representation in the beta field test by oversampling larger programs (i.e., those with more patients), stratifying recruitment efforts for ambulatory palliative care programs by administrative home type (i.e., hospice, hospital, ambulatory, and other administration) and by geographic location to ensure representation across Census Regions. Among the ambulatory palliative care programs in our sample, administrative home types included ten hospice sites, 24 hospitals, and ten ambulatory or other administrative sites. Patient sampling was conducted each month between November 2019 and February 2021, with a pause between March and September 2020 due to the COVID-19 pandemic. 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). See section 2a.06 for a detailed description of the patient sample.

Based on the testing sample (n=44 palliative care programs), the average adjusted measure score is 80.2 (see sp.13 for explanation of measure scoring). The standard deviation in average program scores is 5.25. Analyses from the beta field test further demonstrate room for improvement in the *Receiving Desired Help for Pain* measure:

- The observed variability across programs (adjusted ICC point estimate = 0.079) supports the potential of the measure to distinguish among programs with high, medium, and low performance.
- Across the 44 palliative care programs in our sample, adjusted program scores range from 66.20 to 89.72 with a standard deviation of 5.25. Confidence intervals for the highest and lowest program scores do not overlap: Lowest Program CI: (48.6, 79.6); Highest Program CI: (78.9, 96.2).
- When programs are ranked by their measure performance, we calculated that a program at the median of measure performance would need a large increase of 5.29 points in their measure score to improve to the 20th top-ranked program. A program at the bottom of the ranking (e.g., the 10th lowest ranked program) would need a 6-point increase measure score to improve to the median.

The mean, std dev, min, max, and interquartile range of the program adjusted scores are provided below:

Mean Score	S.D.	Min Score	Max Score	25th Percentile	75th Percentile	IQR
80.2%	5.25	66.1%	89.4%	76.8%	84.7%	7.9%

The deciles of the observed program adjusted scores (N=44) are

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
66.1	74.0	76.0	77.0	78.6	81.0	81.7	83.4	85.4	86.7	89.4

[Response Ends]

1b.03. If no or limited performance data on the measure as specified is reported above, then provide a summary of data from the literature that indicates opportunity for improvement or overall less than optimal performance on the specific focus of measurement. Include citations.

[Response Begins]
See 1b.02 above.
[Response Ends]

1b.04. Provide disparities data from the measure as specified (current and over time) by population group, e.g., by race/ethnicity, gender, age, insurance status, socioeconomic status, and/or disability.

Describe the data source including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included. Include mean, std dev, min, max, interquartile range, and scores by decile. For measures that show high levels of performance, i.e., "topped out", disparities data may demonstrate an opportunity for improvement/gap in care for certain sub-populations. This information also will be used to address the sub-criterion on improvement (4b) under Usability and Use.

[Response Begins]
The measure is not currently in use.

To understand if and to what extent disparities in measure reporting and patient experience exist, we evaluated the relationship of various social risk factors to the measure score and the programs. These included patient race/ethnicity, education, and primary language, as well as multiple census-level variables such as race/ethnicity, urbanicity, median household income, gender, marital status, public insurance use, unemployment, and families below poverty line (see sections 2b.23 and 2b.24 for details). After adjustment for multiple comparisons, none of these variables were significant in their relationship with the measure.
[Response Ends]

1b.05. If no or limited data on disparities from the measure as specified is reported above, then provide a summary of data from the literature that addresses disparities in care on the specific focus of measurement. Include citations. Not necessary if performance data provided in above.

[Response Begins]
The *Receiving Desired Help for Pain* measure has been tested and used for research in palliative care and non-palliative care populations in different formats (Anhang Price et al., 2018; Walling et al., 2016; Yoon et al., 2008). The CAHPS Hospice Survey includes several items that ask bereaved family members of hospice patients whether the patient received help wanted for pain and other symptoms at end of life (Anhang Price et al., 2018). However, this measure has not been incorporated into measurement programs, and the exact wording and structure proposed for this quality

measure has not yet been used among ambulatory palliative care populations.

Systematic reviews have identified longstanding disparities in pain management across various health care settings, including underdiagnosis and undertreatment of pain in Black patients (Meghani et al., 2012). Multiple studies have also reported disparities by race/ethnicity and socioeconomic status in the prevalence of unmet needs for symptom management among patients with serious illness (John et al., 2014; Walling et al., 2016; Yoon et al., 2008), underscoring the importance of measuring patients' experience of receiving help for pain. While many existing quality measures assess standardized clinical outcomes and processes of care related to pain assessment, the subjective experience of symptoms does not lend itself to a "one size fits all" evaluation approach. Patients with serious illness make important tradeoffs (e.g., some patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects) and hold different preferences for their care that may only be reflected via patient experience measures, that is, from a measure based on patient or proxy report rather than an evaluation conducted by the provider.

The proposed measure will fill identified measure gaps. First, the proposed measure will assess care experience among patients receiving ambulatory palliative care; a population in which existing measures have not been tested or applied. Second, in contrast to existing measures of pain management which focus on reported reductions in pain levels, the proposed "unmet needs" measure is directly tailored to address whether patients are receiving care in accord with their wishes. This is important because it measures a more patient-centered construct rather than a clinically-imposed construct of "improvement" in pain. Third, the proposed measures adds to a small but growing body of measures focused on patient-reported experience in the context of end-of-life care.

Citations:

Anhang Price, R., Stucky, B., Parast, L., Elliott, M. N., Haas, A., Bradley, M., & Teno, J. M. (2018). Development of Valid and Reliable Measures of Patient and Family Experiences of Hospice Care for Public Reporting. *J Palliat Med*, *21*(7), 924-932.

John, D. A., Kawachi, I., Lathan, C. S., & Ayanian, J. Z. (2014). Disparities in perceived unmet need for supportive services among patients with lung cancer in the Cancer Care Outcomes Research and Surveillance Consortium. *Cancer*, *120*(20), 3178-3191.

Meghani, S. H., Byun, E., & Gallagher, R. M. (2012). Time to take stock: a meta-analysis and systematic review of analgesic treatment disparities for pain in the United States. *Pain Med*, *13*(2), 150-174.

Walling, A. M., Keating, N. L., Kahn, K. L., Dy, S., Mack, J. W., Malin, J., Arora, N. K., Adams, J. L., Antonio, A. L., & Tisnado, D. (2016). Lower Patient Ratings of Physician Communication Are Associated With Unmet Need for Symptom Management in Patients With Lung and Colorectal Cancer. *J Oncol Pract*, *12*(6), e654-669.

Yoon, J., Malin, J. L., Tisnado, D. M., Tao, M. L., Adams, J. L., Timmer, M. J., Ganz, P. A., & Kahn, K. L. (2008). Symptom management after breast cancer treatment: is it influenced by patient characteristics? *Breast Cancer Res Treat*, *108*(1), 69-77.

[Response Ends]

2. Scientific Acceptability of Measure Properties

Extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of care when implemented. Measures must be judged to meet the sub criteria for both reliability and validity to pass this criterion and be evaluated against the remaining criteria.

sp.01. Provide the measure title.

Measure titles should be concise yet convey who and what is being measured (see What Good Looks Like).

[Response Begins]
Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain
[Response Ends]

sp.02. Provide a brief description of the measure.

Including type of score, measure focus, target population, timeframe, (e.g., Percentage of adult patients aged 18-75 years receiving one or more HbA1c tests per year).

[Response Begins]
The percentage of patients aged 18 years and older who had an ambulatory palliative care visit and report getting the help they wanted for their pain from their palliative care provider and team within 6 months of the ambulatory palliative care visit.
Response to NQF request for clarification:

1. Per the recommendation of our technical expert clinical user and patient panel (TECUPP), survey items refer to "this provider and team" which reflects the interdisciplinary team structure of care delivery in ambulatory palliative care. Providers can be one of many MIPS-eligible provider types, ranging from doctors of medicine to clinical nurse specialists. Providers serve as the lead of the palliative care team and are therefore referenced (i.e., named) at the start of the survey instrument. To identify the reference provider named on the survey instrument for each patient, the data set was first filtered to include only visits with MIPS-eligible provider types that occurred in the three months prior to the anticipated start date of survey fielding. We then selected the MIPS-eligible provider whom 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). If patients had multiple visits, we selected the most recent visit for each patient with the reference provider. We did not conduct testing to specifically evaluate how patients differentiated between team members in their responses to the survey items.
2. We will consult with our TECUPP and advisors about potential revisions to the measure description prior to full submission. The proposed measure is intended to have a broad timeframe, as pain interventions and time frames for improvement may vary based on patient preferences and goals, and individual patients with serious illness make important tradeoffs (e.g., patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects). Furthermore, our TECUPP, particularly members with lived experiences of palliative care, emphasized the many different kinds of pain, from physical to emotional to spiritual to existential, and recommended that "pain" not be defined in the measure but be left to the interpretation of the patient. Therefore, this measure is asking about the patient's holistic experience of their pain during the course of treatment and whether the provider and team provided the help they wanted.
3. We were unable to specifically test accuracy of recall of subjective experiences of pain among ambulatory palliative care patients who completed the survey. Ambulatory palliative care is often started earlier in the disease trajectory to promote quality of life over the course of serious illness. We selected the time frame parameters based on discussion with palliative care experts from our technical expert clinical user and patient panel (TECUPP) and advisory board and confirmed the feasibility of these time frame parameters in testing. In addition, prior to field testing, we conducted cognitive testing of the *Receiving Help for Pain* data elements through 25 interviews with ambulatory palliative care patients and their family members to establish the

comprehensibility, readability, and adaptability of survey instructions and data elements, including response options.

[Response Ends]

sp.04. Check all the clinical condition/topic areas that apply to your measure, below.

Please refrain from selecting the following answer option(s). We are in the process of phasing out these answer options and request that you instead select one of the other answer options as they apply to your measure.

Please do not select:

- *Surgery: General*

[Response Begins]
Palliative Care and End-of-Life Care
[Response Ends]

sp.05. Check all the non-condition specific measure domain areas that apply to your measure, below.

[Response Begins]
Person-and Family-Centered Care: Person-and Family-Centered Care
[Response Ends]

sp.06. Select one or more target population categories.

Select only those target populations which can be stratified in the reporting of the measure's result.

Please refrain from selecting the following answer option(s). We are in the process of phasing out these answer options and request that you instead select one of the other answer options as they apply to your measure.

Please do not select:

- *Populations at Risk: Populations at Risk*

[Response Begins]
Adults (Age >= 18)
[Response Ends]

sp.07. Select the levels of analysis that apply to your measure.

Check ONLY the levels of analysis for which the measure is SPECIFIED and TESTED.

Please refrain from selecting the following answer option(s). We are in the process of phasing out these answer options and request that you instead select one of the other answer options as they apply to your measure.

Please do not select:

- *Clinician: Clinician*
- *Population: Population*

[Response Begins]
Clinician: Group/Practice
[Response Ends]

sp.08. Indicate the care settings that apply to your measure.

Check ONLY the settings for which the measure is SPECIFIED and TESTED.
[Response Begins]
Ambulatory Care
[Response Ends]

sp.09. Provide a URL link to a web page specific for this measure that contains current detailed specifications including code lists, risk model details, and supplemental materials.

Do not enter a URL linking to a home page or to general information. If no URL is available, indicate "none available".

[Response Begins]
none available
[Response Ends]

sp.11. Attach the data dictionary, code table, or value sets (and risk model codes and coefficients when applicable). Excel formats (.xlsx or .csv) are preferred.

Attach an excel or csv file; if this poses an issue, contact staff. Provide descriptors for any codes. Use one file with multiple worksheets, if needed.
[Response Begins]
No data dictionary/code table – all information provided in the submission form
[Response Ends]

For the question below: state the outcome being measured. Calculation of the risk-adjusted outcome should be described in sp.22.

sp.12. State the numerator.

Brief, narrative description of the measure focus or what is being measured about the target population, i.e., cases from the target population with the target process, condition, event, or outcome).

DO NOT include the rationale for the measure.

[Response Begins]
The number of patients aged 18 years and older who report getting the help they wanted for their pain from their palliative care provider and team within 6 months of an ambulatory palliative care visit.
[Response Ends]

For the question below: describe how the observed outcome is identified/counted. Calculation of the risk-adjusted outcome should be described in sp.22.

sp.13. Provide details needed to calculate the numerator.

All information required to identify and calculate the cases from the target population with the target process, condition, event, or outcome such as definitions, time period for data collection, specific data collection items/responses, code/value sets.

Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at sp.11.

[Response Begins]
The *Receiving Desired Help for Pain* measure is composed of a single data element: In the last 6 months, did you get as much help as you wanted for your pain from this provider and team?

Individuals can respond using three discrete values: 0 = No, 1= Yes, somewhat, 2 = Yes, definitely. The measure is calculated using the data element response, passing the measure if an individual responds "Yes, definitely" to receiving the help they wanted for their pain from their palliative care provider and team and failing otherwise (i.e., if an individual responds "Yes, somewhat" or "No").
[Response Ends]

For the question below: state the target population for the outcome. Calculation of the risk-adjusted outcome should be described in sp.22.

sp.14. State the denominator.

Brief, narrative description of the target population being measured.

[Response Begins]
All patients aged 18 years and older who had an ambulatory palliative care visit.
[Response Ends]

For the question below: describe how the target population is identified. Calculation of the risk-adjusted outcome should be described in sp.22.

sp.15. Provide details needed to calculate the denominator.

All information required to identify and calculate the target population/denominator such as definitions, time period for data collection, specific data collection items/responses, code/value sets.

Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at sp.11.

[Response Begins]
Denominator Criteria

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

AND

Ambulatory palliative care visit[1] 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.

[2]

[1] Telehealth visits were not included in testing.

[2] Based on 2019 Merit-Based Incentive Program (MIPS) eligible clinician types

Response to NQF request for clarification:

- Yes, we intend for CPT 99211 to be included in the denominator. The list of CPT codes is meant to be as inclusive as possible to ensure that any new or established office visit is allowable in the denominator.
- We used this list of eligible clinicians in measure testing because we were developing the measure specifically for use in MIPS, and we thought it helpful to specify eligible provider types because palliative care is provided by an interdisciplinary team and a wide range of providers may see patients in the ambulatory setting. However, per feedback from CMS, we intend to remove the list of MIPS eligible providers from the denominator statement, replacing it with the statement “with a MIPS eligible provider.”
- Telehealth visits are excluded from the denominator because our TECUPP emphasized variability and incompleteness in coding for telehealth visits among palliative care programs. This was verified at the outset of data collection by programs in our test sample. The COVID-19 pandemic and public health emergency provided new reimbursement policies for telehealth which resulted in improved coding practices however this improvement began in mid- to late-2020 when our national field test was nearing completion. Future work should explore inclusion of telehealth visits in the denominator; however we do not currently have testing data to support inclusion of these visits.
- We will consider adding "applicable to palliative care," given additional guidance on where in the denominator statement to include it.

[Response Ends]

sp.16. Describe the denominator exclusions.

Brief narrative description of exclusions from the target population.

[Response Begins]
Denominator exclusions include:

- Patients who do not complete and return the patient experience survey within 6 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 deceased when the survey reached them;
- Patients for whom a proxy completed the entire survey on their behalf for any reason (no patient involvement);
- Patients who respond “No” to the questions “In the last 6 months, have you ever had pain?” OR “In the last 6 months, did you want help from this provider and team for this pain?”

Response to NQF request for clarification: It is possible that ambulatory palliative care patients may receive pain management from other services in addition to palliative care. However, it is unlikely that the ambulatory palliative care team would not be involved in pain management, as pain is one of the most common reasons for referral to palliative care. Our 30-member TECUPP felt strongly that while other providers might be concurrently involved in the patient’s care, pain management, and attention to the person’s physical and existential distress, is very much a core responsibility of palliative care, and they would want to be held accountable for this very basic care process. Moreover, this measure goes beyond pain management and addresses the patient’s perspective on feeling satisfied with the care and attention they received by the palliative care provider (which as the TECUPP emphasized, could be achieved even if the patient’s pain was not fully resolved).

[Response Ends]

sp.17. Provide details needed to calculate the denominator exclusions.

All information required to identify and calculate exclusions from the denominator such as definitions, time period for data collection, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at sp.11.

[Response Begins]
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 (i.e., deploy the survey per protocol by email, mail, and telephone) 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.

Patients who have already completed the patient experience survey in a given reporting period should not be fielded the survey again to avoid response bias due to priming effects and to minimize patient burden. Patients who do not complete the item set measuring *Receiving Desired Help for Pain* 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.

> **Response to NQF request for clarification:** As relevant background to our response, this measure was developed for use in ambulatory palliative care settings where patients can receive interventions to promote quality of life over the course of serious illness. Ambulatory palliative care is not the same as hospice, where many patients are not admitted until the last days of life. Ambulatory palliative care can be provided at any stage of serious illness, starting from diagnosis.
>
> It should be noted that we looked for eligible outpatient visits within a 3-month lookback period from the date of the program's data pull. For example, a participating program could run a data query on August 1, 2020, covering all visits occurring for a patient in May, June, and July of 2020. The program would then send this file to RAND. Once we cleaned the file and identified the eligible visit in that 3-month timeframe we would field the survey to the patient. Given data processing times and the need to field surveys to all patients in participating programs at the same time (we did this on a quarterly basis through the fielding period), there was often a data lag between the receipt of each program's data and the survey fielding start date. In addition, there was often a 1–2-month data lag between when a program pulled their data and the timeframe they referenced (e.g.: a data pull on August 1, 2020, would most likely include visits occurring during the months of April, May, and June of 2020). Because of these data lags, although we identified visits within a 3-month period, to ensure that patients who received a survey were including that eligible visit in their consideration of their care experience, we used a 6-month reference timeframe in the wording of our survey questions (e.g.: "In the last 6 months, did you get as much help as you wanted for your pain from this provider and team?").
>
> We worked closely with our technical expert, clinical user, and patient panel (TECUPP) to establish all these parameters prior to testing, and our alpha test provided additional support for the feasibility and face validity of this approach. Specifically, the TECUPP discussed and acknowledged that patients would likely (and ideally) have more than a single palliative care visit – potentially with different members of the palliative care interdisciplinary team - in the reference timeframes. They felt strongly that palliative care was a team-based discipline, and the eligible provider was accountable for the care provided by the team overall. They also acknowledged that patients would reflect on their care experience as a whole, which could include experiences with other providers

seen during this timeframe, which is a challenge for patient experience measurement in general. We attempted to mitigate this by clearly specifying the palliative care provider seen by the patient in the eligible visit in the survey materials so as to orient the respondent to the care experience associated with that provider.

Specific to the reference timeframes, TECUPP members also discussed the challenges with a 6-month reference timeframe for patients to consider (e.g.; potential loss to follow-up if the patient became too ill to answer the survey or was moved to hospice by the time it was fielded, and patient recall) but acknowledged the error that data lags could introduce, and ultimately agreed that ensuring the eligible visit was captured in the timeframe referenced in the survey was of utmost importance. We selected the final time frame parameters based on discussion with palliative care experts from our technical expert clinical user and patient panel (TECUPP) and advisory board.

We confirmed the feasibility of these time frame parameters in testing. In the national field test, we found that the median number of days from the start of the eligible visit period to date of survey return was 124 days (about four months), with a minimum of 88 days (about three months) and a maximum of 167 days (about 5.5 months). Programs seeking to implement this performance measure should send the patient experience survey to patients within three months of their eligible visit to reasonably satisfy the six-month lookback time frame referenced in the performance measure. In testing we excluded patients who did not return the survey within the six-month time frame because of concerns regarding recall bias and because of their likely minimal impact (patient who returned a survey outside the six-month time frame n = 61 out of 3,356 nonrespondents, or 1.8 percent).

We are not aware of industry standards for other ambulatory palliative care surveys. In our information gathering activities we identified a gap in quality measures that have been designed for use in, and tested among, patients with serious illness receiving ambulatory palliative care services. The CAHPS Hospice survey evaluates palliative care experience from the perspective of bereaved caregivers, which is conceptually different from the proposed measure. Reference and lookback timeframes for that survey varies by mode of administration but data collection for sampled decedents/caregivers must be initiated two months following the month of patient death.

Response to NQF request for clarification, 8/30/21: We did consider whether to exclude hospice patients and it was indeed a very early exclusion. However, we later realized that since eligibility was based on an ambulatory palliative care visit, hospice patients would rarely be included. If they were included because they were receiving both types of care, that would be okay – we are still asking about the ambulatory palliative care provider and team, and we assume that patients are receiving other health care services; hospice should be no different. The pre-notification letter, the cover letter, and the wording at the start of the survey are intended to orient the patient to the specific provider and team.

We also considered that some patients may be in hospice by the time they receive the survey. If a patient entered hospice during the six-month period following the eligible visit but was able to reflect on their experiences with ambulatory palliative care (the referenced provider and team) and complete the survey, then they should have the opportunity to provide feedback on their experience of care. If the patient was too ill to complete the survey, had passed away, or was no longer living in the community we had processes in place to address these cases. Our data collection approach was to first send eligible patients a letter notifying them of the upcoming survey with a stamped postcard that could be returned in the event of death or a move/new address. If the patient had moved to a residential hospice, this could be indicated in the returned postcard noting they had moved. If they were still at home, but had discontinued their prior outpatient palliative care, they should still be eligible and able to respond about their experience with their ambulatory palliative care provider and team.

[Response Ends]

sp.18. Provide all information required to stratify the measure results, if necessary.

Include the stratification variables, definitions, specific data collection items/responses, code/value sets, and the risk-model covariates and coefficients for the clinically-adjusted version of the measure when appropriate. Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format in the Data Dictionary field.

[Response Begins]

N/A
[Response Ends]

sp.19. Select the risk adjustment type.

Select type. Provide specifications for risk stratification and/or risk models in the Scientific Acceptability section.
[Response Begins]
Statistical risk model
[Response Ends]

sp.20. Select the most relevant type of score.

Attachment: If available, please provide a sample report.
[Response Begins]
Rate/proportion
[Response Ends]

sp.21. Select the appropriate interpretation of the measure score.

Classifies interpretation of score according to whether better quality or resource use is associated with a higher score, a lower score, a score falling within a defined interval, or a passing score
[Response Begins]
Better quality = Higher score
[Response Ends]

sp.22. Diagram or describe the calculation of the measure score as an ordered sequence of steps.

Identify the target population; exclusions; cases meeting the target process, condition, event, or outcome; time period of data, aggregating data; risk adjustment; etc.

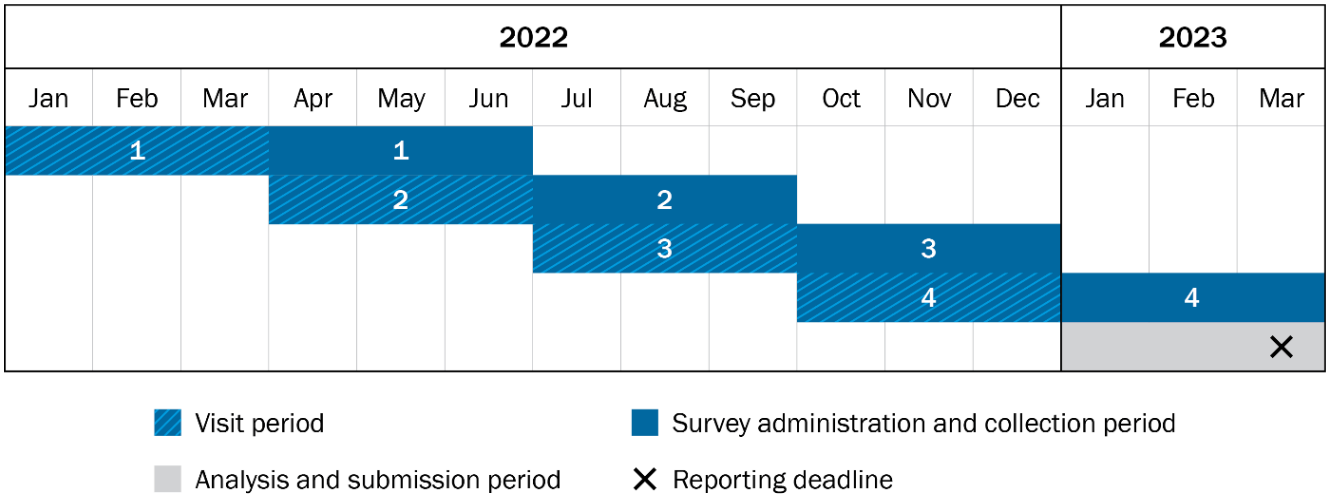
[Response Begins]
Information for the measure calculation is collected via a survey data collection instrument, which will be provided to CMS, to be made available to CMS-approved survey vendors and palliative care programs. The below steps should be completed by an authorized survey vendor to minimize 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 .
    1. Check patient age – 18 years or older?
        1. Yes - Eligible
        2. No - Not eligible
    2. Check patient most recent disposition – alive?
        1. Yes - Eligible
        2. No - Not eligible
    3. 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).

        1. Yes - Eligible
        2. No - Not eligible
    4. Check whether patient has already been fielded a survey in the current 12-month performance period
        1. Yes - Not eligible
        2. No - Eligible
    5. Check whether US-based contact information is available for patient
        1. Yes - Eligible
        2. No - Not eligible
2. Field survey to all eligible cases using enhanced mixed-mode administration (web to mail to phone, i.e., live telephone interview)
3. Receive all returned survey data.
4. Identify any denominator exclusions.
    1. Survey completed (i.e. returned) within six months of the eligible ambulatory palliative care visit?
        1. Yes - Include
        2. No - Exclude
    2. Patient participated in survey completion, with or without proxy assistance?
        1. Yes - Include
        2. No - Exclude
    3. Patient responds in the patient experience survey that they received care by the listed ambulatory palliative care provider in the last six months?
        1. Yes - Include
        2. No - Exclude
    4. Patient responded yes to the questions "In the last 6 months, have you ever had pain?" AND "In the last 6 months, did you want help from this provider and team for this pain?"
        1. Yes - Include
        2. No - Exclude
5. Score program-level quality measure using the data element response
    1. The measure is calculated using the data element response, passing the measure if an individual responds "Yes, definitely" to receiving the help they wanted for their pain from their palliative care provider and team and failing otherwise (i.e., if an individual responds "Yes, somewhat" or "No").
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)
    1. To estimate risk-adjusted program level measure scores, we utilize hierarchical generalized-linear models that relate the proportion of patients responding "Yes, definitely" on the *Receiving Desired Help for Pain* question 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

[Response Ends]

sp.23. Attach a copy of the instrument (e.g. survey, tool, questionnaire, scale) used as a data source for your measure, if available.

[Response Begins]
Copy of instrument is attached.
[Response Ends]

Attachment: Patient Experience Survey - Receiving Desired Help for Pain.pdf

sp.24. Indicate the responder for your instrument.

[Response Begins]
Patient
[Response Ends]

sp.25. If measure is based on a sample, provide instructions for obtaining the sample and guidance on minimum sample size.

[Response Begins]
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 approximately 33 completed responses to the *Receiving Desired Help for Pain* items over the 12-month reporting period.

> **Response to NQF request for clarification:** We will add a minimum sample size requirement of 33 respondents per palliative care group to our measure specifications. However, this estimate is based on our current testing sample and should be revisited in future years.

[Response Ends]

sp.26. Identify whether and how proxy responses are allowed.

[Response Begins]
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.
[Response Ends]

sp.27. Survey/Patient-reported data.

Provide instructions for data collection and guidance on minimum response rate. Specify calculation of response rates to be reported with performance measure results.

[Response Begins]
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). A copy of the survey instrument can be found in the Appendix. Programs will need to contract with a survey vendor to field surveys and process data. The data should be collected from eligible palliative care patients that are representative of the palliative care provider or program within the designated timeframe. Additional details of sampling are described in sp.22. An enhanced mixed-mode survey administration design, web to mail with telephone follow-up, is recommended.

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. We found that measure reliability is sensitive to smaller (i.e., lower patient volume) programs. For a reliable *Receiving Desired Help for Pain* measure we recommend an average sample size, at the program-level, of 33 participants responding to the *Receiving Desired Help for Pain* data elements. As such, an average minimum sample size of 49 respondents to the pain gateway questions will be required, given that approximately 68% of individuals in our sample “passed” the gateway questions and reported i) having pain; and ii) wanting help for that pain. Based on an estimated response rate range of 37% to 46% as was found in the measure testing process, ambulatory palliative care programs with annual visit volume of between approximately 106 and 132 adult patients could achieve the minimum average sample size required for a reliable measure.

Only individuals with outcome data should be used in the final analysis; other cases should be deleted. Missing values for proxy assistance should be imputed as “No Proxy Assist.”
[Response Ends]

sp.28. Select only the data sources for which the measure is specified.

[Response Begins]
Instrument-Based Data
[Response Ends]

sp.29. Identify the specific data source or data collection instrument.

For example, provide the name of the database, clinical registry, collection instrument, etc., and describe how data are collected.

[Response Begins]
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.
[Response Ends]

sp.30. Provide the data collection instrument.

[Response Begins]
Available in attached appendix in Question 1 of the Additional Section
[Response Ends]

Measure testing must demonstrate adequate reliability and validity in order to be recommended for endorsement. Testing may be conducted for data elements and/or the computed measure score. Testing information and results should be entered in the appropriate fields in the Scientific Acceptability sections of the Measure Submission Form.

- Measures must be tested for all the data sources and levels of analyses that are specified. If there is more than one set of data specifications or more than one level of analysis, contact NQF staff about how to present all the testing information in one form.
- All required sections must be completed.
- For composites with outcome and resource use measures, Questions 2b.23-2b.37 (Risk Adjustment) also must be completed.
- If specified for multiple data sources/sets of specifications (e.g., claims and EHRs), Questions 2b.11-2b.13 also must be completed.
- An appendix for supplemental materials may be submitted (see Question 1 in the Additional section), but there is no guarantee it will be reviewed.
- Contact NQF staff with any questions. Check for resources at the Submitting Standards webpage.
- For information on the most updated guidance on how to address social risk factors variables and testing in this form refer to the release notes for the 2021 Measure Evaluation Criteria and Guidance.

Note: The information provided in this form is intended to aid the Standing Committee and other stakeholders in understanding to what degree the testing results for this measure meet NQF's evaluation criteria for testing.
2a. Reliability testing demonstrates the measure data elements are repeatable, producing the same results a high proportion of the time when assessed in the same population in the same time period and/or that the measure score is precise. For instrument-based measures (including PRO-PMs) and composite performance measures, reliability should be demonstrated for the computed performance score.
2b1. Validity testing demonstrates that the measure data elements are correct and/or the measure score correctly reflects the quality of care provided, adequately identifying differences in quality. For instrument-based measures (including PRO-PMs) and composite performance measures, validity should be demonstrated for the computed performance score.
2b2. Exclusions are supported by the clinical evidence and are of sufficient frequency to warrant inclusion in the specifications of the measure;
AND
If patient preference (e.g., informed decision-making) is a basis for exclusion, there must be evidence that the exclusion impacts performance on the measure; in such cases, the measure must be specified so that the information about patient preference and the effect on the measure is transparent (e.g., numerator category computed separately, denominator exclusion category computed separately).
2b3. For outcome measures and other measures when indicated (e.g., resource use):

- An evidence-based risk-adjustment strategy (e.g., risk models, risk stratification) is specified; is based on patient factors (including clinical and social risk factors) that influence the measured outcome and are present at start of care; 14,15 and has demonstrated adequate discrimination and calibration

OR

- rationale/data support no risk adjustment/ stratification.

2b4. Data analysis of computed measure scores demonstrates that methods for scoring and analysis of the specified measure allow for identification of statistically significant and practically/clinically meaningful 16 differences in performance;

OR

there is evidence of overall less-than-optimal performance.

2b5. If multiple data sources/methods are specified, there is demonstration they produce comparable results.

2b6. Analyses identify the extent and distribution of missing data (or nonresponse) and demonstrate that performance results are not biased due to systematic missing data (or differences between responders and non-responders) and how the specified handling of missing data minimizes bias.

2c. For composite performance measures, empirical analyses support the composite construction approach and demonstrate that:

2c1. the component measures fit the quality construct and add value to the overall composite while achieving the related objective of parsimony to the extent possible; and

2c2. the aggregation and weighting rules are consistent with the quality construct and rationale while achieving the related objective of simplicity to the extent possible.

(if not conducted or results not adequate, justification must be submitted and accepted)

Definitions

Reliability testing applies to both the data elements and computed measure score. Examples of reliability testing for data elements include but are not limited to inter-rater/abstractor or intra-rater/abstractor studies; internal consistency for multi-item scales; test-retest for survey items. Reliability testing of the measure score addresses precision of measurement (e.g., signal-to-noise).

Validity testing applies to both the data elements and computed measure score. Validity testing of data elements typically analyzes agreement with another authoritative source of the same information. Examples of validity testing of the measure score include, but are not limited to: testing hypotheses that the measures scores indicate quality of care, e.g., measure scores are different for groups known to have differences in quality assessed by another valid quality measure or method; correlation of measure scores with another valid indicator of quality for the specific topic; or relationship to conceptually related measures (e.g., scores on process measures to scores on outcome measures). Face validity of the measure score as a quality indicator may be adequate if accomplished through a systematic and transparent process, by identified experts, and explicitly addresses whether performance scores resulting from the measure as specified can be used to distinguish good from poor quality. The degree of consensus and any areas of disagreement must be provided/discussed.

Examples of evidence that an exclusion distorts measure results include, but are not limited to frequency of occurrence, variability of exclusions across providers, and sensitivity analyses with and without the exclusion.

Patient preference is not a clinical exception to eligibility and can be influenced by provider interventions.

Risk factors that influence outcomes should not be specified as exclusions.

With large enough sample sizes, small differences that are statistically significant may or may not be practically or clinically meaningful. The substantive question may be, for example, whether a statistically significant difference of one percentage point in the percentage of patients who received smoking cessation counseling (e.g., 74 percent v. 75 percent) is clinically meaningful; or whether a statistically significant difference of $25 in cost for an episode of care (e.g., $5,000 v.$5,025) is practically meaningful. Measures with overall less-than-optimal performance may not demonstrate much variability across providers.

Please separate added or updated information from the most recent measure evaluation within each question response in the Importance to Scientific Acceptability sections. For example:

2021 Submission:

Updated testing information here.

2018 Submission:
Testing from the previous submission here.

2a.01. Select only the data sources for which the measure is tested.

[Response Begins]
Electronic Health Records
Instrument-Based Data
[Response Ends]

2a.02. If an existing dataset was used, identify the specific dataset.

The dataset used for testing must be consistent with the measure specifications for target population and healthcare entities being measured; e.g., Medicare Part A claims, Medicaid claims, other commercial insurance, nursing home MDS, home health OASIS, clinical registry).

[Response Begins]
Does not use existing data.
[Response Ends]

2a.03. Provide the dates of the data used in testing.

Use the following format: "MM-DD-YYYY - MM-DD-YYYY"

[Response Begins]
11-01-2019 – 02-28-21
Analyses include data collected between November 2019 and February 2021, with a pause between March and September 2020 due to the COVID-19 pandemic.
Response to NQF request for clarification: We faced an important and unusual threat to the validity of the *Receiving Desired Help for Pain* data element and performance measure when the COVID-19 pandemic began in March 2020, during our national beta test field period. We realized that the pandemic could alter the provision and experience of receiving outpatient palliative care and thus disrupt the relationship between quality of care and patient responses. To evaluate the potential impact of the pandemic at the data element level, we conducted a chi-squared test to assess whether there were significant differences in the values of the *Receiving Desired Help for Pain* data element pre-COVID-19 pandemic (data collection rounds one through four) and during the COVID-19 pandemic (i.e., after the initial wave of the pandemic, rounds seven through ten). The chi-squared test was not significant (p = 0.85), indicating that there were no meaningful differences in the pre- and mid-pandemic rounds of data collection.
We also compared mean performance measure scores using paired t-tests (i.e., the same programs were included in the pre-pandemic and mid-pandemic groups) to assess whether there were significant differences at the performance measure level pre-COVID-19 pandemic and after the height of the pandemic. The results indicate that there was no significant difference in performance measure scores pre- and mid-pandemic (t(22) = 0.97, p = 0.343). Overall, these results suggest that the *Receiving Desired Help for Pain* data element and proposed performance measure was largely robust to the dramatic changes caused by the COVID-19 pandemic, which is promising for the future validity of the performance measure.

[Response Ends]

2a.04. Select the levels of analysis for which the measure is tested.

Testing must be provided for all the levels specified and intended for measure implementation, e.g., individual clinician, hospital, health plan.

Please refrain from selecting the following answer option(s). We are in the process of phasing out these answer options *and request that you instead select one of the other answer options as they apply to your measure.*

Please do not select:

- *Clinician: Clinician*
- *Population: Population*

[Response Begins]
Clinician: Group/Practice
[Response Ends]

2a.05. List the measured entities included in the testing and analysis (by level of analysis and data source).

Identify the number and descriptive characteristics of measured entities included in the analysis (e.g., size, location, type); if a sample was used, describe how entities were selected for inclusion in the sample.

[Response Begins]
We aimed to recruit a total of 45 ambulatory palliative care programs (i.e., the accountable clinical groups) for the beta field test, based on assumptions informed by our alpha test regarding providers per program and total patient volume. We sought national representation by oversampling larger programs (i.e., those with more patients), stratifying recruitment efforts by administrative home type (i.e., hospice, hospital, ambulatory, and other administration) and by geographic location to ensure representation across Census Regions (Table 1). Using the list of 395 ambulatory palliative care programs, we sorted programs into recruitment queues according to these criteria. RAND's Survey Research Group (SRG) began contacting programs to discuss participation in the beta field test. Recruitment focused on ensuring the program provided ambulatory palliative care, had sufficient established patient volume in the ambulatory setting to ensure a timely contribution to the testing sample, and were MIPS-eligible at both the program and provider levels. Program recruitment contact began with an introductory email followed by a telephone call from SRG staff members. Contact continued until quotas for each queue (i.e., setting type and geographic region) were reached and Data Use Agreements (DUAs) were executed. A total of 238 palliative care programs were contacted about the test, at which point we met desired target numbers and discontinued outreach/recruitment efforts. Of these 238 contacted programs, 70 programs were deemed ineligible to participate in the field tests for one or more of the following reasons:

- did not provide ambulatory care
- were less than six-months old and thus had little established experience providing ambulatory palliative care
- saw fewer than 20 patients in an ambulatory setting over the prior six months and thus would be unlikely to contribute adequate sample size for testing purposes
- were a PACE (Program of All-Inclusive Care for the Elderly) or VA (Veterans Administration) program and thus not eligible for the MIPS program; or
- had no MIPS-eligible practitioners (as of the 2019 MIPS-eligible provider list) who provided ambulatory palliative care to patients.

Of the remaining eligible programs, 44 programs participated (defined as providing at least one sample file during the field-testing period) (Table 1).

Table 1. Beta Field Test Recruitment Targets and Final Recruitment Data

Settings	Targeted Sites	Midwest	Northeast	South	West	TOTAL
Hospice	Targeted sites to recruit	3	1	3	1	8
Hospice Cont.	Sites recruited	2	4	3	1	10
Hospital	Targeted sites to recruit	5	9	7	7	28
Hospital-2	Sites recruited	5	6	6	7	24
Ambulatory/Other	Targeted sites to recruit	3	2	5	5	15
Ambulatory/ Other - 2	Sites recruited	2	3	3	2	10
All Settings	Targeted sites to recruit	11	11	15	13	50
All Settings -2	Sites recruited	9	13	12	10	44

[Response Ends]

2a.06. Identify the number and descriptive characteristics of patients included in the analysis (e.g., age, sex, race, diagnosis), separated by level of analysis and data source; if a sample was used, describe how patients were selected for inclusion in the sample.

If there is a minimum case count used for testing, that minimum must be reflected in the specifications.

[Response Begins]
Our target patient sample was guided by several assumptions based in part on our alpha pilot test findings, including: 1) there would be an average of three MIPS-eligible providers per program, 2) providers would see on average ten unique eligible patients per three-month period, and 3) a 40 percent survey response rate would be achieved, based on existing literature (Parast et al., 2018). Operating under these assumptions, we planned to field between 6,000 and 7,500 surveys to patients receiving ambulatory palliative care at the participating programs and expected between 2,400 and 3,000 completed surveys. These assumptions/criteria were used solely to establish basic parameters for the fielding design. Minimum requirements for participation in the measure were determined based on reliability analyses conducted after the field period (see sections 2a.10-2a.11).

To maximize the chance that we would achieve adequate sample size, we used data from all eligible providers belonging to a program and all eligible patients cared for by these providers. If a program submitted too many patients for SRG to contact within a given period due to capacity constraints, a random sample of eligible patients up to the number SRG could field in that period was selected.

We fielded the survey to 7,595 sampled patients across 10 rounds. Of these, 3,356 were not returned, 1,435 were excluded from any analyses due to ineligibility for the larger study, and 2,804 were returned and included in analyses (37% raw response rate; 46% response rate excluding ineligible patients) (Table 2). Completed surveys are defined as any survey returned within six months of the 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).

Table 2. Final Disposition of Fielded Surveys (n=7,595)

Category	Description	Counts	Percentage	Count	Percentage
Completed Surveys	Mail	1298	17.09%	2804	36.92%
*	Phone	980	12.90%	*	*
*	Web	526	6.93%	*	*
Survey Nonresponse	*	3356	44.19%	3356	44.19%
Excluded Surveys Due to Ineligibility	*	1435	18.89%	1435	18.89%
*	*	*	*	Overall Total	7595

* Indicates the table cell is empty

Table 3 provides descriptive information on survey nonresponse and surveys that were otherwise ineligible for measure analysis. Survey nonresponse includes patient refusals to complete a phone interview, bad or disconnected phone numbers, or inability to reach patient after maximum attempts.

Table 3. Survey Nonresponse (n=3,356)

Category	Counts
Maximum Calls (8) Reached Without Response	2128
Not Found (i.e., Bad Phone Number)	583
Refusals	463
Final Refusal (Patient Reached but Refused Participation)	348
Informant Refusal (Someone Other Than Patient or Proxy Declined)	87
Breakoff (Respondent Discontinued During CATI)	28
Patient Unable and No Available Proxy	121

Category	Counts
Late Complete	61
Mail	58
Web	3
Overall Total	3356

Surveys with other ineligibility factors include patients who were indicated as deceased by the time the survey reached them (a proxy could return a stamped postcard to indicate this, or may have notified us when reached by telephone), returned surveys completely solely by a proxy without patient involvement, surveys where the respondent disavowed the program (i.e., indicated that they had not received care in the past 6 months from the stated palliative care provider and team), or for whom we had bad contact information, such as when a patient had moved or the mailed packet was returned to sender (Table 4).

Table 4. Excluded Surveys Due to Ineligibility (n=1,435)

Ineligibility Category	N (% of total excludes)
Patient deceased	748 (52%)
Proxy-only response	435 (30%)
Disavowed program/provider	146 (10%
Bad contact information; moved	35 (2%)
Multiple ineligibilities (e.g., patient deceased and proxy-only response)	71 (5%)
Overall Total	1435

Survey respondents, i.e., those who comprised our analytic sample (n=2,804), generally reflected the larger patient sample (n=7,595) (Table 5). However, there were slight differences between the respondents and the larger patient sample in terms of age and race. Survey respondents were slightly older than nonrespondents (mean age 63.4 vs 60.9; p<0.01). The proportion of women was also higher among respondents compared to nonrespondents (56.2% vs_54.5%), but the difference was not statistically significant (p = 0.21). 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).

Table 5. Patient Respondent Characteristics

Characteristic	Summary	S.D.	Percent Missing
Number of Observations	N=2804	*	*
Age (Mean)	63.36	13.32	0.04%
Gender (Male %)	43.81%	*	0.04%
Race	N=2753	*	1.82%
White	87.61%	*	*
Black or African American	5.88%	*	*
Asian	0.91%	*	*
Multi-racial	2.76%	*	*
American Indian or Alaska Native	0.44%	*	*
Native Hawaiian or other Pac. Islander	0.25%	*	*
Other	2.14%	*	*
Education	N=2782	*	0.78%
More than 4-year college degree	15.74%	*	*
4-year college graduate	15.46%	*	*
Some college or 2-year degree	34.94%	*	*
High school graduate or GED	25.63%	*	*

Characteristic	Summary	S.D.	Percent Missing
Some high school but did not graduate	6.40%	*	*
8th grade or less	1.83%	*	*
Hispanic	N=2743	*	2.18%
Yes, Hispanic or Latino	4.67%	*	*
No, not Hispanic or Latino	95.33%	*	*

* Indicates the table cell is empty

In order to be eligible for the denominator, individuals had to affirmatively respond to two gateway questions related to: 1) having pain, and 2) wanting help for that pain (Table 6).

Table 6. Response Breakdown for Pain Gateway Data Elements

In the last 6 months, did you want help from this provider and team for this pain?	In the last 6 months, have you ever had pain?	In the last 6 months, have you ever had pain?	In the last 6 months, have you ever had pain?	Pain Totals for the last 6 months
*	**Yes**	**No**	**Missing**	**Totals**
Yes	1,926	*	6	1,932
No	448	*	3	451
(Did Not Have Pain)	*	379	*	379
Missing	17	*	25	42
Totals	2,391	379	34	2,804

* Indicates the table cell is empty

Among the 2,804 completed surveys in our full sample, there were 1,926 respondents who responded that they both had pain and wanted help for their pain (~67% of respondents). Of these 1,926 respondents eligible to answer the *Receiving Desired Help for Pain* data element, 1,531 (~79%) indicated "Yes, definitely", 315 (~16%) responded "Yes, somewhat", and 78 (4%) responded "No", with only two respondents not responding to the data element.

Citations:

Parast, L., Elliott, M. N., Hambarsoomian, K., Teno, J., & Anhang Price, R. (2018). Effects of Survey Mode on Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey Scores. *J Am Geriatr Soc*, *66*(3), 546-552.

Response to NQF: We purposively sampled programs of all sizes from all regions of the U.S. Despite our geographically diverse sample of palliative care programs, the survey data collected during the national beta field test largely reflect the experiences of a non-Hispanic White patient population. The homogeneity of the sample is similar to that in other studies in palliative care populations and may be a function of multiple factors (Temel, Greer, Admane, et al., 2011; Temel, Greer, El-Jawahri, et al., 2017). Such factors include the limited reach of palliative care services into diverse communities and the inaccessibility of palliative care to certain patient groups or survey response, as other studies have also shown that non-White participants may be less likely to respond to mailed surveys (Elliott, Edwards, et al., 2005; Link et al., 2006; Couper et al., 2007). As palliative care groups in our sample did not consistently capture or provide data on patient race in their sampling files, we were unable to evaluate potential response bias (i.e., whether non-White patients were less likely to respond to the survey).

However, to better understand these factors and to capture the experiences of racial and ethnic minority patients with ambulatory palliative care and with receiving desired help for pain, we queried participating programs about the population they serve and interviewed racial and ethnic minority patients and family caregivers who had experience with palliative care. Most programs that participated in interviews reported that the majority of patients in their ambulatory palliative care practice were White (with estimates ranging from 75 percent to 95 percent White). Only one program described its patient population as "pretty diverse." For many programs, their patient population represented the demographics of the larger communities and areas served in the programs' geographical reach. For a few programs, however, interviewees noted that their outpatient palliative care patient population was not representative of their larger communities. Program interviewees observed that access to ambulatory palliative care, a lack of diversity in palliative care providers, cultural mistrust in the medical system, and an overall misperception of palliative care as end-of-life care may be barriers to engaging patients from racial and ethnic minorities in ambulatory palliative care. Some interviewees described institutional outreach efforts to engage patients of diverse racial and ethnic backgrounds, including by establishing a diversity committee or education for providers about perceptions of palliative care among patients from racial or ethnic minorities. Some of this was echoed in the interviews with non-White patient and family caregivers who had experience with palliative care. Interviewees described highly positive experiences with palliative care but also noted certain challenges they faced accessing palliative care. Though our data cannot discern whether the homogeneity of the sample reflects a response bias or a care disparity or some combination of both, these interview data as well as input from our TECUPP suggest that non-White patients likely face various systems- and individual-level barriers to accessing palliative care that reflect an important care disparity.

References:

Couper, Mick P., Arie Kapteyn, Matthias Schonlau, and Joachim Winter, "Noncoverage and Nonresponse in an Internet Survey," Social Science Research, Vol. 36, No. 1, March 2007, pp. 131–148.

Elliott, Marc N., Carol Edwards, January Angeles, Katrin Hambarsoomian, and Ron D. Hays, "Patterns of Unit and Item Nonresponse in the CAHPS Hospital Survey," Health Services Research, Vol. 40, No. 6, Part 2, December 2005, pp. 2096–2119.

Temel, Jennifer S., Joseph A. Greer, Sonal Admane, Emily R. Gallagher, Vicki A. Jackson, Thomas J. Lynch, Inga T. Lennes, Connie M. Dahlin, and William F. Pirl, "Longitudinal Perceptions of Prognosis and Goals of Therapy in Patients with Metastatic Non–Small-Cell Lung Cancer: Results of a Randomized Study of Early Palliative Care," Journal of Clinical Oncology, Vol. 29, No. 17, June 2011, pp. 2319–2326.

Temel, Jennifer S., Joseph A. Greer, Areej El-Jawahri, William F. Pirl, Elyse R. Park, Vicki A. Jackson, Anthony L. Back, Mihir Kamdar, Juliet Jacobsen, Eva H. Chittenden, Simone P. Rindaldi, Emily R. Gallagher, Justin R. Eusebio, Zhigang Li, Alona Muzikansky, and David P. Ryan, "Effects of Early Integrated Palliative Care in Patients with Lung and GI Cancer: A Randomized Clinical Trial," Journal of Clinical Oncology, Vol. 35, No. 8, March 2017, pp. 834–841.

[Response Ends]

2a.07. If there are differences in the data or sample used for different aspects of testing (e.g., reliability, validity, exclusions, risk adjustment), identify how the data or sample are different for each aspect of testing.

[Response Begins]

The same sample was used for all aspects of testing with the exception of a small subset of respondents who also participated in a test-retest design to provide additional reliability evidence for data elements. For the test-retest reliability calculation, we obtained data from a subset of respondents at two timepoints. We invited patients who completed the survey by phone (i.e., the Computer-Assisted Telephone Interview [CATI] survey) to be re-administered a shortened survey, including the *Receiving Desired Help for Pain* data elements, at a second timepoint within two days of the original CATI interview. Once patients were invited, participation in Time 2 was based on willingness and availability of the identified patient respondents. By restricting to telephone-only patients, the time interval could be minimized and standardized (i.e., two days), and the mode of administration would be the same at both data collection time points. Only patient respondents who completed the original CATI survey without proxy assistance were invited to participate in the retest. This subset included 437 respondents at Time 1, with 235 of these respondents also providing responses at Time 2. Respondents with data at both timepoints were included in these analyses. For all other analyses, we used the first responses collected from the test-retest participants. Our analysis of test-retest reliability was intended to establish data element level reliability; future work may need to examine test-retest reliability across survey modes and populations.

[Response Ends]

2a.08. List the social risk factors that were available and analyzed.

For example, patient-reported data (e.g., income, education, language), proxy variables when social risk data are not collected from each patient (e.g. census tract), or patient community characteristics (e.g. percent vacant housing, crime rate) which do not have to be a proxy for patient-level data.

[Response Begins]
Based on input from our project advisory group and TECUPP, we determined it was not appropriate to adjust this measure for social risk factors. However, to understand if and to what extent disparities in measure reporting and patient experience exist, we evaluated the relationship of various social risk factors to the measure score and the programs. These included patient race/ethnicity, education, and primary language, as well as multiple census-level variables such as race/ethnicity, urbanicity, median household income, gender, marital status, public insurance use, unemployment, and families below poverty line (see section 2b.23 for details). After adjustment for multiple comparisons, none of these variables were significant in their relationship with the measure.
[Response Ends]

Note: If accuracy/correctness (validity) of data elements was empirically tested, separate reliability testing of data elements is not required – in 2a.07 check patient or encounter-level data; in 2a.08 enter "see validity testing section of data elements"; and enter "N/A" for 2a.09 and 2a.10.

2a.09. Select the level of reliability testing conducted.

Choose one or both levels.
[Response Begins]
Patient or Encounter-Level (e.g., inter-abstractor reliability; data element reliability must address ALL critical data elements)
Accountable Entity Level (e.g., signal-to-noise analysis)
[Response Ends]

2a.10. For each level of reliability testing checked above, describe the method of reliability testing and what it tests.

Describe the steps—do not just name a method; what type of error does it test; what statistical analysis was used.

[Response Begins]
We first evaluated Data Element Reliability:

The reliability of the *Receiving Desired Help for Pain* data element was evaluated using a test-retest reliability coefficient and percent agreement. For these calculations, we obtained data from a subset of respondents at two timepoints. We invited patients who completed the survey by phone (i.e., the CATI survey) to complete a shortened survey, including the *Receiving Desired Help for Pain* data element within two days of the original CATI interview. Participation in Time 2 was based on willingness and availability of the identified patient respondents. This subset included 437 respondents at Time 1, with 233 of them also providing responses at Time 2. From these 233 respondents, 36 were ultimately determined to be ineligible for the measure analyses, resulting in a final subsample of 197 respondents with complete data for the test-retest analysis. By restricting to telephone-only patients, the time interval could be minimized and standardized (i.e., two days), and the mode of administration would be the same at both data collection time points. Only patient respondents who completed the original CATI survey without proxy assistance were invited to participate in the retest. We evaluated test-retest reliability with a stability coefficient (i.e., correlation coefficient) wherein scores from the initial administration (Time 1) were compared against scores from a second administration (Time 2), with a correlation of at least 0.70 required to demonstrate acceptable reliability.

We then evaluated Quality Measure Score Reliability:

To assess the reliability of the quality measure score at the program level, we used a traditional "signal-to-noise" analysis that decomposes variability in the measure score into a) between-subject variability and b) within-subject variability. If there is a large amount of between-subject variability (i.e. "signal") compared to within-subject variability (i.e., "noise"), then there is evidence that it is possible to discriminate performance among providers. To measure variability, we used hierarchical generalized-linear regression models to relate our outcome measures to our programs and their covariates, where the hierarchy of data is patient observations within the program. We performed hierarchical regressions with binomial outcomes to decompose the variability. The random effects model for analysis across providers is

$$\text{logit}\left(E\left[Y_{ij}\middle|P_i, X_{ij}\right]\right) = (\beta_0 + b_i P_i) + X_{ij}^T \alpha$$

where we assume that

$$b_i \sim N(0, \sigma_b^2)$$

In this model, the term

$$\beta_0$$

represents the overall average performance, each term

$$P_i$$

is an indicator of provider

$$i$$

and therefore

$$b_i$$

represents the provider-specific offset from the overall performance and

$$X_{ij}^T \alpha$$

captures risk adjustment (specifically for survey mode and proxy measures). The variance of the model can be decomposed using the (adjusted) intraclass correlation coefficient (ICC), which provides a summary of the reliability of the measure as tested, with higher values implying more variability between programs(Rodríguez & Elo, 2003; Wu et al., 2012):

$$ICC = \frac{\sigma_b^2}{\sigma_b^2 + \frac{\pi}{3}}$$

We incorporate risk adjustment variables into our models to provide fair comparisons among programs and to provide a best effort to ensure that the observed differences from programs are truly due to differences in performance and not due to baseline differences in risk adjustment variables (including survey mode) that represent the programs. The reliability from the measure test is then projected out based on observed variances and sample sizes from each program, using the Spearman-Brown prophecy formula. This allows us to estimate a required within-program sample size to achieve a desired reliability. Reliability values of approximately 0.7 reflect an acceptable level of reliability and guided determination of required within-provider sample sizes (Nunally, 1978).

Citations:

Nunnally, J. C. (1978). *Psychometric Theory* (2nd ed. ed.). McGraw-Hill.

Rodríguez, G., & Elo, I. (2003). Intra-class Correlation in Random-effects Models for Binary Data. *The Stata Journal*, *3*(1), 32-46.

Wu, S., Crespi, C. M., & Wong, W. K. (2012). Comparison of methods for estimating the intraclass correlation coefficient for binary responses in cancer prevention cluster randomized trials. *Contemp Clin Trials*, *33*(5), 869-880.

Response to NQF request for clarification: All recommended modes of data collection (i.e., web, mail, and phone) were tested in the national field test, though we did not conduct a full mode experiment. A subset of respondents were also asked to participate in a test-retest design to establish data element reliability. To analyze test-retest reliability, we restricted to telephone-only so that the time interval and mode of administration could be standardized, and telephone surveys could be completed close together so that the patient was reflecting on the same time period/visits.

Upon full submission, we will clarify that the recommended mode of implementation is enhanced mixed-mode administration (web to mail to phone, i.e., live telephone interview).

[Response Ends]

2a.11. For each level of reliability testing checked above, what were the statistical results from reliability testing?

For example, provide the percent agreement and kappa for the critical data elements, or distribution of reliability statistics from a signal-to-noise analysis. For score-level reliability testing, when using a signal-to-noise analysis, more than just one overall statistic should be reported (i.e., to demonstrate variation in reliability across providers). If a particular method yields only one statistic, this should be explained. In addition, reporting of results stratified by sample size is preferred (pg. 18, NQF Measure Evaluation Criteria).

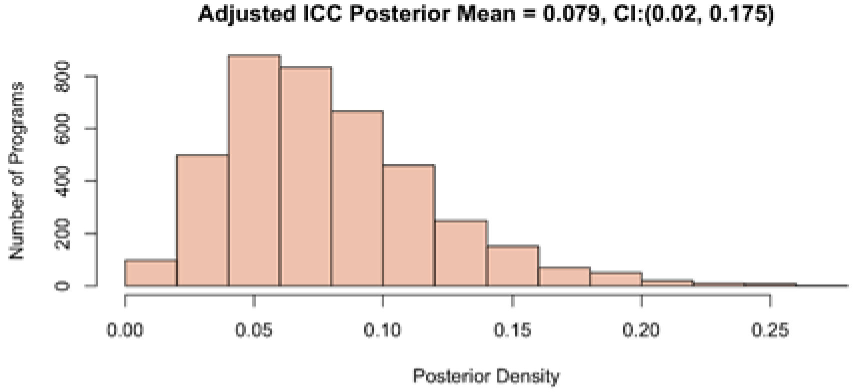
[Response Begins]
Data Element Reliability:

Results provide support for the reliability of the *Receiving Desired Help for Pain* data element. Data element reliability was excellent according to both the test-retest correlation coefficient and percent agreement. The test-retest correlation (*r*) between Time 1 and Time 2 scores was 0.90 and there was 88 percent agreement in responses from Time 1 to Time 2 regarding patients receiving desired help for their pain.

Quality Measure Score Reliability:

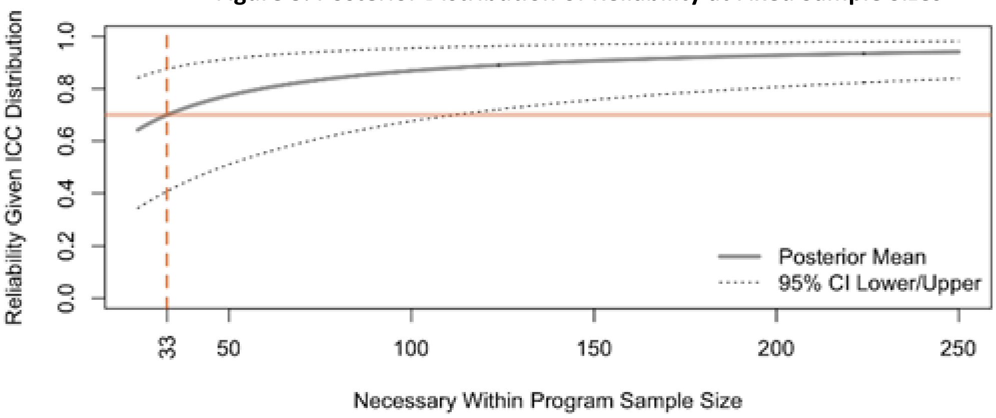
We conducted a formal measure score reliability analysis using Bayesian generalized mixed-effects models to obtain a posterior distribution of the ICC. The estimate of the adjusted ICC is approximately 0.079 (95 percent CI: 0.02, 0.175) (Figure 2). This implies that there is a reasonable level of between-program variability as compared to the within-program variability.

Figure 2. Estimated Posterior Distribution of the Adjusted ICC



We then extended our reliability results to examine performance on future samples using the Spearman-Brown prophecy formula, which estimates the average sample size requirement (i.e., number of patient respondents) within programs to achieve a desired reliability for a given ICC. This is visualized in Figure 3 below for our posterior distribution of the above ICC estimates where we estimate that in order to obtain a nominal reliability of 0.7 (orange horizontal line in the plot), an average sample size of 33 responses to the *Receiving Desired Help for Pain* data element are necessary. As such, an average minimum sample size of 49 respondents to the pain gateway questions will be required, given that approximately 68% of individuals in our sample “passed” the gateway questions and reported i) having pain; and ii) wanting help for that pain.

Figure 3. Posterior Distribution of Reliability at Fixed Sample Sizes



Additionally, we computed estimates of individual program-specific reliability using a method similar to the approach utilized in Adams (2009). Here, to gain consistency between the approach in Adams and our models, we used our models to estimate a posterior distribution for the overall variability of the risk-adjusted program scores (i.e., the variance of the distribution of

$$\text{logit}^{-1}(\beta_0 + b_i)$$

pooling across all

$$i$$

) and estimate a posterior distribution of the variance of each within-program score (i.e.,

$$\widehat{p_i}(1 - \widehat{p_i})/n_i$$

as specified in Adams). We note that the distribution of the number of respondents to the *Receiving Desired Help for Pain* data element (i.e., those who responded that they had pain and wanted help for that pain) skews toward smaller within-program samples. Specifically, 50% of programs had 23 patients or fewer who responded to the *Receiving Desired Help for Pain* data element and only 25% of programs had greater than 35 patients (i.e., exceeded the required minimum number of respondents to the *Receiving Desired Help for Pain* data element). This suggests that some programs may have reliability estimates that fall below the desired value of 0.7, and in fact, the average reliability across all programs is approximately

$$r = 0.482$$

(Figure 4). However, when considering only the 13 of 43 programs (30%) with at least the minimum required 33 respondents who answered the *Receiving Desired Help for Pain* data element, average reliability is

$$r = 0.735$$

. (Figure 5).

Figure 4. Distribution of Program-Specific Reliability

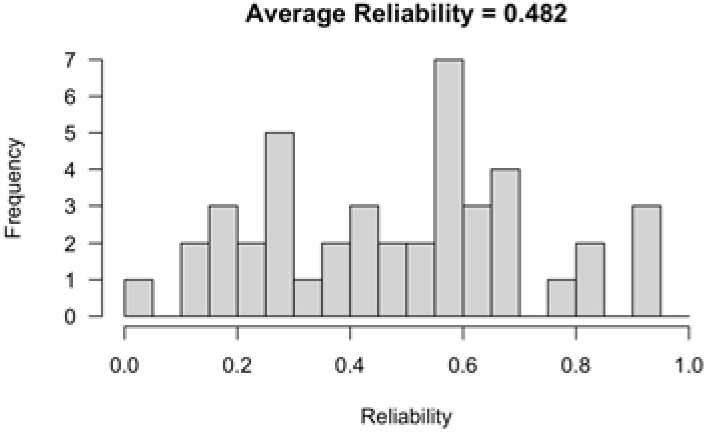
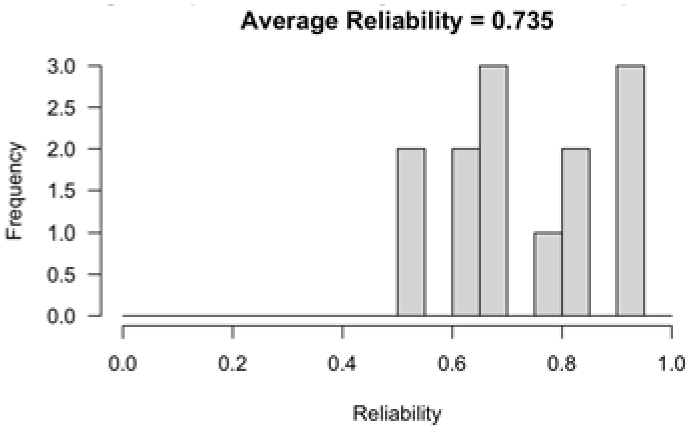


Figure 5. Distribution of Program-Specific Reliability, For Those Programs With At Least 33 Individuals Responding To Having Pain and Wanting Help For That Pain



Citations:

Adams, J. L. (2009). *The Reliability of Provider Profiling: A Tutorial*. https://www.rand.org/pubs/technical_reports/TR653.html

Response to NQF: To be eligible for inclusion in testing, patients had to be receiving ambulatory palliative care, but we did not exclude patients who were later admitted to hospice. We did not have data from palliative care programs to identify patients transferred to hospice and therefore did not compare hospice and non-hospice subgroups.

Response to NQF request for clarification, 8/30/21: We did consider whether to exclude hospice patients and it was indeed a very early exclusion. However, we later realized that since eligibility was based on an ambulatory palliative care visit, hospice patients would rarely be included. If they were included because they were receiving both types of care, that would be okay – we are still asking about the ambulatory palliative care provider and team, and we assume that patients are receiving other health care services; hospice should be no different. The pre-notification letter, the cover letter, and the wording at the start of the survey are intended to orient the patient to the specific provider and team.

We also considered that some patients may be in hospice by the time they receive the survey. If a patient entered hospice during the six-month period following the eligible visit but was able to reflect on their experiences with ambulatory palliative care (the referenced provider and team) and complete the survey, then they should have the opportunity to provide feedback on their experience of care. If the patient was too ill to complete the survey, had passed away, or was no longer living in the community we had processes in place to address these cases. Our data collection approach was to first send eligible patients a letter notifying them of the upcoming survey with a stamped postcard that could be returned in the event of death or a move/new address. If the patient had moved to a residential hospice, this could be indicated in the returned postcard noting they had moved. If they were still at home, but had discontinued their prior outpatient palliative care, they should still be eligible and able to respond about their experience with their ambulatory palliative care provider and team.

[Response Ends]

2a.12. Interpret the results, in terms of how they demonstrate reliability.

(In other words, what do the results mean and what are the norms for the test conducted?)

[Response Begins]

Testing results provide support for the data element reliability and use in the construction of the quality measure. Data element reliability was excellent according to the test-retest correlation coefficient and raw percent agreement. Results of the “signal-to-noise” analysis of quality measure reliability suggest there is a reasonable level of reliability when

programs meet the minimum number of respondents to achieve the nominal 0.7 reliability. We note that only 30% of programs in our testing sample met this minimum requirement; however, our field period did not encompass a full year and included disruptions in patient enrollment due to the COVID-19 pandemic. Thus, we anticipate that more than 30% of programs will be able to meet this minimum sample size in practice.
[Response Ends]

2b.01. Select the level of validity testing that was conducted.

[Response Begins]
Patient or Encounter-Level (data element validity must address ALL critical data elements)
Accountable Entity Level (e.g. hospitals, clinicians)
Empirical validity testing
Systematic assessment of face validity of performance measure score as an indicator of quality or resource use (i.e., is an accurate reflection of performance on quality or resource use and can distinguish good from poor performance)
[Response Ends]

2b.02. For each level of testing checked above, describe the method of validity testing and what it tests.

Describe the steps—do not just name a method; what was tested, e.g., accuracy of data elements compared to authoritative source, relationship to another measure as expected; what statistical analysis was used.

[Response Begins]
We first assessed Data Element Validity:

As there is currently no gold standard to compare with our *Receiving Desired Help for Pain* data element, our data element validity analyses did not address sensitivity and specificity but instead focused on assessing the convergent validity of the *Receiving Desired Help for Pain* data element. We hypothesized that the *Receiving Desired Help for Pain* data element is theoretically related to similar constructs and thus sought to assess whether they were indeed related. As part of the study design we included additional survey data elements taken from other instruments in use (e.g., the Consumer Assessment of Healthcare Providers and Systems [CAHPS] Hospice Survey) and expected to be related to *Receiving Desired Help for Pain*. Selection of additional items was based on theory, prior literature, and clinical practice and/or expert feedback. For example, the four-item CAHPS Communication composite measure (e.g., "In the last 3 months, how often did this provider and team listen carefully to you?") was hypothesized to be associated with the proposed *Receiving Desired Help for Pain* data element. We also examined the association between *Receiving Desired Help for Pain* and the *Feeling Heard and Understood* data element. We hypothesized that receiving the help one wanted for their pain from their palliative care provider and team would be linked with feeling heard and understood by that same palliative care provider and team. Associations between the proposed data element and validity items are evaluated using bivariate correlations. Interpretation of correlations followed standard conventions for small, medium and large associations (i.e., 0.10, 0.30, 0.50) (Rosnow & Rosenthal, 1989).

We then assessed Quality Measure Score Validity:

To evaluate validity of the *Receiving Desired Help for Pain* quality measure, we examined the association between the *Receiving Desired Help for Pain* measure score and the *Feeling Heard and Understood* measure score and the CAHPS communication measure score, with the hypothesis that scores would be associated. We also examined associations between the *Receiving Desired Help for Pain* quality measure with a program-level measure of overall program rating. Associations between the proposed quality measures were evaluated using bivariate correlations. Interpretation of correlations followed standard conventions for small, medium, and large associations (i.e., 0.10, 0.30, 0.50) (Rosnow & Rosenthal, 1989).

Face validity of the quality measure score was determined through a systematic and transparent process by convening experts who explicitly addressed whether scores resulting from the measure, as specified, can be used to distinguish good from poor quality. In May 2021, following completion of testing, a panel of seven advisors with expertise in palliative care and clinical quality measurement were asked to review the final measure specifications and testing results and rate face validity of the measure score. The expert panel consisted of six palliative care physicians and a researcher with expertise in palliative care communication. Six of the seven advisors also had expertise in clinical quality measurement. Advisors were asked to consider how well the measure scoring approach distinguishes between programs with high, medium, and low performance and how useful it is to quality improvement efforts. Advisors rated face validity on a scale of 1 (lowest rating) to 9 (highest rating); numeric ratings corresponded with descriptive ratings of low (1-3), moderate (4-6), or high (7-9).

Citations:

Rosnow, R. L., & Rosenthal, R. (1989). Statistical procedures and the justification of knowledge in psychological science. *American Psychologist*, *44*(10), 1276-1284.

Response to NQF: None of the seven experts who completed the face validity exercise were part of the core measure development and testing team. The advisory board is an external group of subject matter experts, including measure developers and palliative care clinicians, who provided input on measure specification and field-testing decisions. We met with the advisory board at specific points during measure development to collect their input. After testing was completed and measure specifications were finalized, advisors were asked to provide their objective ratings of face validity based on their review of the final measure specifications and testing results.

[Response Ends]

2b.03. Provide the statistical results from validity testing.

Examples may include correlations or t-test results.

[Response Begins]
Statistical results include correlations.

Data Element level:

Testing results support the validity of the *Receiving Desired Help for Pain* data element. As hypothesized, receiving desired help for pain was positively associated with a higher CAHPS communication composite score (r = 0.57, p<.001). Also as expected, receiving desired help for pain was positively associated with feeling heard and understood (r =0.61, p<.001). Taken together, these results support the convergent validity of the *Receiving Desired Help for Pain* data element.

Quality Measure level:

Results of validity testing at the quality measure level provide evidence supporting the use of the *Receiving Desired Help for Pain* quality measure as constructed. As hypothesized, the *Receiving Desired Help for Pain* quality measure was significantly associated with the CAHPS communication quality measure (r = 0.386, p =.014), the *Feeling Heard and Understood* quality measure (r = 0.410, p =.009), and the overall rating of the palliative care provider and team (r = 0.56, p=<.001). Taken together, these results provide support for the convergent validity of the *Receiving Desired Help for Pain* quality measure.

Seven expert advisors rated face validity of the *Receiving Desired Help for Pain* measure score. On average, advisors rated face validity of the measure score 7.7 on a scale of 1-9, corresponding with an average rating of “high.” These ratings reflect strong support for face validity of the proposed quality measure from experts in palliative care and quality measurement.
[Response Ends]

2b.04. Provide your interpretation of the results in terms of demonstrating validity. (i.e., what do the results mean and what are the norms for the test conducted?)

[Response Begins]
Testing results support the convergent validity of the *Receiving Desired Help for Pain* data element and the *Receiving Desired Help for Pain* quality measure. Further expert ratings reflect strong support for the face validity of the proposed quality measure.
[Response Ends]

2b.05. Describe the method for determining if statistically significant and clinically/practically meaningful differences in performance measure scores among the measured entities can be identified.

Describe the steps—do not just name a method; what statistical analysis was used? Do not just repeat the information provided in Importance to Measure and Report: Gap in Care/Disparities.

[Response Begins]
We guided our analyses based on the literature and lessons learned from the CAHPS program (Quigley et al., 2018). For example, we tested for statistically significant differences among programs using techniques similar to analysis of variance (ANOVA) that aim to compare a "full model" and a "reduced model" (or "nested model"). The reduced (or nested) model assumes that there are no differences among the programs, and the full model assumes that there is at least one difference. Under a generalized linear model, the above null and alternative hypotheses can be tested using a likelihood ratio statistic.

As the concept of clinically meaningful or practical significance difference is a notion without perfect agreement among researchers on how it should be defined, we assessed such difference with a ranking approach that uses all programs that participated in the national beta field test. To that end, we estimated equivalence of a difference in measure score to ranking of program performance. This equivalence method is intended to relate the magnitude of difference in the program's score to its ranking and potentially gives patients and decisionmakers a magnitude that can have practical choice implications for them.

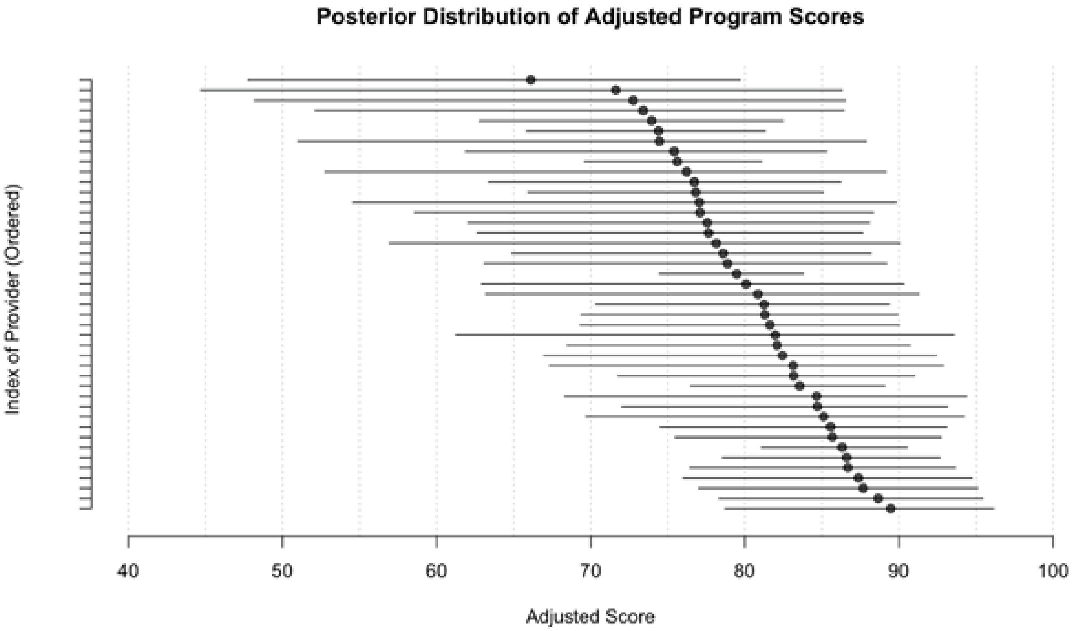
Citations:
Quigley, D. D., Elliott, M. N., Setodji, C. M., & Hays, R. D. (2018). Quantifying Magnitude of Group-Level Differences in Patient Experiences with Health Care. Health services research, 53 Suppl 1(Suppl Suppl 1), 3027-3051.
[Response Ends]

2b.06. Describe the statistical results from testing the ability to identify statistically significant and/or clinically/practically meaningful differences in performance measure scores across measured entities.

Examples may include number and percentage of entities with scores that were statistically significantly different from mean or some benchmark, different from expected; how was meaningful difference defined.

[Response Begins]
We found evidence of statistically significant differences in program scores; however, interpreting the meaning of those differences requires information about both the score and the rank order. For score differences, Figure 6 shows the adjusted measure scores for each program with the dot indicating the mean score and the extended line to left and right of the dot indicating the variability in scores within each program. The lines extend to reflect a 95 percent credible interval, thus programs that are statistically different from one another are represented by non-overlapping lines. Visual inspection of this plot – though imprecise - suggests that there are a few, but not many program differences. To formally test the significance of the performance differences, we compared the fit of nested models, where the difference in models is the inclusion of a program-level effect. Results of this additional analysis showed that the model that included a program-level indicator was significantly different from the model without one ($c^2_{(42)}$=98.99, *p*<.05), demonstrating that there are differences among program scores from the "grand" mean score, suggesting the potential for movement in program scores (i.e., potential to improve or worsen).

Figure 6. Posterior Distribution of Adjusted Program Scores



To consider the score and the rank order together, Table 7 displays the magnitude of change in the *Receiving Desired Help for Pain* program-level measure scores associated with selected program rank differences. The program scores in our sample range from 66.20 to 89.72 and the practical interpretation of differences between program score and/or rank order varies depending on the location in the distribution and the distance between programs of interest. For example, assuming 100 programs participated in the scoring, the difference in measure scores between programs that are 5th and 10th top ranked is a relatively small value of 0.91 in the *Receiving Desired Help for Pain* measure score. The difference in measure scores between programs that are at the top 10th and 20th is 1.60 points. On the other hand, a program at the median (in the middle of the ranking) will need a large increase in measure score of 5.29 points to improve to the 20th top ranked. Similarly, a program very low in the ranking (at the 20th or the 10th ranking from the bottom) will need a large 4.20 points or 6.07 points increase respectively to improve at least to the middle of the ranking (median). These changes in score by program rank also suggest that measure performance is actionable; i.e., there is room for programs to improve their score.

Table 7. Change in Measure Score, Assuming 100 Ranked Programs

Program Rank Difference	**Change in Score**
5th top to 10th top	0.91 points drop
10th top to 20th top	1.60 points drop
Median to 20th top	5.29 points increase
20th lowest to Median	4.20 points increase
10th lowest to Median	6.07 points increase

[Response Ends]

2b.07. Provide your interpretation of the results in terms of demonstrating the ability to identify statistically significant and/or clinically/practically meaningful differences in performance across measured entities.

In other words, what do the results mean in terms of statistical and meaningful differences?

[Response Begins]
When programs are ranked by their measure performance, we calculated that a program at the median of measure performance would need a large increase of 5.29 points in their measure score to improve to the 20th top-ranked program. A program at the bottom of the ranking (e.g., the 10th lowest ranked program) would need a 6-point increase

measure score to improve to the median. These changes in score by program rank suggest that measure performance is actionable; i.e., there is room for programs to improve their score.

Face validity of the quality measure scores was determined through a systematic and transparent process by convening experts who explicitly addressed whether scores resulting from the measure, as specified, can be used to distinguish good from poor quality. In May 2021, following completion of testing, a panel of seven advisors with expertise in palliative care and clinical quality measurement were asked to review the final measure specifications and testing results and rate face validity of the measure score. Providers were asked to consider how well the approach distinguishes between programs with high, medium, and low performance and how useful it is to quality improvement efforts. Advisors rated face validity on a scale of 1 (lowest rating) to 9 (highest rating); numeric ratings corresponded with descriptive ratings of low (1-3), moderate (4-6), or high (7-9). On average, advisors rated face validity of the measure score for *Receiving Desired Help for Pain* 7.7 on a scale of 1-9, corresponding with an average rating of "high." These ratings reflect strong support for face validity of the proposed quality measure from experts in palliative care and quality measurement.
[Response Ends]

2b.08. Describe the method of testing conducted to identify the extent and distribution of missing data (or non-response) and demonstrate that performance results are not biased due to systematic missing data (or differences between responders and non-responders). Include how the specified handling of missing data minimizes bias.

Describe the steps—do not just name a method; what statistical analysis was used.

[Response Begins]
Only individuals with outcome data should be used in the final analysis; other cases should be deleted. Missing values for proxy assistance should be imputed as "No Proxy Assist."

Within palliative care programs 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 using statistical tests (e.g., t-tests to compare distribution means, Kolmogorov-Smirnoff statistics to assess cumulative distribution functions) that provide quantifications of the discrepancies between distributions.

To better understand the potential for bias due to nonresponse, we used available patient data to characterize the differences between respondents (n=2,804) and non-respondents (3,356). 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.

We also examined missing data among completed surveys, such as not responding to individual items or demographic questions. To handle this, we again assessed the distributions and patterns of missing data, including an assessment to see if a missing-at-random assumption seemed plausible.
[Response Ends]

2b.09. Provide the overall frequency of missing data, the distribution of missing data across providers, and the results from testing related to missing data.

For example, provide results of sensitivity analysis of the effect of various rules for missing data/non-response. If no empirical sensitivity analysis was conducted, identify the approaches for handling missing data that were considered and benefits and drawbacks of each).

[Response Begins]
We fielded the survey to 7,595 sampled patients in the beta test across 10 rounds. Of these, 3,356 were not returned, 1,435 were excluded from any analyses due to ineligibility for the larger study, and 2,804 were returned and included in

analyses (37% raw response rate; 46% response rate excluding ineligible patients). 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, comparing responders to non-responders (but removing those ineligible responders due to exclusions). There were no clear outliers in terms of program nonresponse. The proportion of women was 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). Additionally, survey respondents were slightly older than patients who did not complete a survey (mean age 63.4 vs 60.9; p<0.01). Though significant, patient age was not significantly related to response patterns (see Table 10 in section 2b.24) and therefore we do not believe that non-response related to age should significantly bias results.

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). Though significant, as with age, patient race was not significantly related to the pain data element responses (see section 2b.24, Table 10), and therefore we do not think non-response related to race should significantly bias results. However, due to inconsistency in reporting of the race variable across programs for non-responders, nonresponse due to race will need to be evaluated in the future to explore the need for adjustment with nonresponse weights.

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. There were 1,926 respondents who responded that they both had pain and wanted help for their pain (~67% of respondents). Among these 1,926 respondents eligible to answer the *Receiving Desired Help for Pain* data element missingness is approximately <1%, which is very low (appropriately skipped survey items are not counted as missing).
[Response Ends]

2b.10. Provide your interpretation of the results, in terms of demonstrating that performance results are not biased due to systematic missing data (or differences between responders and non-responders), and how the specified handling of missing data minimizes bias.

In other words, what do the results mean in terms of supporting the selected approach for missing data and what are the norms for the test conducted; if no empirical analysis was conducted, justify the selected approach for missing data.

[Response Begins]
Overall, we achieved a good survey response rate, comparable to those typical to CAHPS surveys (Parast et al., 2018); there were no clear outliers in terms of program nonresponse; there were low levels of missingness in completed surveys; and our non-response analysis did not identify any evidence of systematic bias (see 2b.09 for details). This conclusion is largely supported by the fact that many of the candidate variables with differences in non-response are unrelated to outcomes (see section 2b.24, Table 10).

Citations:

Parast, L., Elliott, M. N., Hambarsoomian, K., Teno, J., & Anhang Price, R. (2018). Effects of Survey Mode on Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey Scores. *J Am Geriatr Soc*, *66*(3), 546-552.

[Response Ends]

Note: This item is directed to measures that are risk-adjusted (with or without social risk factors) OR to measures with more than one set of specifications/instructions (e.g., one set of specifications for how to identify and compute the measure from medical record abstraction and a different set of specifications for claims or eCQMs). It does not apply to measures that use more than one source of data in one set of specifications/instructions (e.g., claims data to identify the denominator and medical record abstraction for the numerator). Comparability is not required when comparing performance scores with and without social risk factors in the risk adjustment model. However, if comparability is not demonstrated for measures with more than one set of specifications/instructions, the different specifications (e.g., for medical records vs. claims) should be submitted as separate measures.

2b.11. Indicate whether there is more than one set of specifications for this measure.

[Response Begins]
No, there is only one set of specifications for this measure
[Response Ends]

2b.12. Describe the method of testing conducted to compare performance scores for the same entities across the different data sources/specifications.

Describe the steps—do not just name a method. Indicate what statistical analysis was used.

[Response Begins]
[Response Ends]

2b.13. Provide the statistical results from testing comparability of performance scores for the same entities when using different data sources/specifications.

Examples may include correlation, and/or rank order.

[Response Begins]
[Response Ends]

2b.14. Provide your interpretation of the results in terms of the differences in performance measure scores for the same entities across the different data sources/specifications.

In other words, what do the results mean and what are the norms for the test conducted.

[Response Begins]
[Response Ends]

2b.15. Indicate whether the measure uses exclusions.

[Response Begins]
Yes, the measure uses exclusions.
[Response Ends]

2b.16. Describe the method of testing exclusions and what was tested.

Describe the steps—do not just name a method; what was tested, e.g., whether exclusions affect overall performance scores; what statistical analysis was used?

[Response Begins]

We considered five exclusions from the proposed denominator of all adult patients with an ambulatory palliative care visit:

1. Patients who did not respond or responded "No" to either having pain (n=413 out of 2,804) or wanting help for that pain (n=465 out of 2,391).
2. Patients who did not complete the patient experience survey within six months of the eligible ambulatory palliative care visit (n=3,356).
3. 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; n=146).
4. Patients who were deceased when the survey reached them (n=748).
5. Patients for whom a proxy completed the entire survey on their behalf for any reason (no patient involvement; n=435).

Patients who did not respond or responded "No" to the two gateway data elements, who did not return the survey at all, those who disavowed the program, or those who died before the survey could be completed, were necessary exclusions because no survey data for the quality measure would be available. We further excluded the small number of patients who did not return the survey within the 6-month timeframe because of concerns regarding recall bias and due to their likely minimal impact (n=61 out of 3,356 nonrespondents, or 1.8%). Although we could not analyze the impact on measure outcomes of excluding these groups because of the absence of survey data, we did compare respondent and nonrespondent (n=3,356) characteristics.

Our exclusion analysis primarily focused on exploring the impact of proxy-involved survey data. Existing CAHPS surveys (e.g., Medicare CAHPS, Prescription Drug Plan CAHPS) use proxy response as a case-mix adjustment variable; despite evidence that proxy response contributes only weakly to differences in measure scores it is retained to alleviate ongoing concerns about the potential for impact. Respondents were categorized into three distinct groups based on proxy assistance as follows: respondent only (no proxy assistance at all), proxy assisted (proxy helped patient complete the survey but patient supplied answers e.g., proxy read questions and wrote down answers), proxy only (proxy answered all questions and patient was not involved) (CMS, 2020; National Cancer Institute, 2021). We compared descriptive statistics for the measure components for each of these three groups to inform the impact of proxy assistance and to determine whether to include/exclude proxy responses.

Citations:

Centers for Medicare & Medicaid Services. (2020). *Medicare Advantage and Prescription Drug Plan CAHPS® Survey: Quality Assurance Protocols & Technical Specifications V11.0*.

National Cancer Institute. (2021). *Case Mix Adjustment Guidance*. Retrieved May 20, 2021, from https://healthcaredelivery.cancer.gov/seer-cahps/researchers/adjustment_guidance.html

[Response Ends]

2b.17. Provide the statistical results from testing exclusions.

Include overall number and percentage of individuals excluded, frequency distribution of exclusions across measured entities, and impact on performance measure scores.

[Response Begins]
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). 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). As age and race may differentially impact patient experiences of care, future work to improve response rates among specific demographic groups, such that measure performance may more robustly reflect the experiences of all patients, is important, though out of scope of the current testing effort.

Among patients who had pain and wanted help for pain, a total of 1,783 completed surveys by patients without proxy assistance, 151 completed by patients with proxy assistance, and 255 completed by proxies alone with no patient involvement. Table 8 shows the mean (SD) *Receiving Desired Help for Pain* measure score according to these three groups.

Table 8. Mean Receiving Desired Help for Pain measure score according to proxy group

Group	N	Mean (SD)
Patient only	1783	0.79 (0.41)
Proxy assisted	151	0.83 (0.37)
Proxy only	255	0.79 (0.41)

A one-way ANOVA test for differences among these three means was not significant ($F_{(2,\ 2186)}$=0.80, *p*=0.45), and follow-up pairwise mean comparisons also revealed no difference between patient only and proxy only ($t_{(331)}$=-0.03, *p*=0.98), between proxy assisted and patient only ($t_{(182)}$=-1.35, *p*=0.18), or between proxy assisted and proxy only ($t_{(337)}$=-1.07, *p*=0.29).

[Response Ends]

2b.18. Provide your interpretation of the results, in terms of demonstrating that exclusions are needed to prevent unfair distortion of performance results.

In other words, the value outweighs the burden of increased data collection and analysis. Note: If patient preference is an exclusion, the measure must be specified so that the effect on the performance score is transparent, e.g., scores with and without exclusion.

[Response Begins]
Despite the lack of a significant difference in *Receiving Desired Help for Pain* measure score means among groups, after discussing these results with our advisory board, we decided to exclude surveys that were completed solely by a proxy with no patient involvement for conceptual reasons. As a patient-reported measure of palliative care experience, we wanted to ensure that at least some direct patient report was reflected in the measure response, a rationale for excluding proxy-only responses that was endorsed by the advisory board. Further, 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. This allowed us to retain as much patient-reported data as possible, while acknowledging that patients in this population will likely need some assistance with survey completion.
[Response Ends]

2b.19. Check all methods used to address risk factors.

[Response Begins]
Statistical risk model with risk factors (specify number of risk factors)
2 risk factors.
[Response Ends]

2b.20. If using statistical risk models, provide detailed risk model specifications, including the risk model method, risk factors, risk factor data sources, coefficients, equations, codes with descriptors, and definitions.

[Response Begins]
The measure is risk adjusted for 1) survey mode and 2) an indicator of proxy assistance. To estimate risk-adjusted quality measure scores, we utilize hierarchical generalized-linear models that relate the proportion of top-box patient-level outcome responses to provider scores (conditioned on risk adjustment covariates). The hierarchy of data is patient observations within the designated accountable health care entity, i.e., programs. The model is calculated at all baseline covariate values of the model (i.e., with risk adjustment indicators set to 0).
[Response Ends]

2b.21. If an outcome or resource use measure is not risk-adjusted or stratified, provide rationale and analyses to demonstrate that controlling for differences in patient characteristics (i.e., case mix) is not needed to achieve fair comparisons across measured entities.

[Response Begins]
N/A
[Response Ends]

2b.22. Select all applicable resources and methods used to develop the conceptual model of how social risk impacts this outcome.

[Response Begins]
Published literature
Internal data analysis
[Response Ends]

2b.23. Describe the conceptual and statistical methods and criteria used to test and select patient-level risk factors (e.g., clinical factors, social risk factors) used in the statistical risk model or for stratification by risk.

Please be sure to address the following: potential factors identified in the literature and/or expert panel; regression analysis; statistical significance of p<0.10 or other statistical tests; correlation of x or higher. Patient factors should be present at the start of care, if applicable. Also discuss any "ordering" of risk factor inclusion; note whether social risk factors are added after all clinical factors. Discuss any considerations regarding data sources (e.g., availability, specificity).

[Response Begins]
As suggested by our technical expert clinical user and patient panel (TECUPP) and project advisory group, we sought to develop a measure that reflects the quality of care. We considered that adjustment of the measure calculation might be appropriate to account for differences in performance due to extrinsic factors beyond the control of the palliative care program or provider. Relevant factors are those that systematically differ across programs and also are related to the measure score. To identify the latter, we conducted a broader literature review of palliative and serious illness care assessments to identify patient, provider, and practice factors that could impact a patient's experiences of *Receiving Desired Help for Pain*. We examined the following factors:

- ***Patient age, education, financial, physical, and mental health:*** Research suggests that age, education, and self-reported health can be related to reports about care and/or response tendencies (Elliott et al., 2001; Elliott et al., 2009; Ingersoll et al., 2018; Zaslavsky et al., 2001). For example, Ingersoll et. al. found that among individuals hospitalized with metastatic cancer, older age, financial security, and low emotional distress were some of the factors associated with feeling completely heard and understood prior to palliative care consultation (Ingersoll et al., 2018). Studies using CAHPS Hospice Survey data show that respondents with lower education, older age, and better self-reported mental health tended to report higher patient experience ratings (Anhang Price et al., 2014). For pain specifically, patient age, sex, comorbid anxiety/depression, and health insurance have been found to impact unmet needs including pain management (John et al., 2014).
- ***Patient race and ethnicity:*** Disease-specific studies (e.g., advanced cancer) have demonstrated that racial and ethnic minorities are more likely to report an unmet need for pain management even after controlling for social-demographic factors and patient-rated physician communication quality (Anderson et al., 2009; Dy et al., 2016; John et al., 2014; Lee et al., 2019; Stephenson et al., 2009).
- ***Proxy response:*** Prior CAHPS survey research has demonstrated that proxy respondents tend to give lower ratings than non-proxy respondents (O'Malley et al., 2005).

Based on our literature review and guided by TECUPP and project advisory group feedback, we selected a set of potential risk factors, shown below, to be evaluated in our final models. Data were selected from three sources: patient information provided by programs in their submitted data files, responses from completed surveys (e.g., proxy respondent characteristics), and Census data matched to the ZIP code of patient residence. Variables were assessed for inclusion in a risk model using statistical testing to determine whether each variable was associated with the measure and whether it differed substantially across programs at the a=0.05 level of significance. Binary or categorical variables were tested for association with the *Receiving Desired Help for Pain* measure using Fisher's exact test. Fisher's exact test was also used to assess the association of these variables by program to determine whether the variable differed substantially across programs. For continuous variables, a Z-test from a generalized linear model was used to test for an association with the *Receiving Desired Help for Pain* measure, and an analysis of variance (ANOVA) F-test was used to test for differences between programs. P values were adjusted using the Benjamini-Hochberg correction for multiple comparisons to control the false discovery rate (Benjamini & Hochberg, 1995).

Potential risk adjusters:

Survey data or program information

- Patient education
- Patient Hispanic
- Patient language
- Patient race
- Proxy level
- Survey mode

Program data

- Patient age
- Patient female

Census data

- Female residents (%)
- Marriage status (% of residents age 15+)
- Disabled residents (%)
- Labor force participation (% of residents age 16+)
- Employed residents (% of residents age 16+)
- Unemployed residents (% of residents age 16+)
- Median household income ($)
- Families below the poverty line (%)
- Urban residents (%)
- Owner-occupied housing units (%)
- Residents with health insurance (%)
- Private health insurance only (% of non-institutionalized residents)
- Public health insurance only (% of non-institutionalized residents)
- Race = American Indian or Alaska Native (%)
- Race = Asian (%)
- Race = Black (%)
- Race = White (%)
- Ethnicity = Hispanic (%)

We also considered the potential for patient diagnoses to vary across programs and impact measure scores. In the development of the Hospice CAHPS measures, investigators found that primary diagnosis varied across hospice programs and were significantly and strongly associated with assessments of experience and were thus included as a case-mix adjustment variable (Parast et al., 2018). Although the target respondent population and setting were different than ours (bereaved caregiver vs. patient; hospice vs. ambulatory palliative care), both the Hospice CAHPS measures and our proposed measure seek to assess the patient's experience of palliative care. However, we were severely constrained in our ability to explore potential risk adjustment by diagnosis because of the inadequacy of diagnosis data we received from programs in their submitted files:

- Not all programs consistently provided diagnostic information across the 10 rounds of fielding;
- Programs that did provide any data typically did not clarify primary, secondary, or other diagnosis, but instead provided multiple diagnoses per patient;
- We received different types of diagnostic information in submitted data files, both within programs and across programs, including ICD-10 codes, CPT codes, problem codes, reasons for visit codes, and program- or software-specific codes, and sometimes free text.

Instead, we undertook an exploratory descriptive analysis to identify any signals that measure performance might vary by diagnosis and thus that future work should assess the role of diagnosis as a risk-adjustment variable.

Using our full survey respondent sample of 2,804, we assigned primary diagnoses in a two-step process: 1) where primary diagnosis was indicated in the program file, we used that; and 2) if primary diagnosis was not indicated but usable diagnosis data was provided, we assigned primary diagnosis by applying a condition hierarchy based on prevalence in our sample, prior research (Keating et al., 2016; Wachterman et al., 2016; Wennberg et al., 2004), and our research team physicians' expert opinion:

1. cancer (both solid and liquid);
2. non-neurologic end-organ disease (e.g. heart failure, end-stage liver disease, renal failure, chronic obstructive pulmonary disease);
3. dementia (e.g. Alzheimer's, vascular, and others);
4. movement disorders (e.g. stroke, Parkinson's, multiple sclerosis, ALS); and
5. other diagnosis (e.g. fibromyalgia, sequelae of diabetes, AIDS, symptom only diagnoses such as dyspnea)

All other data was categorized as missing (e.g., non-interpretable diagnostic information). A physician then reviewed these group to ensure clinical accuracy. See Table 9 for counts of each assigned diagnosis group.

Table 9. Diagnosis Groupings

Diagnosis grouping	**Count**	**Percentage** (numbers do not add to 100 due to rounding)
Cancer (solid and liquid)	1685	60%
End-organ disease (non-neurological)	225	8
Dementia	14	0.5
Movement disorders (e.g. Parkinson's, multiple sclerosis)	29	1
Other	561	20
Missing	290	10
Total = 2804	*	*

* Indicates the table cell is empty

Because of the low numbers of respondents with assigned primary diagnosis of dementia or movement disorders, we focused on comparing differences between the cancer, end-organ disease, and other diagnosis groups for our analysis (i.e., ignoring the dementia, movement disorders, and missing groups). For the single *Receiving Desired Help for Pain* data element, we performed a chi-squared test for independence between the data element and the assigned diagnosis. We conducted an ANOVA F-test for *Receiving Desired Help for Pain* (% of top-box response) by diagnosis group.

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Anderson, K. O., Green, C. R., & Payne, R. (2009). Racial and ethnic disparities in pain: causes and consequences of unequal care. *J Pain*, *10*(12), 1187-1204.

Anhang Price, R., Elliott, M. N., Zaslavsky, A. M., Hays, R. D., Lehrman, W. G., Rybowski, L., Edgman-Levitan, S., & Cleary, P. D. (2014). Examining the role of patient experience surveys in measuring health care quality. *Medical care research and review : MCRR*, *71*(5), 522-554.

Benjamini, Y., & Hochberg, Y. (1995). Controlling the False Discovery Rate: A Practical and Powerful Approach to Multiple Testing. *Journal of the Royal Statistical Society. Series B (Methodological)*, *57*(1), 289-300.

Dy, S. M., Herr, K., Bernacki, R. E., Kamal, A. H., Walling, A. M., Ersek, M., & Norton, S. A. (2016). Methodological research priorities in palliative care and hospice quality measurement. *Journal of pain and symptom management*, *51*(2), 155-162.

Elliott, M. N., Swartz, R., Adams, J., Spritzer, K. L., & Hays, R. D. (2001). Case-mix adjustment of the National CAHPS benchmarking data 1.0: a violation of model assumptions? *Health services research*, *36*(3), 555-573.

Elliott, M. N., Zaslavsky, A. M., Goldstein, E., Lehrman, W., Hambarsoomians, K., Beckett, M. K., & Giordano, L. (2009). Effects of survey mode, patient mix, and nonresponse on CAHPS hospital survey scores. *Health services research*, *44*(2 Pt 1), 501-518.

Ingersoll, L. T., Saeed, F., Ladwig, S., Norton, S. A., Anderson, W., Alexander, S. C., & Gramling, R. (2018). Feeling Heard & Understood in the Hospital Environment: Benchmarking Communication Quality Among Patients with Advanced Cancer Before and After Palliative Care Consultation. *J Pain Symptom Manage*, *56*(2), 239-244.

John, D. A., Kawachi, I., Lathan, C. S., & Ayanian, J. Z. (2014). Disparities in perceived unmet need for supportive services among patients with lung cancer in the Cancer Care Outcomes Research and Surveillance Consortium. *Cancer*, *120*(20), 3178-3191.

Keating, N. L., Landrum, M. B., Huskamp, H. A., Kouri, E. M., Prigerson, H. G., Schrag, D., Maciejewski, P. K., Hornbrook, M. C., & Haggstrom, D. A. (2016). Dartmouth Atlas Area-Level Estimates of End-of-Life Expenditures: How Well Do They Reflect Expenditures for Prospectively Identified Advanced Lung Cancer Patients? *Health services research*, *51*(4), 1584-1594.

Lee, P., Le Saux, M., Siegel, R., Goyal, M., Chen, C., Ma, Y., & Meltzer, A. C. (2019). Racial and ethnic disparities in the management of acute pain in US emergency departments: Meta-analysis and systematic review. *Am J Emerg Med*, *37*(9), 1770-1777.

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.

Parast, L., Haas, A., Tolpadi, A., Elliott, M. N., Teno, J., Zaslavsky, A. M., & Price, R. A. (2018). Effects of Caregiver and Decedent Characteristics on CAHPS Hospice Survey Scores. *Journal of pain and symptom management*, *56*(4), 519-529.e511.

Stephenson, N., Dalton, J. A., Carlson, J., Youngblood, R., & Bailey, D. (2009). Racial and ethnic disparities in cancer pain management. *J Natl Black Nurses Assoc*, *20*(1), 11-18.

Wachterman, M. W., Pilver, C., Smith, D., Ersek, M., Lipsitz, S. R., & Keating, N. L. (2016). Quality of End-of-Life Care Provided to Patients With Different Serious Illnesses. *JAMA Intern Med*, *176*(8), 1095-1102.

Wennberg, J. E., Fisher, E. S., Stukel, T. A., Skinner, J. S., Sharp, S. M., & Bronner, K. K. (2004). Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States. *BMJ (Clinical research ed.)*, *328*(7440), 607.

Zaslavsky, A. M., Zaborski, L. B., Ding, L., Shaul, J. A., Cioffi, M. J., & Cleary, P. D. (2001). Adjusting Performance Measures to Ensure Equitable Plan Comparisons. *Health care financing review*, *22*(3), 109-126.

[Response Ends]

2b.24. Detail the statistical results of the analyses used to test and select risk factors for inclusion in or exclusion from the risk model/stratification.

[Response Begins]
Table 10 below shows the test statistics for the association of potential risk factors with measure scores and with programs. None of the potential risk adjustment variables were significant in their relationship with the measure after adjustment for multiple comparisons. While no variables are statistically associated with the data element related to the measure score, our TECUPP emphasized the importance of considering inclusion of some variables, such as survey mode and proxy assistance, to increase the face validity of our modeling.

Table 10. Association of Potential Risk Factors with Receiving Desired Help for Pain Outcome Score and Program

Survey Data	**Association with Outcome**	**Association with Program**	*	*	*	*	*	*	*
Potential Risk Adjuster	Effect Size	Test	Statistic	p-value	Adjusted p-value	Test	Statistic	p-value	Adjusted p-value
Survey data	*	*	*	*	*	*	*	*	*
Proxy Assistance	NA	Fisher	NA	0.290	0.721	Fisher	NA	0.695	0.695
Patient Hispanic	NA	Fisher	NA	0.297	0.721	Fisher	NA	0.000	0.001
Patient Language	NA	Fisher	NA	0.387	0.775	Fisher	NA	0.002	0.003
Survey Mode	NA	Fisher	NA	0.488	0.793	Fisher	NA	0.000	0.001

Survey Data	**Association with Outcome**	**Association with Program**	*	*	*	*	*	*	*
Patient Race	NA	Fisher	NA	0.759	0.822	Fisher	NA	0.000	0.001
Patient Education	NA	Fisher	NA	0.902	0.938	Fisher	NA	0.000	0.001
Program data	*	*	*	*	*	*	*	*	*
Patient Age	0.002	Z	0.352	0.725	0.822	F	6.78	0.000	0.000
Patient Female	NA	Fisher	NA	0.733	0.822	Fisher	NA	0.051	0.054
Census data	*	*	*	*	*	*	*	*	*
Owner occupied housing unit	0.009	Z	2.285	0.022	0.580	F	6.437	0.000	0.000
Female	0.048	Z	1.902	0.057	0.721	F	4.591	0.000	0.000
Employed	-0.010	Z	-1.512	0.130	0.721	F	19.242	0.000	0.000
Labor force participation	-0.009	Z	-1.389	0.165	0.721	F	17.231	0.000	0.000
Urban population	0.002	Z	1.320	0.187	0.721	F	9.109	0.000	0.000
Race Hispanics	0.005	Z	1.294	0.196	0.721	F	71.635	0.000	0.000
Health insurance public only	-0.008	Z	-1.195	0.232	0.721	F	20.076	0.000	0.000
Married	0.006	Z	1.131	0.258	0.721	F	7.378	0.000	0.000
Race AIAN	-0.015	Z	-0.999	0.318	0.721	F	3.674	0.000	0.000
Health insurance insured	-0.012	Z	-0.969	0.333	0.721	F	21.273	0.000	0.000
Unemployed	0.015	Z	0.718	0.473	0.793	F	21.4	0.000	0.000
Disabled	-0.009	Z	-0.715	0.475	0.793	F	12.87	0.000	0.000
Family below poverty line	-0.005	Z	-0.631	0.528	0.808	F	12.19	0.000	0.000
Median household income	0.000	Z	0.506	0.613	0.822	F	17.682	0.000	0.000
Race Black	0.002	Z	0.494	0.622	0.822	F	23.627	0.000	0.000
Race Asian	-0.006	Z	-0.364	0.716	0.822	F	20.859	0.000	0.000
Race White	-0.001	Z	-0.359	0.719	0.822	F	21.027	0.000	0.000
Health insurance private only	0.000	Z	0.038	0.970	0.970	F	15.454	0.000	0.000

* Indicates the table cell is empty

The *Receiving Desired Help for Pain* data element was significantly associated with diagnosis group (p<0.01). The quality measure score was also significantly associated with diagnosis group (Table 11). These results held after multiple comparison adjustment. Due to challenges with data quality, we were unable to conduct further analyses within the scope of this effort, but this finding provides preliminary indication that diagnosis may impact responses to the data element and overall measure performance, underscoring the importance of further research in this area.

Table 11. Mean Score by Diagnosis Grouping

Diagnosis grouping	Mean	N
Cancer (solid and liquid)	.815	1268
End-organ disease (non-neurological)	.683	104
Other	.790	390
Chi-squared test p-value: p < 0.01	*	*

* Indicates the table cell is empty

[Response Ends]

2b.25. Describe the analyses and interpretation resulting in the decision to select or not select social risk factors.

Examples may include prevalence of the factor across measured entities, availability of the data source, empirical association with the outcome, contribution of unique variation in the outcome, or assessment of between-unit effects and within-unit effects. Also describe the impact of adjusting for risk (or making no adjustment) on providers at high or low extremes of risk.

[Response Begins]
The selection of the variables to be collected for consideration in the statistical risk model was informed by statistical results presented in section 2b.24 (Table 10) on the potential risk factors. Based on these results and input from our project advisory group and TECUPP, we determined it was not appropriate to adjust this measure for social risk factors.
[Response Ends]

2b.26. Describe the method of testing/analysis used to develop and validate the adequacy of the statistical model or stratification approach (describe the steps—do not just name a method; what statistical analysis was used). Provide the statistical results from testing the approach to control for differences in patient characteristics (i.e., case mix) below. If stratified ONLY, enter "N/A" for questions about the statistical risk model discrimination and calibration statistics.

Validation testing should be conducted in a data set that is separate from the one used to develop the model.

[Response Begins]
We used Kendall's tau to assess the unadjusted and adjusted scores and explore how rankings among providers change after risk-adjustment. We also used statistical tests to assess the significance of covariates in the risk adjusted model and discussed results on what variables to include with our technical expert panel.

Tests using Kendall's tau look at comparing the rank order of unadjusted scores to the order of risk-adjusted scores and assessing the proportion of cases where the order has changed. A statistic of 1 would imply that risk-adjustment has no effect on the rank order of programs and a statistic of -1 would imply that the order is completely reversed by risk adjustment (Parast et al., 2018). Values of 0.8 to. 0.95 are typical of those reported in NQF documentation for the CAHPS surveys.

Description	Result
Kendall's τ Test Statistic	0.79
Proportion Where Rank Order Changed = ($1 - \tau)/2$ %	10.5%

We also discussed results from the risk adjustment and exclusion analyses with our project advisory group to assess the adequacy of the statistical model and arrived at a final model that contained two risk adjusters (despite a lack of statistical significance, these variables increase face validity of adjustment procedures): 1) survey mode, and 2) an indicator of proxy assistance. Table 12 below provides a summary of regression coefficients of the fixed effects of the adjustment model (i.e., ignoring the

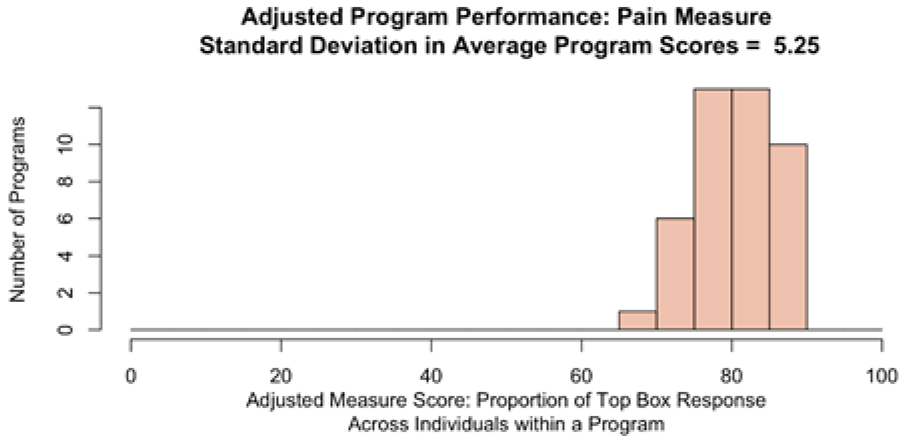
b_i
terms).

Table 12. Summary of Regression Coefficients of Adjustment Model Fixed Effects

Parameter	Estimate	Error	Lower 95%	Upper 95%
Intercept - β_0	1.44	0.14	1.17	1.71
Survey Mode – Phone	-0.10	0.13	-0.35	0.16
Survey Mode – Web	0.02	0.17	-0.33	0.36
Proxy Status – Assisted	0.26	0.24	-0.20	0.73

The model above can be used to assess the distribution for the estimated (i.e. adjusted) program scores shown in Figure 7. The adjustments result in reduced variability (SD=5.25) in program performance of adjusted average program scores. However, the measure still demonstrates variability across programs.

Figure 7. Adjusted Program Performance



Citations:
Parast, L., Haas, A., Tolpadi, A., Elliott, M. N., Teno, J., Zaslavsky, A. M., & Price, R. A. (2018). Effects of Caregiver and Decedent Characteristics on CAHPS Hospice Survey Scores. *Journal of pain and symptom management*, *56*(4), 519-529.e511.

[Response Ends]

2b.27. Provide risk model discrimination statistics.

For example, provide c-statistics or R-squared values.

[Response Begins]
N/A
[Response Ends]

2b.28. Provide the statistical risk model calibration statistics (e.g., Hosmer-Lemeshow statistic).

[Response Begins]
N/A
[Response Ends]

2b.29. Provide the risk decile plots or calibration curves used in calibrating the statistical risk model.

The preferred file format is .png, but most image formats are acceptable.

[Response Begins]
N/A
[Response Ends]

2b.30. Provide the results of the risk stratification analysis.

[Response Begins]
N/A
[Response Ends]

2b.31. Provide your interpretation of the results, in terms of demonstrating adequacy of controlling for differences in patient characteristics (i.e., case mix).

In other words, what do the results mean and what are the norms for the test conducted?

[Response Begins]
We incorporate risk adjustment variables into our models to provide fair comparisons among programs and to provide a best effort to ensure that the observed differences from programs are truly from differences in performance and not due to baseline differences in risk variables (including survey mode) that represent the programs. We also retained proxy response as a case-mix adjustment variable, consistent with existing CAHPS surveys (e.g., Medicare CAHPS, Prescription Drug Plan CAHPS), to alleviate ongoing concerns about the potential for impact.

Based on input from our project advisory group and TECUPP, we determined it was not appropriate to adjust this measure for social risk factors (e.g., race/ethnicity, urbanicity, median household income, gender, marital status, public insurance use, unemployment, and families below poverty line). After adjustment for multiple comparisons, none of these variables were significant in their relationship with the measure.

We did not have clinical data to evaluate risk adjustment for disease type or severity/acuity and note this as an important area for future research. Exploratory descriptive analyses based on a rough grouping of diagnostic categories showed the *Receiving Desired Help for Pain* raw measure score was significantly associated with diagnosis group, i.e., patients with end-organ disease such as heart failure and kidney disease had slightly lower scores than patients with any cancer and those in the “other” category. Due to challenges with data quality, we were unable to conduct further analyses within the scope of this effort, but these findings provide preliminary indication that diagnosis may impact responses to the measure data elements and overall measure performance, underscoring the importance of further research in this area. However, we hypothesize that any differences in measure performance based on disease type (e.g., cancer versus heart failure) may be a proxy for other variables such as where a patient was receiving care. We also hypothesize that any differences in the measure based on disease severity/acuity are likely due to differences in care processes that should and could be targeted for quality improvement and therefore from a conceptual standpoint, would not be a good candidate for inclusion in risk adjustment models.
[Response Ends]

2b.32. Describe any additional testing conducted to justify the risk adjustment approach used in specifying the measure.

Not required but would provide additional support of adequacy of the risk model, e.g., testing of risk model in another data set; sensitivity analysis for missing data; other methods that were assessed.

[Response Begins]
N/A
[Response Ends]

3. Feasibility

Extent to which the specifications including measure logic, require data that are readily available or could be captured without undue burden and can be implemented for performance measurement.

3.01. Check all methods below that are used to generate the data elements needed to compute the measure score.

[Response Begins]
Other (Please describe)
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.
[Response Ends]

3.02. Detail to what extent the specified data elements are available electronically in defined fields.

In other words, indicate whether data elements that are needed to compute the performance measure score are in defined, computer-readable fields.
[Response Begins]
Patient/family reported information (may be electronic or paper)
[Response Ends]

3.03. If ALL the data elements needed to compute the performance measure score are not from electronic sources, specify a credible, near-term path to electronic capture, OR provide a rationale for using data elements not from electronic sources.

[Response Begins]
Rationale for using other than electronic sources: This is a patient-reported measures of experience that is not currently collected in structured electronic fields or EMR-based clinical data fields. Future work should explore options for embedding these measures in the EMR. These data should optimally be collected post-visit, away from the point of care, via survey. Findings from the alpha pilot test and beta field test indicate the feasibility of identifying eligible patients using administrative data and using a survey vendor to support survey administration and data collection. Interviews with programs who participated in the alpha pilot test and beta field test also support the perceived feasibility of the measures in clinical practice across providers and administrators.
[Response Ends]

3.04. Describe any efforts to develop an eCQM.

[Response Begins]
This is not an eMeasure.
[Response Ends]

3.06. Describe difficulties (as a result of testing and/or operational use of the measure) regarding data collection, availability of data, missing data, timing and frequency of data collection, sampling, patient confidentiality, time and cost of data collection, other feasibility/implementation issues.

[Response Begins]

Information for the measure calculation is collected via a survey data collection instrument, which will be provided to CMS, to be made available to CMS-approved survey vendors and palliative care programs. Palliative care programs will contract with a survey vendor to administer the survey to eligible patients. 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.

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. Interviews with programs that participated in the alpha pilot test and beta field test support the perceived feasibility of the measure in clinical practice across providers and administrators. The survey response rate (37% raw response rate; 46% response rate excluding ineligible patients) achieved during the beta field test also supports ease of use for patients responding to the survey.

The majority of respondents to the 2021 public comment period supported feasibility of the proposed measures. When asked “How feasible would it be to implement these measures (e.g., contracting with a survey vendor, identifying eligible patients through administrative or medical record data, submitting scores to CMS, etc.)?” 21.8% of respondents said “very feasible” and 42.7% said “somewhat feasible.” The majority of comments indicated support for feasibility of the proposed measure, although some commenters raised concerns about the cost of hiring a survey vendor and implementation burden (e.g., staffing and support limitations).
[Response Ends]

Consider implications for both individuals providing data (patients, service recipients, respondents) and those whose performance is being measured.

3.07. Detail any fees, licensing, or other requirements to use any aspect of the measure as specified (e.g., value/code set, risk model, programming code, algorithm),

Attach the fee schedule here, if applicable.

[Response Begins]
No fees or licensing requirements will be necessary for users to implement the proposed measure. However, implementation costs include the cost of hiring an authorized survey vendor to field surveys and process data.
[Response Ends]

4. Usability and Use

Extent to which potential audiences (e.g., consumers, purchasers, providers, policy makers) are using or could use performance results for both accountability and performance improvement to achieve the goal of high-quality, efficient healthcare for individuals or populations.

Extent to which intended audiences (e.g., consumers, purchasers, providers, policy makers) can understand the results of the measure and are likely to find them useful for decision making.

NQF-endorsed measures are expected to be used in at least one accountability application within 3 years and publicly reported within 6 years of initial endorsement, in addition to demonstrating performance improvement.

4a.01.

Check all current uses. For each current use checked, please provide:

Name of program and sponsor

URL

Purpose

Geographic area and number and percentage of accountable entities and patients included

Level of measurement and setting

[Response Begins]
Not in use
Newly developed measure
[Response Ends]

4a.02. Check all planned uses.

[Response Begins]
Payment Program
[Response Ends]

4a.03. If not currently publicly reported OR used in at least one other accountability application (e.g., payment program, certification, licensing), explain why the measure is not in use.

For example, do policies or actions of the developer/steward or accountable entities restrict access to performance results or block implementation?

[Response Begins]
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 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. AAHPM has partnered with the National Coalition for Hospice and Palliative Care and RAND Health Care to develop the proposed measures for use in CMS's Quality Payment Program.

[Response Ends]

4a.04. If not currently publicly reported OR used in at least one other accountability application, provide a credible plan for implementation within the expected timeframes: used in any accountability application within 3 years, and publicly reported within 6 years of initial endorsement.

A credible plan includes the specific program, purpose, intended audience, and timeline for implementing the measure within the specified timeframes. A plan for accountability applications addresses mechanisms for data aggregation and reporting.

[Response Begins]
The goal of this project is to produce quality measures that can be used by providers eligible for CMS' Merit-Based Incentive Payment System (MIPS) who provide palliative care services to their patients, so that the patient experience of core components of high-quality palliative care can be attributed to their providers and used to incentivize quality improvement. Medicare providers now choose one of two payment tracks – alternative payment models (APMs) and MIPS – which offer different combinations of incentives and requirements to encourage high-quality, low-cost care. Although MIPS applies to all Medicare patients, with no limit or focus on patients with serious illness, a strong portfolio of MIPS quality measures helps ensure measurement is meaningful and relevant to providers and their patients. The two palliative care measures were submitted to the 2021 MUC list for inclusion into CMS' Quality Payment Programs, including MIPS and APMs, and will be reviewed by the MAP in December 2021.
[Response Ends]

4a.05. Describe how performance results, data, and assistance with interpretation have been provided to those being measured or other users during development or implementation.

Detail how many and which types of measured entities and/or others were included. If only a sample of measured entities were included, describe the full population and how the sample was selected.

[Response Begins]
Performance data from our test has been provided to all participating programs (i.e., those who were being measured) as well as key stakeholder groups, e.g., the technical expert clinical user and patient panel (TECUPP) and project advisory panel.

For the testing sample, we identified approximately 360 palliative care programs in the United States that reported providing ambulatory palliative care to the Mapping Community Palliative Care Project and The National Palliative Care Registry. An additional 35 programs were added to the recruitment list because they submitted a project interest form via email, or attended an informational webinar hosted by the National Coalition for Hospice and Palliative Care (NCHPC) in June 2019. We sought national representation by oversampling larger programs (i.e., those with more patients) and stratifying recruitment efforts by administrative home type (i.e., hospice, hospital, ambulatory, and other administration) and by geographic location to ensure representation across U.S. Census Regions. A detailed description of the program sample is included in section 2a.05.

Five ambulatory palliative care programs participated in the alpha pilot test. Programs were included in the alpha pilot test based on their ability to sign-up and complete the required participation agreement processes in time for the start of the test. We included only five programs because our goal was primarily to evaluate and refine our fielding procedures in advance of the beta field test, and to identify any critically important changes to the data collection parameters and processes. At the end of the alpha pilot test, each program was provided a summary of their own data, including frequency and percent of responses to each survey item, including the items proposed to comprise the *Receiving Desired Help for Pain* measure. We connected each program with a contact from the project for assistance with interpretation. Because this was a pilot test, the conclusions that can be drawn from the data were limited but did offer each program a preliminary assessment of their patients' experience with the program.

A total of 44 programs ever participated in the beta field test, defined as providing at least one sample file during the test

(see description of programs in section 2a.05). All programs that participated in the beta field test will also receive a summary report describing their performance on each survey item as well as their performance on the *Receiving Desired Help for Pain* measure. Based on feedback from alpha pilot test programs, the summary reports were refined to better suit the needs of programs that participated in the beta field test.
[Response Ends]

4a.06. Describe the process for providing measure results, including when/how often results were provided, what data were provided, what educational/explanatory efforts were made, etc.

[Response Begins]
Reports of performance data from testing were provided to all participating alpha palliative care programs (n=5) and all beta programs (n=44 programs). For the alpha programs, data from patient experience surveys was aggregated by program and sent only to that program via emailed report. Data were sent once, upon the completion of the test. Each report provided a summary of frequency and percent of responses to each survey item along with brief narrative descriptions of the results.

All programs that participated in the beta field test have also received a summary report describing their performance on each survey item as well as their performance on the *Receiving Desired Help for Pain* measure. For the beta field test, we provided comparative data so each program could understand their performance against the performance of comparable programs. Data were sent once, upon the completion of the test.
[Response Ends]

4a.07. Summarize the feedback on measure performance and implementation from the measured entities and others. Describe how feedback was obtained.

[Response Begins]
AAHPM conducted interviews with 25 palliative care programs that participated in the alpha pilot test and beta field test to better understand potential implementation challenges, resource requirements for measure implementation, how the proposed measure may be used to facilitate quality improvement, and the perceived financial and administrative burden of measure implementation and associated quality improvement activities. Because of the different topics discussed, interviews included a palliative care provider and/or a data specialist or program manager. We encouraged the point of contact for each palliative care program (typically a Program Manager or Medical Director) to invite a data specialist or provider to participate with them in the interview depending on their role.

AAHPM also obtained feedback on potential implementation challenges and usefulness of the proposed palliative care measures for quality improvement during the 2021 public comment period. Respondents included patients, family caregivers, and advocates living with serious illness; providers/clinicians caring for those living with serious illness; representatives from national organizations; and other professionals.
[Response Ends]

4a.08. Summarize the feedback obtained from those being measured.

[Response Begins]
Factors Influencing Measure Implementation

In interviews with palliative care providers and administrators, AAHPM inquired about potential challenges related to implementation of the proposed measures. Some providers raised practical issues including “survey fatigue,” especially for patients who are seriously ill, as well as the need for question phrasing to be understandable or “resonate” for a broad range of patient populations, including those with low literacy levels. Providers expressed concern that allowing proxy responses might introduce bias, particularly if family member perceptions were not aligned with patient perceptions (e.g., thinking that pain was undertreated). Palliative care providers also expressed concerns about attribution given that patients see multiple providers. Providers also raised concerns about selection of survey modalities (i.e., email, mail, in-person) that will yield high response rates and thoughtful responses (i.e., after patients have had a chance to think about their experience). In addition, the financial and administrative burden for programs to implement the measure was an important consideration, often dependent on program size, organizational type, and existing resources.

Resources Required for Measure Implementation

In interviews with palliative care providers and administrators, including program managers and data specialists, AAHPM inquired about resources that will be necessary for successful measure implementation and use. Resources required to implement the measure would likely include IT staff hours to extract patient visit data from the electronic health record and the cost of hiring a survey vendor to administer the survey to eligible patients. Most programs had previously worked with a vendor to administer patient surveys. Important factors cited in the decision to invest in support from a survey vendor included cost, sensitivity and tracking issues (i.e., concerns about sending surveys to deceased patients), patient survey fatigue, ability to compare measure performance with other programs, and unstable patient mailing addresses (although, in light of COVID-19, one program noted that they now consistently collect patient emails for telehealth). Finally, another concern for implementation was the cost of quality improvement associated with the measure. Anticipated quality improvement activities related to measure implementation included provider communication training; encouraging providers to establish expectations with patients and set realistic goals; and root cause analysis to identify the sources of patient dissatisfaction, including external factors (i.e., experience in clinic or delays, long wait times to get an appointment).
[Response Ends]

4a.09. Summarize the feedback obtained from other users.

[Response Begins]
In addition to palliative care providers, we sought feedback from administrators, including program managers and data specialists, regarding measure implementation. Please see 4a.08 for details.

Public comment respondents also provided feedback on feasibility of measure implementation. When asked, “How feasible would it be to implement these measures (e.g., contracting with a survey vendor, identifying eligible patients through administrative or medical record data, submitting scores to CMS, etc.)?” 22% of respondents said “very feasible,” 43% said “somewhat feasible,” 8% said “not feasible,” and 27% said “I don’t know.” The majority of comments indicated support for feasibility of the proposed measures. Some respondents raised concerns about implementation burden related to staffing and support limitations, as well as the cost of hiring a survey vendor. See 4b.01 for details of feedback from public comment on usefulness of the proposed measure for performance improvement.
[Response Ends]

4a.10. Describe how the feedback described has been considered when developing or revising the measure specifications or implementation, including whether the measure was modified and why or why not.

[Response Begins]
Findings from palliative care program interviews support the perceived feasibility of the measures in clinical practice across providers and administrators, including the feasibility of data collection via survey vendor. This is the proposed mechanism for measure implementation. The survey response rate (37% raw response rate; 46% response rate excluding ineligible patients) achieved during the beta field test also supports ease of use for patients responding to the survey. To minimize patient burden, the final patient experience survey was reduced to 10 items (see Appendix for survey instrument). To prevent survey fatigue, surveys will be fielded to eligible patients no more often than once per year. Patients who have already completed the patient experience survey in a given 12-month reporting period will be excluded from measurement to avoid response bias due to priming effects and minimize patient burden. To address concerns about possible challenges with attribution given that patients see multiple providers, we referenced a specific provider and team in the patient survey. To address concerns about sending surveys to deceased patients, our recommended data collection approach is to first send eligible patients a letter notifying them of the upcoming survey with a stamped postcard that can be returned in the event of death or a move/new address.

To address potential concerns around bias from proxy responses, measure testing data were used to establish exclusion criteria related to proxy response. Respondents were categorized into three distinct groups based on proxy assistance as follows: respondent only (no proxy assistance at all), proxy assisted (proxy helped patient complete the survey but patient supplied answers e.g., proxy read questions and wrote down answers), proxy only (proxy answered all questions and patient was not involved). We compared descriptive statistics for the measure components for each of these three groups to inform the impact of proxy assistance and to determine whether to include/exclude proxy responses. A one-way ANOVA test for differences among these three means was not significant (F(2, 2186)=0.80, p=0.45), and follow-up pairwise mean comparisons also revealed no difference between patient only and proxy only (t(331)=-0.03, p=0.98), between proxy assisted and patient only (t(182)=-1.35, p=0.18), or between proxy assisted and proxy only (t(337)=-1.07, p=0.29). Despite the lack of a significant difference in *Receiving Desired Help for Pain* measure score means among groups, after discussing these results with our advisory board, we decided to exclude surveys that were completed solely by a proxy with no patient involvement for conceptual reasons. As a patient-reported measure of palliative care experience, we wanted to ensure that at least some direct patient report was reflected in the measure response, a rationale for excluding proxy-only responses that was endorsed by the advisory board. Further, 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. This allowed us to retain as much patient-reported data as possible, while acknowledging that patients in this population will likely need some assistance with survey completion.
[Response Ends]

4b.01. You may refer to data provided in Importance to Measure and Report: Gap in Care/Disparities, but do not repeat here. Discuss any progress on improvement (trends in performance results, number and percentage of people receiving high-quality healthcare; Geographic area and number and percentage of accountable entities and patients included). If no improvement was demonstrated, provide an explanation. If not in use for performance improvement at the time of initial endorsement, provide a credible rationale that describes how the performance results could be used to further the goal of high-quality, efficient healthcare for individuals or populations.

[Response Begins]
The measure is newly developed and not currently in use.

Respondents to the 2021 public comment period were largely supportive of the proposed *Receiving Desired Help for Pain* measure and its usefulness for performance improvement. We received 236 responses to public comment, including responses from patients, family caregivers, and advocates living with serious illness (38%); providers/clinicians caring for those living with serious illness (42%); representatives from national organizations (5%); and other professionals (15%). Overall, 73.2% of respondents agreed that the *Receiving Desired Help for Pain* measure captures important information. When asked “How likely is it that ambulatory (e.g., clinic-based) palliative care providers or programs would choose to report on these measures?” 37.6% of respondents said “very likely” and 40.8% said “somewhat likely.” When asked “How likely are you to use the *Receiving Desired Help for Pain* measure to improve your practice and/or the care you provide?” 47.2% of clinician respondents said “very likely” and 24.0% said “somewhat likely,” demonstrating support from palliative care clinicians for usefulness of the proposed measure for performance improvement.
[Response Ends]

4b.02. Explain any unexpected findings (positive or negative) during implementation of this measure, including unintended impacts on patients.

[Response Begins]
To date, we have not encountered any unintended adverse consequences from measuring the extent to which patients received desired help for pain. However, we have considered possible unintended consequences of the measure. In focus groups and interviews with palliative care providers, patients, caregivers, and family members during both the alpha pilot test and beta field test, several concerns emerged regarding measurement of whether patients received the help they wanted for pain. Although many of these concerns relate to more typical pain measures that focus on reducing symptom severity rather than ensuring that patient needs are met, they could reflect potential unintended consequences of the proposed measure.

The first concern is that providers may be held accountable for a symptom experience over which they may have little impact. Providers noted that patients may have unrealistic expectations about pain control, with some patients wanting to be completely pain free when that might not be feasible for their clinical situation. Some providers voiced concern that truly addressing patient pain is a complex endeavor, and providers may not always be able to meet patient needs.

Another concern related to pain measures was around opioid prescribing. It is possible that a measure focused on pain could incentivize providers to prescribe more opioids, or unfairly penalize them for not prescribing opioids. Many ambulatory palliative care programs have implemented opioid prescribing policies in an attempt to prevent opioid misuse and diversion. As a precaution to avoid unintended consequences related to opioid prescribing, programs should consider implementing opioid prescribing policies as part of this quality measure.

Other concerns included: i) inadequate insurance coverage may limit providers' ability to fully manage pain; ii) comparison across palliative care programs may be challenging because patient populations and needs for pain management vary; and iii) patients may receive pain management from other services in addition to palliative care, so their responses could possibly reflect care received from other providers. Strategies to address some of the stated concerns included implementing protocols for opioid prescribing, encouraging providers to discuss expectations with patients up front, and setting realistic goals for pain management.

Finally, it is possible that patients who have died may be contacted to complete the survey, potentially causing distress for families. Our recommended data collection approach is to first send eligible patients a letter notifying them of the upcoming survey with a stamped postcard that can be returned in the event of death or a move/new address.
[Response Ends]

4b.03. Explain any unexpected benefits realized from implementation of this measure.

[Response Begins]
In qualitative interviews with palliative care programs that participated in the alpha pilot test and beta field test, providers were asked about perceived benefits of the measure. Overall, providers noted that asking patients to report on their experiences of receiving help for their pain would be useful for their program and the field of palliative care: "The goal is to get patient pain under control. If we aren't doing that, we aren't doing our job at all. It is a solid thing to be assessing." Another provider noted that the measure may inform quality improvement efforts to help their program move toward a more comprehensive and multidisciplinary approach to pain management. Continued assessment of measure benefits as well as negative consequences is needed.
[Response Ends]

5. Comparison to Related or Competing Measures

If a measure meets the above criteria and there are endorsed or new related measures (either the same measure focus or the same target population) or competing measures (both the same measure focus and the same target population), the measures are compared to address harmonization and/or selection of the best measure.

If you are updating a maintenance measure submission for the first time in MIMS, please note that the previous related and competing data appearing in question 5.03 may need to be entered in to 5.01 and 5.02 if the measures are NQF endorsed. Please review and update questions 5.01, 5.02, and 5.03 accordingly.

5.01. Search and select all NQF-endorsed related measures (conceptually, either same measure focus or target population).

(Can search and select measures.)
[Response Begins]
2651: CAHPS® Hospice Survey (experience with care)
[Response Ends]

5.02. Search and select all NQF-endorsed competing measures (conceptually, the measures have both the same measure focus or target population).

(Can search and select measures.)
[Response Begins]
[Response Ends]

5.03. If there are related or competing measures to this measure, but they are not NQF-endorsed, please indicate the measure title and steward.

[Response Begins]
N/A
[Response Ends]

5.04. If this measure conceptually addresses EITHER the same measure focus OR the same target population as NQF-endorsed measure(s), indicate whether the measure specifications are harmonized to the extent possible.

[Response Begins]
Yes
[Response Ends]

5.05. If the measure specifications are not completely harmonized, identify the differences, rationale, and impact on interpretability and data collection burden.

[Response Begins]
N/A
[Response Ends]

5.06. Describe why this measure is superior to competing measures (e.g., a more valid or efficient way to measure quality). Alternatively, justify endorsing an additional measure.

Provide analyses when possible.

[Response Begins]

N/A
[Response Ends]

Appendix

Supplemental materials may be provided in an appendix.: Available in attached file
Attachment: Patient Experience Survey - Receiving Desired Help for Pain.pdf

Contact Information

Measure Steward (Intellectual Property Owner) : American Academy of Hospice and Palliative Medicine
Measure Steward Point of Contact: Ast, Katherine, kast@aahpm.org
Measure Developer if different from Measure Steward: American Academy of Hospice and Palliative Medicine
Measure Developer Point(s) of Contact: Ast, Katherine, kast@aahpm.org

Additional Information

1. Provide any supplemental materials, if needed, as an appendix. All supplemental materials (such as data collection instrument or methodology reports) should be collated one file with a table of contents or bookmarks. If material pertains to a specific criterion, that should be indicated.

[Response Begins]
Available in attached file
[Response Ends]

Attachment: Patient Experience Survey - Receiving Desired Help for Pain.pdf

2. List the workgroup/panel members' names and organizations.

Describe the members' role in measure development.

[Response Begins]
The Advisory Panel provided input on measure specification and value and field-testing decisions.

Robert Gramling, MD, DSc, University of Vermont Medical Center

Laura Hanson, MD, MPH, University of North Carolina School of Medicine

Amy Kelley, MD, MSHS, Mount Sinai Health System

Karl Lorenz, MD, MSHS, Palo Alto Veterans Affairs Medical Center

Joanna Paladino, MD, Dana-Farber Cancer Institute and Ariadne Labs

VJ Periyakoil, MD, Stanford University School of Medicine

Christine Ritchie, MD, MSPH, University of California San Francisco School of Medicine

Richard Street, PhD, Texas A&M University

Joan Teno, MD, MS, Oregon Health and Science University School of Medicine

Neil Wenger, MD, MPH, University of California Los Angeles School of Medicine

The Technical Expert Clinical User Patient Panel (TECUPP) provided expertise and feedback on the proposed quality measures for patients with serious illness throughout the measure development lifecycle. The Measure Specifications Panel (MSP), a small subgroup of experts with highly technical measure development and specification expertise, were selected to evaluate the proposed measures for initial feasibility and review later testing results to guide decision-making regarding the measures.

**Indicates Measure Specification Panelists (MSP)*

Sydney M. Dy, MD (Co-Chair)*, Johns Hopkins Bloomberg School of Public Health

Mary T. Ersek, PhD, RN, FPCN (Co-Chair)*, University of Pennsylvania School of Nursing, Philadelphia Veterans Affairs Medical Center

Steven M. Asch, MD, MPH*, VA Palo Alto Healthcare System

Kathleen Bickel, MD, MPhil, MS*, University of Colorado, Denver School of Medicine, Veterans Affairs Eastern Colorado Healthcare System

Lori Bishop, MHA, BSN, RN, CHPN*, National Hospice and Palliative Care Organization

Brenda Blunt, DHA, MSN, RN, CVP Corp

Amy Ciancarelli, BS, CPXP, Care Dimensions

Amy L. Davis, DO, MS, FACP, FAAHPM, Drexel University School of Medicine, Main Line Health System

Sa'Brina Davis, AmerisourceBergen

Torrie Fields, MPH*, Blue Shield of California

Elizabeth L. Fricklas, PA-C, Duke Palliative Care

Joy Goebel, RN, PhD, FPCN, California State University Long Beach School of Nursing

Matthew J. Gonzales, MD, FAAHPM, Institute for Human Caring

Anna Gosline, SM, Blue Cross Blue Shield of Massachusetts

Marian Grant, DNP, CRNP, ACHPN, FPCN, RN, Marian Grant Consulting

Rev. George F.Handzo, MA, Mdiv, BCC, CSSBB, HealthCare Chaplaincy Network

Denise Hess, MDiv, BCC-PCHAC, LMFT, Supportive Care Coalition

Sarah E. Hetue Hill, PhD*, Ascension Medical Group

Faye Hollowell, National Patient Advocate Foundation

Arif Kamal MD, MBA, MHS, FACP, FAAHPM, FASCO*, Duke University School of Medicine

Rebecca Kirch, JD, National Patient Advocacy Foundation

Cari Levy, MD, PhD, CMD, University of Colorado, Denver School of Medicine, Veterans Affairs Eastern Colorado Health Care System

Phillip M. Rodgers, MD, FAAHPM*, University of Michigan Medical School

Benjamin D. Schalet, PhD*, Northwestern University

Tracy A. Schroepfer, PhD, MSW, MA, University of Wisconsin-Madison School of Social Work

Cardinale B. Smith, MD, PhD*, Mount Sinai Health System

Hannah Luetke-Stahlman, MPA, Cerner Corporation

Paul E. Tatum, III, MD, MSPH, CMD, FAAHPM, AGSF, Dell Seaton Medical Center at the University of Texas, Austin

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[Response Ends]

3. Indicate the year the measure was first released.

[Response Begins]
N/A
[Response Ends]

4. Indicate the month and year of the most recent revision.

[Response Begins]
N/A
[Response Ends]

5. Indicate the frequency of review, or an update schedule, for this measure.

[Response Begins]
unknown
[Response Ends]

6. Indicate the next scheduled update or review of this measure.

[Response Begins]
N/A
[Response Ends]

7. Provide a copyright statement, if applicable. Otherwise, indicate "N/A".

[Response Begins]
N/A
[Response Ends]

8. State any disclaimers, if applicable. Otherwise, indicate "N/A".

[Response Begins]
N/A
[Response Ends]

9. Provide any additional information or comments, if applicable. Otherwise, indicate "N/A".

[Response Begins]
N/A
[Response Ends]

Attachment: Patient Experience Survey - Receiving Desired Help for Pain.pdf