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Geriatrics and Palliative Care, Fall 2021 Cycle: CDP Report

TECHNICAL REPORT
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Contents

Executive Summary

Palliative care focuses on improving the overall quality of life by addressing medical, emotional, spiritual, and social needs during the last stages of a person's terminal illness.[1] Despite its comprehensive focus, only about 14 percent of those in need of palliative care receive it.[2] As the population in the United States (U.S.) ages, the number of those living with chronic illness, disabilities, and functional limitations continues to increase. Therefore, improving access to quality geriatric and palliative care for the almost 90 million Americans living with a serious illness is crucial.[3] The National Quality Forum's (NQF) Geriatric and Palliative Care (GPC) Standing Committee oversees a portfolio of quality measures that address geriatric, palliative, and end-of-life care. These measures not only address the health aspects of care, but also the physical, spiritual, and legal aspects of it.

The GPC Standing Committee evaluated three newly submitted measures against NQF's standard evaluation criteria. The Standing Committee recommended all three measures for endorsement. The Consensus Standards Approval Committee (CSAC) upheld the Standing Committee's recommendations.

The Standing Committee endorsed the following measures:

- NQF #3645 Hospice Visits in the Last Days of Life (Centers for Medicare & Medicaid Services [CMS]/Abt Associates)
- NQF #3665 Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood (American Academy of Hospice and Palliative Medicine [AAHPM])
- NQF #3666 Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain (AAHPM)

Brief summaries of the measures and their evaluations are included in the body of the report; detailed summaries of the Standing Committee's discussion and ratings of the criteria for each measure are in Appendix A.

Introduction

Palliative care is essential to the quality of life for patients who are experiencing varying levels of chronic or terminal illness. Such care demands a whole-person, problem-oriented approach that evolves with the needs of the patient, optimizes functional independence, and prevents or reduces the progression of disability in older or chronically ill patients. Developments in palliative care continue to be met with a growing population in the U.S., most notably the longevity of earlier generations. The U.S. has seen an increase in the population, from about 228 million to over 300 million people within the past decade.[4] Additionally, between the years of 2000 and 2010, the U.S. population consisting of ages 65 and older grew 15 percent; 5 million more people were ages 65 and older in 2010 compared to the prior decade.[4] Furthermore, Medicare spending indicates that beneficiaries ages 65 and older in their last year of life account for 25 percent of total Medicare spending.[5]

Such growth presents a concurrent rise in chronic illnesses, disabilities, functional limitations, and ethnic and cultural diversity, as well as healthcare expenditures that require constant examination of the quality and models of palliative and end-of-life care.[4] Palliative care focuses on improving the overall quality of life by addressing medical, emotional, spiritual, and social needs during the last stages of a person's terminal illness.[1] Despite its comprehensive focus, only about 14 percent of those in need of palliative care receive it.[2] Therefore, improving access to quality geriatric and palliative care for the almost 90 million Americans living with serious illness is crucial.[3] Measuring quality allows providers to determine how well they are performing and provides them with an opportunity to improve the overall care they provide to their patients. Three measures were reviewed during the GPC Standing Committee's fall 2021 measure evaluation cycle, one of which focused on hospice visits in the last days of life while the other two were patient-reported outcome measures (PROMs) that addressed ambulatory care palliative patients' experience of feeling heard and understood and receiving desired help for pain.

Hospice Visits in the Last Days of Life

During the last days of life, patients may experience additional physical and emotional symptoms; caregivers often also experience more distress during this time.[6] To provide quality care, hospice organizations must be able to meet the demand required during a patient's last days of life. Hospice staff visits during the final days of a patient's life provide support to the patient and caregiver, help to improve the quality of life during the patient's last days, and decrease the risk of hospitalization and emergency room visits.[7]

Ambulatory Care Palliative Patients' Experience Feeling Heard and Understood and Receiving Desired Help for Pain

Seriously ill patients often report feeling silenced, ignored, and misunderstood.[8] The ability to monitor, report, and respond to how well patients feel heard and understood is critical to ensuring a caring environment for seriously ill individuals.[9] Pain is often a significant and the most prevalent symptom experienced by palliative care patients.[10] Palliative care providers are in a unique position to improve pain management. The use of patient-reported measures provides data, which allows providers to improve their communication and the patient's pain management, thereby reducing the patient's pain severity, improving the quality of life for palliative care patients, and improving patient satisfaction.[11]

NQF Portfolio of Performance Measures for Geriatrics and Palliative Care Conditions

The GPC Standing Committee (Appendix C) oversees NQF's portfolio of GPC measures (Appendix B), which includes measures relating to physical, spiritual, religious, ethical, and legal aspects of palliative/end-of-life care; general care of the patient nearing the end of life; and geriatrics. This portfolio contains 21 measures: 11 process measures, nine outcome (including patient-reported outcome performance measures [PRO-PM]) and resource use measures, and one composite measure.

Some of the measures in the GPC portfolio will be evaluated by other NQF Standing Committees. These include a cultural communication measure (Patient Experience and Function) and pain measures for cancer patients (Cancer).

Geriatrics and Palliative Care Measure Evaluation

On February 18, 2022, the GPC Standing Committee evaluated three new measures against NQF's standard measure evaluation criteria.

Table 1. Geriatrics and Palliative Care Measure Evaluation Summary

Measure	Maintenance	New	Total
Measures under review for endorsement	0	3	3
Measures endorsed	0	3	3

Scientific Methods Panel Measure Evaluation

Prior to the Standing Committee's review, the Scientific Methods Panel (SMP) reviewed two complex measures in this topic area. The SMP passed both measures during its review.

A meeting summary detailing the SMP's measure evaluation for the fall 2021 cycle is available on the SMP webpage.

Comments Received Prior to Standing Committee Evaluation

NQF accepts comments on endorsed measures on an ongoing basis through the Quality Positioning System (QPS). In addition, NQF solicits comments for a continuous 16-week period during each evaluation cycle via an online tool located on the project webpage. For this evaluation cycle, the commenting period opened on December 6, 2021, and pre-meeting commenting closed on January 19, 2022. As of January 19, 2022, 18 comments have been submitted and shared with the Standing Committee prior to the measure evaluation meeting (Appendix F).

Comments Received After Standing Committee Evaluation

The continuous 16-week public commenting period with NQF member support closed on April 29, 2022. Following the Standing Committee's evaluation of the measures under review, NQF received 15 comments from seven organizations (including four member organizations) and individuals pertaining to the draft report and the measures under review (Appendix G). All comments for each measure under

review have also been summarized in Appendix A. These comments were sent to the Standing Committee and discussed during the post-comment meeting.

NQF members had the opportunity to express their support ("support" or "do not support") for each measure submitted for endorsement consideration to inform the Standing Committee's recommendations during the commenting period. Three NQF members expressed "support" for NQF #3665 and NQF #3666. One NQF member expressed "do not support" and one NQF member expressed "support" for NQF #3645.

Summary of Measure Evaluation

The following brief summaries of the measure evaluation highlight the major issues that the Standing Committee considered. Details of the Standing Committee's discussion and ratings of the criteria for each measure are included in Appendix A.

Hospice Visits in the Last Days of Life

NQF #3645 Hospice Visits in the Last Days of Life (CMS/Abt Associates): Endorsed

Description: The proportion of hospice patients who have received visits from a Registered Nurse or Medical Social Worker (non-telephonically) on at least two out of the final three days of the patient's life; **Measure Type**: Process; **Level of Analysis**: Facility; **Setting of Care**: Behavioral Health, Home Care, Inpatient/Hospital, Post-Acute Care; **Data Source**: Claims

This facility-level measure was newly submitted for endorsement. The Standing Committee agreed that the body of literature demonstrated evidence to support the measure. The Standing Committee also noted that the variation among the hospice community suggests a gap, which warrants a national performance measure. The Standing Committee ultimately passed the measure on evidence and performance gap.

The Standing Committee agreed that the measure was reliable but suggested that it could be further strengthened by expanding the care disciplines covered, conducting a more holistic review of patient and caregiver end-of-life desires, and including postmortem visits and pediatric palliative care hospice patients. The Standing Committee noted that the reliability testing was strong but expressed concerns about the exclusion of respite care from the denominator of the measure. The developer explained that respite care is rare in the last two to three days of life, and inpatient respite care is a matter of institutionalization; therefore, the chance of encounter with various care personnel and disciplines is already very likely. The Standing Committee ultimately passed the measure on reliability. The Standing Committee agreed that the validity testing results were moderate and that end-of-life visits are an important care process and a valid indication of quality care. The Standing Committee expressed no further concerns with validity and passed the measure on this criterion.

The Standing Committee noted that the measure is available in an electronic format and did not add undue burden; it is expected to be used in a public reporting program. No unintended consequences were identified. Therefore, the Standing Committee passed the measure on feasibility, use, usability, and overall suitability for endorsement. The CSAC upheld the Standing Committee's decision to recommend the measure for endorsement. No appeals were received.

Ambulatory Care Palliative Patients' Experience Feeling Heard and Understood

NQF #3665 Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood (American Academy of Hospice and Palliative Medicine): Endorsed

Description: This is a multi-item measure consisting of 4 items: Q1: "I felt heard and understood by this provider and team", Q2: "I felt this provider and team put my best interests first when making recommendations about my care", Q3: "I felt this provider and team saw me as a person, not just someone with a medical problem", Q4: "I felt this provider and team understood what is important to me in my life"; **Measure Type**: Outcome: PRO-PM; **Level of Analysis**: Clinician: Group/Practice; **Setting of Care**: Ambulatory Care; **Data Source**: Instrument-Based Data, Electronic Health Records

This clinician group-level PRO-PM was newly submitted for endorsement. The Standing Committee agreed that the evidence supported the measure; it also agreed that the measure is meaningful to patients. The Standing Committee noted that a performance gap was present and passed the measure on evidence and performance gap.

Prior to the Standing Committee measure evaluation meeting, the SMP reviewed the measure and passed it on reliability and validity with a rating of moderate. The Standing Committee questioned why pediatric patients were excluded from the measure. Additionally, the Standing Committee also questioned whether patients are able to be surveyed when their first language is not English. The developer addressed this concern and advised that developing a pediatric measure would be the next step. The developer also noted that the survey would be available to patients in different languages. The Standing Committee reviewed the validity testing results and expressed no concerns. The Standing Committee agreed that the measure was both reliable and valid and accepted the SMP's rating.

The Standing Committee questioned whether the measure was truly feasible, considering that outside vendors would be needed to assist with survey distribution. Although the developer confirmed that vendors are needed to assist with survey distribution, this was not an issue that was noted during testing. The Standing Committee also expressed concern regarding providers being unfairly rated due to the patient perception of palliative care; however, it agreed, overall, that it had no concern with the usability of the measure. The measure is not currently in use; however, the developer is attempting to put the measure in use. The Standing Committee ultimately passed the measure on feasibility, use, and usability.

The Standing Committee passed the measure on all criteria and on overall suitability for endorsement. It recommended the PRO-PM for initial endorsement. The CSAC upheld the Standing Committee's decision to recommend the measure for endorsement. No appeals were received.

Ambulatory Care Palliative Patients' Experience of Receiving Desired Help for Pain

NQF #3666 Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain (American Academy of Hospice and Palliative Medicine): Endorsed

Description: 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; **Measure Type**: Outcome: PRO-PM; **Level of**

Analysis: Clinician: Group/Practice; **Setting of Care**: Ambulatory Care; **Data Source**: Instrument-Based Data

This clinician group-level measure was newly submitted for endorsement. The Standing Committee noted that an extensive body of evidence was present and that it supported the measure. The Standing Committee noted high variability in performance, indicating a need for a national performance measure. The Standing Committee acknowledged the importance of the measure and passed it on evidence and performance gap.

The Standing Committee stated that the SMP reviewed the measure prior to the measure evaluation meeting and passed it on reliability and validity with a rating of moderate. The Standing Committee also stated that the reliability testing results were acceptable; therefore, it voted to accept the SMP's rating for reliability. The Standing Committee expressed concerns about measure accuracy when responses are highly variable from patient to patient. It also expressed concerns that the measure does not exclude those with substance abuse issues and does not include pediatric patients. The Standing Committee urged the developers to consider these matters strongly as they move forward, to which the developer confirmed they would. Ultimately, the Standing Committee voted to accept the SMP's rating for validity.

The Standing Committee noted that the measure was regarded as feasible, with the only burden identified as the cost of a survey vendor. The Standing Committee noted that the measure is not currently in use; however, the developer is attempting to have the measure put into use. In terms of usability, the Standing Committee highlighted that the developer gathered feedback from users of the measure, and survey fatigue was the main concern identified. Although the Standing Committee raised this concern, it recognized there is not much the developer can do to address this concern. The Standing Committee passed the measure on feasibility, use, usability and recommended it for initial endorsement. The CSAC upheld the Standing Committee's decision to recommend the measure for endorsement. No appeals were received.

Measures Withdrawn From Consideration

One measure previously endorsed by NQF was either not resubmitted for maintenance of endorsement or was withdrawn during the endorsement evaluation process. Endorsement for this measure has been removed.

Table 2. Measures Withdrawn From Consideration

Measure	Reason for withdrawal
NQF #1617, Patients Treated With an Opioid Who Are Given a Bowel Regimen	The steward is not maintaining endorsement of the measure.

References

1 Committee on Approaching Death: Addressing Key End of Life Issues, Institute of Medicine. *The Delivery of Person-Centered, Family-Oriented End-of-Life Care*. National Academies Press (US); 2015. https://www.ncbi.nlm.nih.gov/books/NBK285676/. Last accessed March 2022.

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4 Hughes MT, Smith TJ. The Growth of Palliative Care in the United States. *Annu Rev Public Health*. 2014;35(1):459-475.

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6 Dellon EP, Shores MD, Nelson KI, et al. Family caregiver perspectives on symptoms and treatments for patients dying from complications of cystic fibrosis. *J Pain Symptom Manage*. 2010;40(6):829-837.

7 Phongtankuel V, Adelman RD, Trevino K, et al. Association Between Nursing Visits and Hospital-Related Disenrollment in the Home Hospice Population. *Am J Hosp Palliat Care*. 2018;35(2):316-323.

8 Committee on Approaching Death: Addressing Key End of Life Issues, Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington (DC): National Academies Press (US); 2015. http://www.ncbi.nlm.nih.gov/books/NBK285681/. Last accessed March 2022.

9 Gramling R, Stanek S, Ladwig S, et al. Feeling Heard and Understood: A Patient-Reported Quality Measure for the Inpatient Palliative Care Setting. *J Pain Symptom Manage*. 2016;51(2):150-154.

10 Johnson CE, Girgis A, Paul CL, et al. Cancer specialists' palliative care referral practices and perceptions: results of a national survey. *Palliat Med*. 2008;22(1):51-57.

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

Appendix A: Details of Measure Evaluation

Rating Scale: H=High; **M**=Moderate; **L**=Low; **I**=Insufficient; **NA**=Not Applicable

National Quality Forum (NQF) ensures that quorum is maintained for all live voting. Quorum is 66 percent of active Standing Committee members minus any recused Standing Committee members. Due to the exclusion of recused Standing Committee members from the quorum calculation, the required quorum for live voting may vary among measures. Quorum (14 out of 20 Standing Committee members for NQF #3645 and 10 out of 15 Standing Committee members for both NQF #3665 and NQF #3666) was reached and maintained during the full measure evaluation meeting on February 18, 2022. Vote totals may differ between measure criteria and between measures, as Standing Committee members may have joined the meeting late, stepped away for a portion of the meeting, or had to leave the meeting before voting was complete. The vote totals listed below reflect Standing Committee members present and eligible to vote at the time of the vote. Voting results are provided below.

A measure is recommended for endorsement by the Standing Committee when greater than 60 percent of voting members select a passing vote option (Pass, High and Moderate, or Yes) on all must-pass criteria and overall suitability for endorsement. A measure is not recommended for endorsement when less than 40 percent of voting members select a passing vote option on any must-pass criterion or overall suitability for endorsement.

Measures Endorsed

NQF #3645 Hospice Visits in the Last Days of Life

Measure Worksheet | Specifications

Description: The proportion of hospice patients who have received visits from a Registered Nurse or Medical Social Worker (non-telephonically) on at least two out of the final three days of the patient's life.

Numerator Statement: The numerator of this measure is the number of patient stays in the denominator in which the patient and/or caregiver received visits from registered nurses or medical social workers on at least two of the final three days of the patient's life, as captured by hospice claims records.

Denominator Statement: The denominator for the measure includes all hospice patient enrollments in hospice with the patient discharged to death, except those meeting exclusion criteria outlined below.

Exclusions: Patient stays are excluded from the measure if the patient: (1) received any continuous home care, respite care, or general inpatient care in the final three days of life or (2) was enrolled in hospice fewer than three calendar days.

Adjustment/Stratification:

No risk adjustment or stratification

N/A; no risk adjustment or stratification for this process measure

Level of Analysis: Facility

Setting of Care: Behavioral Health, Home Care, Inpatient/Hospital, Post-Acute Care

Type of Measure: Process

Data Source: Claims

Measure Steward: Centers for Medicare & Medicaid Services (CMS)

STANDING COMMITTEE MEETING [February 18, 2022]

1. Importance to Measure and Report:

(1a. Evidence, 1b. Performance Gap)

1a. Evidence: **Total votes-17**; **H-N/A**; **M-16**; **L-1**; **I-0**; 1b. Performance Gap: **Total votes-17; H-11**; **M-6**; **L-0**; **I-0**
Rationale:

- The Standing Committee noted that the literature provides evidence supporting that the last week of life is typically the period in the terminal illness trajectory with the highest symptom burden. The Standing Committee agreed that the evidence supports that clinician visits are associated with decreased risk of hospitalization and emergency room visits in the last two weeks of the patient's life.
- The Standing Committee noted disparities among race and ethnic groups and observed that White patients are more likely to receive visits in the last days of life (68.5 percent) versus other groups (Black: 61.0 percent, Asian: 57.2 percent, Hispanic: 57.5 percent, Other/Unknown: 63.7 percent) and by Medicare/Medicaid dual status (Medicare-only – 69.1 versus Medicare/Medicaid dual status – 63.2 percent). Additionally, patients in rural areas were found to have higher rates of success for this measure (rural – 71.0 percent versus urban – 67.0 percent).
- The Standing Committee agreed that the measure was important and passed the measure on evidence and performance gap.

2. Scientific Acceptability of Measure Properties:
(2a. Reliability - precise specifications, testing; 2b. Validity - testing, threats to validity)
2a. Reliability: **Total votes-18**; **H-5**; **M-11**; **L-2**; **I-0**; 2b. Validity: **Total votes-18**; **H-4**; **M-13**; **L-1**; **I-0**
Rationale:

- The SMP did not review this measure.
- The Standing Committee agreed that the measure is fully specified and tested for reliability. The Standing Committee reviewed the accountable entity-level reliability testing methodology and results. The facility level signal-to-noise ratio mean average reliability score was 0.973, with a median score of 0.986. Additionally, over 95 percent of facilities had a signal-to-noise ratio value at or above 0.9. The Standing Committee agreed that the measure score reliability is precise and capable of detecting a true difference within and among facilities for the process being measured.
- The Standing Committee had no further concerns with the reliability testing results and agreed that the measure is reliable.
- The Standing Committee reviewed the empirical validity testing results for the accountable entity-level validity testing the developer conducted. The Standing Committee noted that the accountable entity-level testing revealed a positive correlation between NQF #3645 *Hospice Visits in the Last Days of Life* and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey responses. As a result, the Standing Committee agreed that end-of-life visits are a valid indication of quality care and an important care process.
- The Standing Committee reviewed the results from testing the exclusions and noted differences in rates for receiving visits in two of the last three days among excluded individuals. The Standing Committee deemed the exclusions appropriate and expressed understanding in the rationale for exclusion.
- The Standing Committee had no further concerns with the validity testing results and agreed that the measure was valid.

3. Feasibility: Total votes-18; **H-12; M-6; L-0; I-0**
(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c. Susceptibility to inaccuracies/ unintended consequences identified; 3d. Data collection strategy can be implemented)
Rationale:

- The Standing Committee noted that all data elements needed to calculate this measure are defined and available in Medicare claims records.
- The Standing Committee expressed no concerns with the feasibility of this measure and passed the measure on this criterion.

4. Usability and Use:

(Used and useful to the intended audiences for 4a. Accountability and Transparency; 4b. Improvement; and 4c. Benefits outweigh evidence of unintended consequences)

4a. Use**: Total votes-18**; **Pass-17; No Pass-1**; 4b. Usability: **Total votes-18**; **H-5; M-12; L-1; I-0**

Rationale:

- The Standing Committee recognized that the measure is new but deemed the plan for use acceptable. The measure is projected to be publicly reported sometime in 2022 via the CMS Care Compare website. The Standing Committee also noted the developer confidentially released individual hospice scores benchmarked to national averages to hospices during the fall of 2021.
- Although the developer did not identify any unintended harms, the Standing Committee posited that unnecessary visits might be provided simply to meet measure expectations, and such action could interfere with care personnel resource allocation. The Standing Committee also asserted that unwanted visitation during the latter days of life could be a reality for many patients. The Standing Committee ultimately acknowledged that these unintended consequences do not necessarily outweigh the benefits of the measure and passed the measure on use and usability.

5. Related and Competing Measures

- No related or competing measures were noted.

6. Standing Committee Recommendation for Endorsement: **Total votes-18**; **Yes-18**; **No-0**

7. Public and Member Comment

- No public or member pre-evaluation comments were received.
- Six post-evaluation comments were submitted. Three commenters requested the Standing Committee to reconsider its endorsement for NQF #3645 until the developer alters the measure's specifications. During the post-comment web meeting, the Standing Committee noted that value exists in monitoring the quality of care provided by registered nurses and social workers during the last days of life but recognized the concern that certain disciplines are excluded from the measure. Ultimately, the Standing Committee maintained that the measure met NQF criteria as specified and stood by the decision to recommend the measure for endorsement. The Standing Committee encouraged the developer to monitor data and billing codes, as they become available, to support the inclusion of other interdisciplinary groups (e.g., chaplains, licensed practical nurses) in future iterations of the measure. The Standing Committee also recommended the developer consider returning for an early NQF maintenance review, prior to the designated three years, if including additional disciplines becomes more feasible.

8. Consensus Standards Approval Committee (CSAC) Endorsement Decision: Total votes- 8; Yes-8; No-0 (July 26, 2022: Endorsed)

- The CSAC upheld the Standing Committee's decision to recommend the measure for endorsement.

9. Appeals

- No appeals were received.

NQF #3665 Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood

Measure Worksheet | Specifications

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

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

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

Exclusions: Denominator exclusions include patients who do not complete at least one of the four items in the multi-item measure; patients who do not complete the patient experience survey within six months of the eligible ambulatory palliative care visit; patients who respond on the patient experience survey that they did not receive care by the listed ambulatory palliative care provider in the last six months; 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).

Adjustment/Stratification:

Statistical risk model with risk factors (specify number of risk factors)

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).

Level of Analysis: Clinician: Group/Practice

Setting of Care: Ambulatory Care

Type of Measure: Outcome: PRO-PM

Data Source: Electronic Health Records, Instrument-Based Data

Measure Steward: American Academy of Hospice and Palliative Medicine (AAHPM)

STANDING COMMITTEE MEETING [February 18, 2022]

1. Importance to Measure and Report:

(1a. Evidence, 1b. Performance Gap)

1a. Evidence: **Total votes-11**; **Pass-11; No Pass-0**; 1b. Performance Gap: **Total votes- 13; H-4**; **M-9**; **L-0**; **I-0**

Rationale:

- The Standing Committee considered the evidence presented for the measure, which included numerous studies in support of the measure's goal to improve the quality of care in palliative care settings. The Standing Committee agreed that the literature was sufficient.
- The Standing Committee reviewed measure testing data that highlighted variability in the care received in ambulatory clinics, with a range in adjusted program numerator measure scores from 54.05 to 85.18 and a standard deviation of 7.04, suggesting room for improvement.
- The Standing Committee passed the measure on evidence and performance gap.

2. Scientific Acceptability of Measure Properties:

(2a. Reliability - precise specifications, testing; 2b. Validity - testing, threats to validity)

2a. Reliability: **Total votes-12**; **Yes-11**; **No-1**; 2b. Validity: **Total votes-12**; **Yes-12**; **No-0**

Rationale:

- The SMP reviewed this measure and passed it with a rating of moderate for reliability **(Total votes-11; H-3, M-6, L-1, I-1)** and validity **(Total votes-11; H-3, M-5, L-3, I-0).**
- The Standing Committee discussed the measure's target population and specifically expressed concern that the measure does not capture pediatric patients. The developer noted that pediatric patients are not the target of this measure and that pediatric measures are typically separate measures from adult measures; however, they agreed that the goal is to develop a measure specifically focusing on pediatric patients.
- The Standing Committee was also concerned about how the survey would be delivered to patients, considering not all demographics will feel comfortable responding to surveys via mail or email. The Standing Committee also asked whether the survey would be administered in additional languages if English was not the patient's first language. The developer advised that the survey is sent out to patients via mail and email and by contacting patients via phone to allow for a wide variation in data collection. They also advised that once the survey is implemented, it will be made available in languages other than English for patients to complete via mail or email.
- The Standing Committee reviewed the reliability testing, which was performed at the patient/encounter and accountable-entity levels. The Standing Committee agreed that the reliability testing was high, with Cronbach's Alpha results of 0.90 for the scale evaluated, the test-retest reliability at 0.85, and the signal-to-noise analysis all suggesting that a reasonable level of reliability exists. The Standing Committee accepted the SMP's rating on reliability.
- The Standing Committee reviewed the validity testing, which was conducted at the patient/encounter and accountable-entity levels and via face validity. They agreed with the SMP's assessment that the empirical validity testing at the patient/encounter level shows that the data elements are valid. The Standing Committee also agreed that the accountable-entity level testing was significantly and positively associated with the CAHPS communication quality measure ($r = 0.635$, $p = 0.011$). Additionally, seven expert advisors rated the face validity of the measure score. On average, advisors rated the face validity of the measure score as 8.3 on a scale of 1–9, corresponding with an average rating of "high."
- The Standing Committee had no further concerns regarding the validity testing results; it agreed that the measure was valid and accepted the SMP's rating.

3. Feasibility: Total votes-12; **H-5; M-6; L-1; I-0**

(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c. Susceptibility to inaccuracies/ unintended consequences identified; 3d. Data collection strategy can be implemented)

Rationale:

- The Standing Committee agreed that the measure was feasible but questioned whether the use of vendors to deliver the surveys added burden to implementing the measure due to cost. The developer stated that vendors were used during measure testing, and test organizations did not voice any issues regarding the burden of vendor use or the additional cost of using a vendor.
- The Standing Committee noted that when the developer held a commenting period on the measure, most respondents noted that the measure was either very feasible (21.8 percent) or somewhat feasible (42.7 percent).

4. Usability and Use:

(Used and useful to the intended audiences for 4a. Accountability and Transparency; 4b. Improvement; and 4c. Benefits outweigh evidence of unintended consequences)

4a. Use**: Total votes-12**; **Pass-12; No Pass-0**; 4b. Usability: **Total votes-12**; **H-1; M-11; L-0; I-0**

Rationale:

- This measure is not currently in use; however, the developer is attempting to have the measure put in use in federal programs.
- The Standing Committee highlighted that the developer obtained feedback from measure testing organizations. Submitted feedback revealed that survey fatigue was an issue, in addition to the possibility that proxy responses could be biased, and that a provider could be unfairly penalized due to a patient's perception of care. The Standing Committee agreed that the measure is important and that collecting patient feedback to improve care outweighs these concerns.

5. Related and Competing Measures

- This measure is related to the following measure:
  - NQF #2651 CAHPS Hospice Survey (Experience With Care)
- The Standing Committee agreed that the measures were harmonized to the extent possible and did not provide suggestions for improvements.

6. Standing Committee Recommendation for Endorsement: Total votes-12; Yes-12; No-0

7. Public and Member Comment

- The developer submitted 11 pre-evaluation comments as clarifications regarding the SMP's feedback.
- Five post-evaluation comments were submitted. All five comments were in support of the Standing Committee's recommendation to endorse the measure.

8. Consensus Standards Approval Committee (CSAC) Endorsement Decision: Total votes- 8; Yes-8; No-0 (July 26, 2022: Endorsed)

- The CSAC upheld the Standing Committee's decision to recommend the measure for endorsement.

9. Appeals

- No appeals were received.

NQF #3666 Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain

Measure Worksheet | Specifications

Description: 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.

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.

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

Exclusions: Denominator exclusions include patients who do not complete and return the patient experience survey within six months of the eligible ambulatory palliative care visit; patients who respond on the patient experience survey that they did not receive care by the listed ambulatory palliative care provider in the last six months (disavowal); patients who were 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?"

Adjustment/Stratification:

Statistical risk model with risk factors (specify number of risk factors)

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).

Level of Analysis: Clinician: Group/Practice

Setting of Care: Ambulatory Care
Type of Measure: Outcome: PRO-PM
Data Source: Instrument-Based Data
Measure Steward: American Academy of Hospice and Palliative Medicine

STANDING COMMITTEE MEETING [February 18, 2022]
1. Importance to Measure and Report:
(1a. Evidence, 1b. Performance Gap)
1a. Evidence: **Total votes-12**; **Yes-12; No-0**; 1b. Performance Gap: **Total votes-13; H-2**; **M-11**; **L-0**; **I-0**
Rationale:

- The Standing Committee reviewed the evidence and the logic model, noting that both demonstrate that the measure leads to lower levels of pain and improves the patient's overall care experience. The Standing Committee also acknowledged that patients, caregivers, and family members found the measure to be meaningful.
- The Standing Committee noted that this measure is looking at the patients' desired support of their pain, as opposed to other measures that have been clinician facing. Clinician-facing measures focus on clinician decisions/treatments and do not always account for a patient's wishes; thus, the Standing Committee agreed that this measure is a step in the right direction for this population.
- The Standing Committee agreed that the testing data revealed a gap in performance, with the minimum score being 66.1 percent and the maximum score being 89.4 percent.
- The Standing Committee reviewed the disparities data, noting that despite the absence of any significant relationships with the social risk factors, the literature identified long-standing disparities in pain management. The Standing Committee asked the developer to clarify how the measure identified disparities. The developer responded by stating that to achieve optimal performance on this measure, the provider must tailor their communication to the individual patient so that the measure is sensitive to person-centered differences. The developer also added that the survey given to patients captures demographic data, which can be used to identify disparities.

2. Scientific Acceptability of Measure Properties:
(2a. Reliability - precise specifications, testing; 2b. Validity - testing, threats to validity)
2a. Reliability: **Total votes-13**; **Yes-12**; **No-1**; 2b. Validity: **Total votes-13**; **Yes-12**; **No-1**
Rationale:

- The SMP reviewed this measure and passed it with a rating of moderate on reliability **(Total votes-11; H-4, M-5, L-2, I-0)** and validity **(Total votes-11; H-2, M-6, L-3, I-0).**
- The Standing Committee reviewed the SMP's evaluation of the measure, noting its concern with the specifications of the measure. Overall, the Standing Committee agreed that the specifications were clear but requested clarity on how the developer defines the domains of pain and whether patients understand the different domains of pain. The developer noted that the expert panel did not feel the different domains of pain needed to be further defined.
- The Standing Committee reviewed the reliability testing that was performed at both the patient/encounter and accountable-entity levels, specifically noting that the test-retest analysis for patient/encounter-level testing and the signal-to-noise analysis for accountable entity-level testing were both appropriate methods. Furthermore, it noted that the result of the test-retest analysis, which found that the polychoric correlation coefficient was 0.90 with 88 percent agreement for the computer-assisted

telephone interviewing (CATI) data collection method, demonstrated reliability. The Standing Committee also agreed that the result of the signal-to-noise analysis, which found that the average adjusted reliability of individual programs was approximately 0.75, demonstrated reliability.

- The Standing Committee reviewed the validity testing performed at both the patient/encounter and accountable-entity levels and agreed that the convergent validity analysis with two other measures for the patient/encounter level testing and the correlation analysis and face validity for the accountable-entity level testing were all appropriate. Furthermore, it noted that the result of the bivariate correlation analysis conducted for convergent validity showed moderate correlations between both hypothesized relationships. The correlation with the CAHPS measure was 0.57, and the correlation with NQF #3665 was 0.61. Additionally, it noted that the results of the correlation analysis of the measure scores for the accountable-entity level showed the following: The association with NQF #3665 was 0.41, which is a weak positive correlation; the association with the CAHPS communication quality measure was 0.386, which is also a weak positive correlation; and the association with the overall rating of the palliative care provider and team was 0.56. For face validity, the Standing Committee noted that it convened a panel of seven palliative care communication experts and noted that the average ratings for the measure were high. Overall, the Standing Committee determined that these results demonstrated validity.
- The Standing Committee expressed a major concern regarding validity: the lack of adjustment for some risk factors, such as substance abuse. The Standing Committee noted the measure could allow for "cherry-picking" patients who are more receptive to palliative care, thereby skewing the results.
- The Standing Committee also expressed concerns about the measure's lack of exclusions and measure accuracy when responses are highly variable from patient to patient. The Standing Committee urged the developers to consider these concerns strongly as they move forward; however, it still noted that the measure was valid. The developer noted that they would take these recommendations under consideration as they continue to improve the measure.
- The Standing Committee asked the developer to clarify whether the measure is disadvantageous against organizations that have a higher percentage of underserved populations. The developer noted that they removed demographic information from the risk adjustment model so as to not penalize programs that serve disadvantaged populations. However, initial testing of the risk adjustment model, which included demographic information, such as race, showed that demographics were not correlated with the measure. The developers also clarified that the measure data can be stratified to inform quality improvement.
- The Standing Committee voted to accept the SMP's ratings for reliability and validity and passed the measure on both criteria.

3. Feasibility: Total votes-13; **H-2; M-11; L-0; I-0**

(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c. Susceptibility to inaccuracies/ unintended consequences identified; 3d. Data collection strategy can be implemented)

Rationale:

- The Standing Committee acknowledged that the survey instrument can be completed via web, on paper, or through telephone in English; it also acknowledged that eligibility is determined based on coded visit information in the electronic health record.
- The Standing Committee discussed that using a vendor to deliver the survey would add burden to organizations due to cost. The developer noted that although this is true, they further reduced the burden for the measure users by designating responsibility to the survey vendor for identifying eligible cases using electron/automated queries, fielding the survey in appropriate time frames, summarizing the data

for program-level quality improvement, and submitting the data to CMS. The Standing Committee agreed that this was a feasible strategy.

- The Standing Committee noted that the developer held a commenting period, and most respondents noted that data collection was very feasible (21.8 percent) or somewhat feasible (42.7 percent).

4. Usability and Use:

(Used and useful to the intended audiences for 4a. Accountability and Transparency; 4b. Improvement; and 4c. Benefits outweigh evidence of unintended consequences)

4a. Use**: Total votes-12**; **Pass-12; No Pass-0**; 4b. Usability: **Total votes-13**; **H-2; M-10; L-1; I-0**

Rationale:

- The Standing Committee noted that this new measure is not currently in use; however, the developer is attempting to have the measure put in use in federal programs, specifically the Merit-Based Payment System (MIPS).
- The Standing Committee noted that when the developer gathered feedback from measure users, survey fatigue was the issue that stood out the most. The Standing Committee noted there is not much the developer can do to improve survey fatigue, and despite this concern, it believed that the measure still met the criteria for use and usability.
- The Standing Committee questioned whether the measure incentivizes gaming of the system as patients may feel the need to report positive results. However, the Standing Committee noted that because this is a patient-reported measure, gaming is a behavior that is difficult to control for in the results.

5. Related and Competing Measures

- This measure is related to the following measure:
    - NQF #2651 CAHPS Hospice Survey (Experience With Care)
- The Standing Committee highlighted the different target populations between the two measures and noted that the measures have been harmonized to the extent possible.

6. Standing Committee Recommendation for Endorsement: **Total votes- 13**; **Yes-12**; **No-1**

7. Public and Member Comment

- The developers submitted seven pre-evaluation comments in favor of the measure and provided clarifications and responses to the SMP's review in these comments.
- Four post-evaluation comments were received. Three commenters were in support of the measure. However, one commenter did not support the endorsement of the measure, stating that the measure should be broadened to include more serious illness symptom management actions beyond just pain management. The commenter highlighted that this would better align the measure with best practices. The Standing Committee noted that the measure met NQF criteria as specified and maintained its decision to recommend the measure for endorsement.

8. Consensus Standards Approval Committee (CSAC) Endorsement Decision: Total votes- 8; Yes-8; No-0 (July 26, 2022: Endorsed)

- The CSAC upheld the Standing Committee's decision to recommend the measure for endorsement.

9. Appeals

- No appeals were received.

Appendix B: Geriatrics and Palliative Care Portfolio—Use in Federal Programs*

NQF#	Title	Federal Programs (Finalized or Implemented)
0167	Improvement in Ambulation and Locomotion	None
0174	Improvement in Bathing	Home Health Compare Home Health Quality Reporting
0175	Improvement in Bed Transferring	Home Health Compare Home Health Quality Reporting
0176	Improvement in Management of Oral Medications	Home Health Compare Home Health Quality Reporting
0177	Improvement in Pain Interfering With Activity	None
0326	Advanced Care Plan	HEDIS Quality Measure Rating System
1628	Patients With Advanced Cancer Screened for Pain at Outpatient Visits	None
1626	Patients Admitted to ICU Who Have Care Preferences Documented	None
1641	Hospice and Palliative Care – Treatment Preferences	Hospice Compare
0210	Proportion Receiving Chemotherapy in the Last 14 Days of Life	Merit-Based Incentive Payment System (MIPS) Program Prospective Payment System – Exempt Cancer Hospital Quality Reporting
0213	Proportion Admitted to the ICU in the Last 30 Days of Life	Merit-Based Incentive Payment System (MIPS) Program Prospective Payment System – Exempt Cancer Hospital Quality Reporting
0216	Proportion Admitted to Hospice for Less Than Three Days	Merit-Based Incentive Payment System (MIPS) Program Prospective Payment System – Exempt Cancer Hospital Quality Reporting
1623	Bereaved Family Survey	None
1625	Hospitalized Patients Who Die an Expected Death With an ICD That Has Been Deactivated	None

NQF#	Title	Federal Programs (Finalized or Implemented)
3497	Evaluation of Functional Status (Basic and Instrumental Activities of Daily Living [ADL]) for Home-Based Primary Care and Palliative Care Patients	None
3500	Evaluation of Cognitive Function for Home-Based Primary Care and Palliative Care Patients	None
2651	CAHPS Hospice Survey (Experience With Care)	Hospice Quality Reporting Hospice Compare
3235	Hospice and Palliative Care Composite Process Measure—Comprehensive Assessment at Admission	Hospice Quality Reporting Hospice Compare
3645	Hospice Visits in the Last Days of Life	Hospice Quality Reporting
3665	Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood	None
3666	Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain	None

* CMS Measures Inventory Tool Last Accessed on August 11, 2022.

Appendix C: Geriatrics and Palliative Care Standing Committee and NQF Staff

STANDING COMMITTEE

R. Sean Morrison, MD (Co-Chair) (recused from review of NQF #3645, NQF #3665, and NQF #3666)
Co-Director, Patty and Jay Baker National Palliative Care Center
Director, National Palliative Care Research Center
Director, Hertzberg Palliative Care Institute, Icahn School of Medicine at Mount Sinai
New York, New York

Deborah Waldrop (Co-Chair)
Professor, University of Buffalo, School of Social Work
Buffalo, New York

Sree Batu, MD, FAAPMR, FAAHPM
Veteran Affairs Health System
Austin, Texas

Samira Beckwith, LCSW, FACHE, LHD
President and CEO, Hope HealthCare Services
Fort Myers, Florida

Amy J Berman, BSN, LHD, FAAN
Senior Program Officer, John A. Hartford Foundation
New York, New York

Cleanne Cass, DO, FAAHPM, FAAFP
Director of Community Care and Education, Hospice of Dayton
Dayton, Ohio

Jeff Garland, DMin, EdS, BCC – PCHAC
Chaplain, VNA Health Group Barnabas Health Home and Hospice & Palliative Care Center
Orange, New Jersey

Marian Grant, DNP, ACNP-BC, ACHPN (recused from review of NQF #3665 and NQF #3666)
Senior Regulatory Advisor, Coalition to Transform Advanced Care (C-TAC)
Washington, District of Columbia

George Handzo, BCC, CSSBB (recused from review of NQF #3665 and NQF #3666)
Health Services Research and Quality, HealthCare Chaplaincy
Los Angeles, California

Arif H. Kamal, MD, MBA, MHS, FACP, FAAHPM (recused from review of NQF #3645, NQF #3665, and NQF #3666)
Physician Quality and Outcomes Officer, Duke Cancer Institute
Durham, North Carolina

Janice Knebl, DO, MBA, FACOI, FACP
Director and Chief, Center for Geriatrics, University of North Texas Health Science Center
Fort Worth, Texas

Christopher Laxton, CAE
Executive Director, AMDA - The Society for Post-Acute and Long-Term Care Medicine
Columbia, Maryland

Katherine Lichtenberg, DO, MPH, FAAFP
Physician Director, Enhanced Personal Health Care, Anthem Blue Cross and Blue Shield
Saint Louis, Missouri

Kelly Michelson, MD, MPH, FCCM, FAP
Professor of Pediatrics and Julia and David Uihlein Professor of Bioethics and Medical Humanities
Director, Center for Bioethics and Medical Humanities, Northwestern University Feinberg School of Medicine
Attending Physician, Ann and Robert H. Lurie Children's Hospital of Chicago
Chicago, Illinois

Douglas Nee, PharmD, MS
Clinical Pharmacist
San Diego, California

Laura Porter, MD
Co-Investigator, Cancer Research United Kingdom
Washington, District of Columbia

Tracy Schroepfer, PhD, MSW (recused from review of NQF #3665 and NQF #3666)
Professor of Social Work, University of Wisconsin, Madison, School of Social Work
Madison, Wisconsin

Linda Schwimmer, JD
Attorney, President and CEO, New Jersey Health Care Quality Institute
Pennington, New Jersey

Christine Seel Ritchie, MD, MSPH (recused from review of NQF #3665 and NQF #3666)
Professor of Medicine in Residence, Harris Fishbon Distinguished Professor for Clinical Translational Research in Aging, University of California San Francisco, Jewish Home of San Francisco Center for Research on Aging
San Francisco, California

Janelle Shearer, RN, BSN, MA, CPHQ
Program Manager, Stratis Health
Bloomington, Minnesota

Karl Steinberg, MD, CMD, HMDC, HEC-C
Chief Medical Officer, Mariner Health Central
Chief Medical Officer, Beecan Health
Medical Director, Hospice by the Sea, Life Care Center of Vista, Carlsbad by the Sea Care Center
Oceanside, California

Paul E. Tatum, MD, MSPH, CMD, FAAHPM, AGSF (recused from review of NQF #3645, NQF #3665, and NQF #3666)
Associate Professor in the Division of Geriatrics and Palliative Medicine at the Dell Medical School, University of Texas, Austin
Austin, Texas

Sarah Thirlwell, MSc, MSc(A), RN, AOCNS, CHPN, CHPCA, CPHQ (recused from review of NQF #3665 and NQF #3666)
Clinical Administrator, LifePath Hospice, a Chapters Health System Affiliate
Tampa, Florida

NQF STAFF
Kathleen F. Giblin, RN
Senior Vice President, Emerging Initiatives and Program Operations
Acting Senior Vice President, Measurement Science and Application *(Former)*

Elizabeth Drye, MD, SM
Chief Scientific Officer, Measurement Science and Application

Tricia Elliott, DHA, MBA, CPHQ, FNAHQ
Senior Managing Director, Measurement Science and Application

Poonam Bal, MHSA
Senior Director, Measurement Science and Application

Matthew K. Pickering, PharmD
Senior Director, Measurement Science and Application

Mike DiVecchia, MBA, PMP
Director, Program Operations

Erica Brown, MHA, PMP
Project Manager, Program Operations

Paula Farrell, MSHQS, BSN, RN, CPHQ, LSSGB
Director, Measurement Science and Application

Oroma Igwe, MPH
Manager, Measurement Science and Application

Gabrielle Kyle-Lion, MPH
Analyst, Measurement Science and Application

Matilda Epstein, MPH
Temp Associate, Measurement Science and Application

Appendix D: Measure Specifications

NQF #3645 Hospice Visits in the Last Days of Life

STEWARD

CMS - DCPAC

DESCRIPTION

The proportion of hospice patients who have received visits from a Registered Nurse or Medical Social Worker (non-telephonically) on at least two out of the final three days of the patient's life.

TYPE

Process

DATA SOURCE

Claims

Data are obtained from Medicare Part A Hospice Fee-For-Service Claims with dates of discharge ending in Federal Fiscal Years 2018-2019; access was through the CMS Research Data Assistance Center (ResDAC) Chronic Conditions Warehouse (CCW).

LEVEL

Facility

SETTING

Behavioral Health, Home Care, Inpatient/Hospital, Post-Acute Care

NUMERATOR STATEMENT

The numerator of this measure is the number of patient stays in the denominator in which the patient and/or caregiver received visits from registered nurses or medical social workers on at least two of the final three days of the patient's life, as captured by hospice claims records.

NUMERATOR DETAILS

Registered nurse visits are identified by revenue code 055x (with the presence of HCPCS code G0299); Non-telephone visits by medical social workers are identified by revenue code 056x (other than 0569; HCPCP code G0155).

DENOMINATOR STATEMENT

The denominator for the measure includes all hospice patient enrollments in hospice with the patient discharged to death except those meeting exclusion criteria outlined below.

DENOMINATOR DETAILS

The denominator for the measure includes all hospice patient stays where the patient expired in hospice except for those with exclusions as identified below. Patients that expired in hospice care are indicated by reason for discharge code on the claim (PTNT_DSCHRG_STUS_CD equals [40, 41, or 42]]). Hospice patient dates of death must occur during the target period (in the development data, pooled Federal Fiscal Years 2018-2019).

EXCLUSIONS

Patient stays are excluded from the measure if the patient (1) received any continuous home care, respite care, or general inpatient care in the final three days of life or (2) if the patient was enrolled in hospice fewer than three calendar days.

EXCLUSION DETAILS

The exclusion criteria are:

1. Patient received any continuous home care, respite care or general inpatient care in the final three days of life (exclude if revenue codes = [0652, 0655, or 0656])

2. Patient was enrolled in hospice one or two calendar days, only.

The rationale for these exclusions is provided below (in section 2b.16).

RISK ADJUSTMENT

No risk adjustment or stratification

N/A; no risk adjustment or stratification for this process measure.

STRATIFICATION

N/A; no stratification for this process measure.

TYPE SCORE

Rate/proportion

Better quality = Higher score

ALGORITHM

1. The data are all Medicare hospice fee-for-service claims within the relevant time period; this measure is calculated over two pooled years (the measure development time period was Federal Fiscal Years 2018-2019; 10/1/17 – 9/30/19)

2. Identify all Medicare hospice decedents discharged to death within the time period of data as identified by the claims discharge stats code, PTNT_DSCHRG_STUS_CD equals [40, 41, or 42].

3. The exclusion criteria are that the:

1. Patient received any continuous home care, respite care or general inpatient care in the final three days of life (exclude if revenue codes = [0652, 0655, or 0656])

2. Patient was enrolled in hospice one or two days, only

4. Cases meeting the target process are identified as the number of patient stays in the denominator for which the patient and/or caregiver received visits from registered nurses or medical social workers on at least two days of the final three days of life

1. Registered nurse visits are identified by revenue code 055x (with the presence of HCPCS code G0299)

2. Non-telephone visits by medical social workers are identified by revenue code 056x (other than 0569; HCPCP code G0155)

5. The rates of patients meeting the target process are calculated for each hospice provider with at least 20 patients in the denominator during the time period of date

1. For each hospice, divide the total number of patients in the numerator (Step 4) by the total number of patients in the denominator (Steps 2 and 3) and multiply by 100

2. The measure is not calculated for hospices with fewer than 20 patients in the denominator

6. For this process measure there are no risk adjustments to measure scores

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N/A

N/A

NQF #3665 Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood

STEWARD

American Academy of Hospice and Palliative Medicine

DESCRIPTION

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

Response to NQF request for clarification: 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.

TYPE

Outcome: PRO-PM

DATA SOURCE

Instrument-Based Data, Electronic Health Records

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.

LEVEL

Clinician: Group/Practice

SETTING

Ambulatory Care

NUMERATOR STATEMENT

The Feeling Heard and Understood measure is calculated using top-box scoring. The top-box score refers to the percentage of patient respondents that give the most positive response. For

all four questions in this measure, the top box numerator is the number of respondents who answer "Completely true." An individual's score can be considered an average of the four top-box responses and these scores are adjusted for mode of survey administration and proxy assistance. Individual scores are combined to calculate an average score for an overall palliative care program.

NUMERATOR DETAILS

Data for this measure is collected by survey. For the Feeling Heard and Understood 4-item scale, "top box scoring" takes each data element and defines "Completely true" (i.e., the top-box response) as passing for that item, where 1 = passing and 0 = not passing. The number of top-box responses (up to four) can be averaged across the number of responded items to provide an individual's estimate for their proportion of Feeling Heard and Understood. The within-individual estimates are averaged at the program level to provide the measure score. Missing data in the outcome is naturally accommodated among the four response items by the modeling procedure for adjusted score estimation; thus no outcome imputation is necessary and should not be performed. Risk-adjusted program level measure scores are estimated using hierarchical generalized-linear models that relate the proportion of top-box patient-level outcome responses to program scores, conditioned on risk adjustment covariates (survey mode and proxy assistance).

DENOMINATOR STATEMENT

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

DENOMINATOR DETAILS

Denominator criteria:

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

AND

Ambulatory palliative care visit defined as:

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

WITH

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

[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 this statement, given additional guidance on where in the denominator statement to include it.

EXCLUSIONS

Denominator exclusions include:

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

EXCLUSION DETAILS

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 minimize patient burden. Patients who do not complete the item set measuring Feeling Heard and Understood will be excluded from the denominator as no data will be available on the proposed measure. Providers and programs will not be penalized for non-response. Patients who have died or are unable to complete the patient experience survey due to cognitive impairment will be excluded. Proxy assistance with the survey is allowed; however, following discussion with the project advisory board, we decided to exclude surveys that were completed solely by a proxy with no patient involvement for conceptual reasons. We elected to include proxy-assisted surveys and to add an adjustment for proxy assistance to account for small differences in measure components due to the proxy involvement.

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 (eg: 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 (eg: "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.

RISK ADJUSTMENT

Statistical risk model with risk factors (specify number of risk factors)

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).

STRATIFICATION

N/A

TYPE SCORE

Rate/proportion

Better quality = Higher score

ALGORITHM

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N/A

N/A

NQF #3666 Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain

STEWARD

American Academy of Hospice and Palliative Medicine

DESCRIPTION

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: 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. 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. 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.

TYPE

Outcome: PRO-PM

DATA SOURCE

Instrument-Based Data

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.

LEVEL

Clinician: Group/Practice

SETTING

Ambulatory Care

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.

NUMERATOR DETAILS

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").

DENOMINATOR STATEMENT

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

DENOMINATOR DETAILS

Denominator Criteria

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

AND

Ambulatory palliative care visit defined as:

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

WITH

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

[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.

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?"

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).

EXCLUSION DETAILS

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 (eg: 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 (eg: "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.

RISK ADJUSTMENT

Statistical risk model with risk factors (specify number of risk factors)

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).

STRATIFICATION

N/A

TYPE SCORE

Rate/proportion

Better quality = Higher score

ALGORITHM

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N/A

N/A

Appendix E: Related and Competing Measures

Comparison of NQF #3665 and NQF #2651

Steward/Developer

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

American Academy of Hospice and Palliative Medicine

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Centers for Medicare & Medicaid Services

Description

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

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

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death.

The publicly reported measures described here include the following six multi-item measures.

• Hospice Team Communication

• Getting Timely Care

• Treating Family Member with Respect

• Getting Emotional and Religious Support

• Getting Help for Symptoms

• Getting Hospice Training

In addition, there are two global rating items that are publicly-reported measures.

• Rating of the hospice care

• Willingness to recommend the hospice

Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS surveys.

List of CAHPS Hospice Survey Measures

Multi-Item Measures

Hospice Team Communication (Composed of 6 items)

- While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?
- While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
- How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?
- While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?
- While your family member was in hospice care, how often did the hospice team listen carefully to you?
- While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

Getting Timely Care (Composed of 2 items)

- While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
- How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

Treating Family Member with Respect (Composed of 2 items)

+ While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

+ While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

Providing Emotional Support (Composed of 3 items)

- While your family member was in hospice care, how much emotional support did you get from the hospice team?
- In the weeks after your family member died, how much emotional support did you get from the hospice team?
- +Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

Getting Help for Symptoms (Composed of 4 items)

- Did your family member get as much help with pain as he or she needed?
- How often did your family member get the help he or she needed for trouble breathing?
- How often did your family member get the help he or she needed for trouble with constipation?
- How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?

Getting Hospice Care Training (Composed of 5 items)

- Did the hospice team give you enough training about what side effects to watch for from pain medicine?
- Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?

- Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?
- Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?
- Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with your or your family member?

Global Rating Measures:

In addition to the multi-item measures, there are two "global" ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice.

- Rating of Hospice Care: Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?
- Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family?

The CAHPS Hospice Survey is part of the CAHPS family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/. CMS initiated national implementation of the CAHPS Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a "dry run" for at least one month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care)

A list of the CAHPS Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A

Numerator Statement

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

The Feeling Heard and Understood measure is calculated using top-box scoring. The top-box score refers to the percentage of patient respondents that give the most positive response. For all four questions in this measure, the top box numerator is the number of respondents who answer "Completely true." An individual's score can be considered an

average of the four top-box responses and these scores are adjusted for mode of survey administration and proxy assistance. Individual scores are combined to calculate an average score for an overall palliative care program.

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

CMS calculates CAHPS Hospice Survey measure scores using top-, middle- and bottom- box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below.

Denominator Statement

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

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

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection.

The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility.

Target Population

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

Adults (Age >= 18)

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Adult primary caregivers of hospice decedents

Type

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

Outcome: PRO-PM

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Outcome: PRO-PM

Data Source

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

Instrument-Based Data, Electronic Health Records

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Instrument-Based Data

Level

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

Clinician: Group/Practice

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Facility

Setting

NQF #3665 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF FEELING HEARD AND UNDERSTOOD

Ambulatory Care

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Other

Comparison of NQF #3666 and NQF #2651

Steward

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

American Academy of Hospice and Palliative Medicine

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Centers for Medicare & Medicaid Services

Description

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

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: 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. 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. 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.

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death.

The publicly reported measures described here include the following six multi-item measures.

- Hospice Team Communication
- Getting Timely Care
- Treating Family Member with Respect
- Getting Emotional and Religious Support
- Getting Help for Symptoms
- Getting Hospice Training

In addition, there are two global rating items that are publicly-reported measures.

• Rating of the hospice care

• Willingness to recommend the hospice

Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS surveys.

List of CAHPS Hospice Survey Measures

Multi-Item Measures

Hospice Team Communication (Composed of 6 items)

- While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?
- While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
- How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?
- While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?
- While your family member was in hospice care, how often did the hospice team listen carefully to you?
- While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

Getting Timely Care (Composed of 2 items)

- While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
- How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

Treating Family Member with Respect (Composed of 2 items)

- While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

- While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

Providing Emotional Support (Composed of 3 items)

- While your family member was in hospice care, how much emotional support did you get from the hospice team?
- In the weeks after your family member died, how much emotional support did you get from the hospice team?
- Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

Getting Help for Symptoms (Composed of 4 items)

- Did your family member get as much help with pain as he or she needed?
- How often did your family member get the help he or she needed for trouble breathing?
- How often did your family member get the help he or she needed for trouble with constipation?
- How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?

Getting Hospice Care Training (Composed of 5 items)

- Did the hospice team give you enough training about what side effects to watch for from pain medicine?
- Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?
- Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?
- Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?
- Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with your or your family member?

Global Rating Measures:

In addition to the multi-item measures, there are two "global" ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice.

- Rating of Hospice Care: Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?
- Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family?

The CAHPS Hospice Survey is part of the CAHPS family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/. CMS initiated national implementation of the CAHPS Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a "dry run" for at least one month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care)

A list of the CAHPS Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A

Numerator Statement

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

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.

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

CMS calculates CAHPS Hospice Survey measure scores using top-, middle- and bottom- box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below.

Denominator Statement

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

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

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection.

The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility.

Target Population

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

Adults (Age >= 18)

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Adult primary caregivers of hospice decedents

Type

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

Outcome: PRO-PM

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Outcome: PRO-PM

Data Source

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

Instrument-Based Data

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Instrument-Based Data

Level

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

Clinician: Group/Practice

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Facility

Setting

NQF #3666 AMBULATORY PALLIATIVE CARE PATIENTS' EXPERIENCE OF RECEIVING DESIRED HELP FOR PAIN

Ambulatory Care

NQF #2651 CAHPS® HOSPICE SURVEY (EXPERIENCE WITH CARE)

Other

Appendix F: Pre-Evaluation Comments

Comments received as of January 19, 2022.

#3665 Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood

Comment 1 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 (eg: 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.

Comment 2 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 (eg: "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 3 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 ***surveys that were completely filled out by a proxy are excluded*.** 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 ***no*** 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 4 by: American Academy of Hospice and Palliative Medicine

This comment is in response to SMP review.

- **Issue 3: Measure Score Calculation**

  R3: Additionally, the developer should clearly describe how the measure score is calculated. Specifically, how the results from the hierarchical logistic regression model are rolled up to a measure score. The model specified seems to be a 2-level model, what's unit of analysis? Survey item level response (which is binary) or patient level score (which is not binary)? Measure score reliability was assessed via hierarchical logistic regression model, although it is not clear how it was done, at survey item response level or patient score level?

- **Developer Response 3:** The Feeling Heard and Understood measure score is calculated using a hierarchical (two-level) risk-adjusted binomial model (see mathematical details below). The scores are rolled up using a set of baseline characteristics (in this case proxy assistance status and survey mode) such that each provider has the same set of characteristics. The patient is the unit of analysis. We use a binomial model because each respondent contributes two pieces of information: 1) the number of responses provided across the four Feeling Heard and Understood items; and 2) the number of top-box responses. The individual's score on this measure is the proportion of top-box responses on

these four items, i.e., a set of n = 4 trials with probability p of success. The average score is the estimated p (that as the reviewer notes, is not binary).

Please see mathematical calculations and equations provided separately to NQF staff due to inability to copy them in this form.

Comment 5 by: American Academy of Hospice and Palliative Medicine

This comment is in response to SMP review.

- **Issue 4: Measure Score Calculation**

  R1:(Re: reliability testing) I was unclear if the hierarchical model accounted for nesting within patient and facility. It looks like items (not patient scores) were the level of analysis, but without accounting for the nesting within patient? If the patient score was the level of analysis, then I don't understand the model form (logistic); Entity-level testing revealed good signal to noise reliability, but I'm a little unclear how the beta binomial distribution was used when the patient score is a proportion (not binomial).

- **Developer Response 4:** We believe we understand where the confusion arises. The model is estimated at the patient-level, where a patient's score is a summary of the four binary items. We use a binomial model where the number of trials (i.e., n) are the items and the outcome is the proportion (i.e., p) of top-box (binary) responses to these items and represents an individual's average top-box response. We are considering an individual's score as a simple average and not explicitly modeling an individual effect for items (i.e., no nesting). Where there might be confusion is that under a binomial model, the form of the model is very similar to a standard logistic regression, but the number of trials (i.e., n) is included in the actual estimation (see the probability distribution here https://en.wikipedia.org/wiki/Binomial_distributionand when n = 1 we get back what is normally the logistic regression model for binary outcomes). There are more details in the previous response that explicitly mathematically describes the model that was estimated.

  We also should make clear that the model in the previous response is not exactly the same as the traditional beta-binomial model (https://en.wikipedia.org/wiki/Beta-binomial_distribution) because we do not place beta priors on each individual's probability of success. Beta-binomial models have historical relevance in Bayesian estimation because of computational tractability, but recent software (e.g. the Stan programming language for Bayesian models https://mc-stan.org/) have made alternative models possible. Our model is a hierarchical generalized linear model where we assume a linear form on the probability of success to perform risk-adjustment and differs somewhat in structure from the beta-binomial but achieves the same effect.

Comment 6 by: American Academy of Hospice and Palliative Medicine

This comment is in response to SMP review.

- **Issue 5: Data Element Reliability**

  R3: The developer ascertained both internal consistency and test-retest reliability for data elements. Each survey item has 5 response categories, however, for the measure, top box scoring is used. Therefore, the developer needs to clarify if the testing was consistent with the top box scoring approach; Data element reliability testing needs to be consistent with the top box scoring approach.

- **Developer Response 5:** To clarify, reliability of the four-data element scale using all 5 categorical options was high (Cronbach's alpha = 0.90) and similarly high for the dichotomous top-box option (Cronbach's alpha = 0.84).

Comment 7 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 8 by: American Academy of Hospice and Palliative Medicine

These comments are in response to SMP review.

- **Issue 7: Cognitive Testing**

  R6: Was *cognitive debriefing* done with patients before the measure was tested? I have a few issues with the survey items. Specifically, *item #2 is double barreled*, and research indicates that this leads to measurement error.

- **Developer Response 7:** We conducted 25 one-hour telephone cognitive interviews using a convenience sample of outpatient palliative care patients and caregivers to cognitively test survey items, with positive results. Participants generally understood the intended meaning of the question content. Some changes were made to improve the clarity of specific items. (See published manuscript: Rollison et al, Incorporating the Patient and Caregiver Voice in Palliative Care Quality Measure Development, Journal of Pain and Symptom Management, 2021)

  In particular, the "feeling heard and understood" concept was generally well-understood in its intended meaning as validation and acknowledgement from one's provider. It was determined necessary the two words – "heard" and "understood" together, because when asked separately, interviewees mistakenly understood the terms to refer to hearing (auditory ability) and comprehension (cognitive ability). This confusion also arose in early work to develop the single-item for use in inpatient settings (see: Gramling R et al, Feeling Heard and Understood: A Patient-Reported Quality Measure for the Inpatient Palliative Care Setting, Journal of Pain and Symptom Management, 2016), reinforcing our decision to

use both words together to represent the single construct of feeling seen, respected, acknowledged.

- **Issue 8: Communicating scores to providers**

  R9: Will there be any effort to communicate to the Provider the Top Box score on each of the four items so that the Provider can take a targeted intervention? The average score, while informative, does not provide the opportunity to make a targeted intervention.

- **Developer Response 8:** AAHPM will consider this option and if it's feasible, we will strive to provide the opportunity for targeted intervention.

Comment 9 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 nonrespondents.

- **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 (eg: 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 10 by: American Academy of Hospice and Palliative Medicine

This comment is in response to SMP review.

- **Issue 3: Risk Adjustment**

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Comment 11 by: American Academy of Hospice and Palliative Medicine

This comment is in response to the SMP's review.

Reliability

- **Issue 3: Measure Score Calculation**

  R3: Additionally, the developer should clearly describe how the measure score is calculated. Specifically, how the results from the hierarchical logistic regression model are rolled up to a measure score. The model specified seems to be a 2-level model, what's unit of analysis? Survey item level response (which is binary) or patient level score (which is not binary)? Measure score reliability was assessed via hierarchical logistic regression model, although it is not clear how it was done, at survey item response level or patient score level?

- **Developer Response 3:** The Feeling Heard and Understood measure score is calculated using a hierarchical (two-level) risk-adjusted binomial model (see mathematical details below). The scores are rolled up using a set of baseline characteristics (in this case proxy assistance status and survey mode) such that each provider has the same set of

characteristics. The patient is the unit of analysis. We use a binomial model because each respondent contributes two pieces of information: 1) the number of responses provided across the four Feeling Heard and Understood items; and 2) the number of top-box responses. The individual's score on this measure is the proportion of top-box responses on these four items, i.e., a set of n = 4 trials with probability p of success. The average score is the estimated p (that as the reviewer notes, is not binary).

More mathematically, our measure assumes that within provider i for each individual j, the k = 1,2,3,4 questions that they respond to are from the following parametric distribution, Y(subscript ij) ~ Binomial(n[subscript ij], p[subscript ij]) where n(subscript ij) = Sigma(subscript k)R(subscript ijk) <= 4 where R(subscript ijk) is one if a question k is responded to and zero otherwise. Thus, the unit of analysis is the patient-level, n(subscript ij) is the number of questions that an individual responded to, and p(subscript ij) represents an individual's average number of top-box responses on the four items. Explicitly, the individual's score arises as a non-continuous value because we have up to four binary outcomes that are contributing to the likelihood function.

Let P(subscript i) represent an indicator that individual j received care from provider i, X(subscript ij) represents the patient's characteristics, then the risk-adjusted model for a provider score assumes the following generalized linear model logit(E[Y(subscript ij)|X(subscript ij), a, standardized beta]) = logit(p[subscript ij]) = (standardized beta[subscript 0] + b[subscript i]P[subscript i]) + X(superscript T, subscript ij)a with an assumption that b(subscript i ~ N(0, lowercase omega[superscript 2, subscript b]). In this model, standardized beta(subscript 0) represents the average score across providers (i.e., grand mean), b(subscript i) is the difference between the average program score across providers (higher values represent better than average care) and a specific provider i's score, and a are risk adjusted coefficients.

To calculate a specific providers score, let X* be a set of "baseline" characteristics to standardize an individual provider's score against, in our example, the characteristics were a fixed survey mode and no proxy assistance. The score for provider i is estimated using the following p-hat(subscript i) = logit(superscript -1)((standardized beta[subscript 0] + b[subscript i]) + X*[superscript T]a)

In our specific submission X* was set to zero (indicating the baseline survey mode and no proxy assistance) and therefore the adjusted score is: p-hat(subscript i) = logit(superscript -1)(standardized beta[subscript 0] + b[subscript i])

Hopefully this clarifies both our model and the estimation of the provider risk-score.

#3666 Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain

Comment 1 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 nonrespondents.

- **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 (eg: 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.

Comment 2 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 (eg:

"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 3 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 ***surveys that were completely filled out by a proxy are excluded.*** 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 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 4 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 5 by: American Academy of Hospice and Palliative Medicine

These comments are in response to SMP review.

Validity

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Comment 6 by: American Academy of Hospice and Palliative Medicine

These comments are in response to SMP review.

Reliability

- **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 ICC's 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 are implemented. It is also possible that the data submitted by participating programs to us for the test was limited (eg: 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 7 by: American Academy of Hospice and Palliative Medicine

This comment is in response to the SMP's 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.**

Appendix G: Post-Evaluation Comments

NQF #3645 Hospice Visits in the Last Days of Life (Recommended)

Anna Kim, American Geriatrics Society; Submitted by Anna Kim

Comment ID#: 7959 (Submitted: 04/25/2022)
Council / Public: HPR
Level of Support: Member Does Support

Comment

The AGS supports Measure # 3645: Hospice Visits in the Last Days of Life. While hospice visits in the last days of life are not necessary for all patients, the overwhelming majority and their families need support in the last days, which are the hardest for both patients and families. We believe that hospice visits are critically important during this time.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Katie Wehri, Katie Wehri

Comment ID#: 7989 (Submitted: 04/29/2022)
Council / Public: Public
Level of Support: N/A

Comment

Since 1982, the National Association for Home Care & Hospice (NAHC) has been the leading association representing the interests of hospice, home health, and home care providers across the nation. Members are providers of all sizes and types -- from small rural agencies to large national companies -- and including government-based providers, nonprofit voluntary hospices, privately-owned companies and public corporations. As such, we welcome the opportunity to comment on NQF# 3645 - Hospice Visits in the Last Days of Life (HVLDL). The Geriatrics and Palliative Care Standing Committee evaluated and voted on this measure in its March 2022 meeting. NAHC recommends to the Committee that it reconsider this vote for the following reasons: • NAHC understands the reason for the focus on hospice visits delivered during the final days of life; however, we strongly urge the Committee to consider visit data in the context of an individualized plan of care reflective of patient and family wishes. The Meaningful Measure area for the Hospice Visits in Last Days of Life measure is “Person Centered Care” and the Healthcare Priority is “Strengthen Person & Family Engagement as Partners in their Care” We believe that, as currently constructed, the proposed measure does not fit within this area or priority and NQF should not

endorse it. Utilizing data that includes whether the patient/family desired a visit from the disciplines that are part of a measure or exclusion criteria that removes patients/caregivers who refuse visits offered by these various disciplines in the last days of life from the measure denominator would better reflect quality of care and better serve the Meaningful Measure and Healthcare Priority. • Care of the imminently dying patient is an important domain of palliative and hospice care. NAHC further appreciates the individualized plan of care based on patient and family needs and desires and the value of visits and services delivered by all members of the hospice interdisciplinary group (IDG) consistent with such plan of care. The core services of hospice care include a full complement of disciplines – physician, registered nurse, and medical social worker, patoral or other counselor. These disciplines are recognized as the core of hospice care because they address pain and symptoms that occur at the physical, emotional and spiritual level. This is the essence of hospice care. Therefore, the services provided by all core members of the IDG should be included in any visit measure. Also of note is the possibility that the majority of patients/families distinguish hospice staff visits by type, i.e. social worker or nurse, chaplain or aide, but do not distinguish further. Specifically, CMS should consider the possibility that patients/families do not distinguish between an RN and LPN but, rather, simply recognize that a "nurse" is making or made a visit. Of course, credentials of the individual making the visit are present on a nametag, but this is often not scrutinized by patients/families once they know the individual and, after time, the LPN versus RN license is forgotten. At a minimum, CMS should consider inclusion of all nursing visits, RN and LPN, in the HVLDL measure. • The 2020 Abt Associates report, Hospice Quality Reporting Program Quality Measures and Assessment Instruments Development, Modification and Maintenance, and Quality Reporting Oversight Support, provides background information on the development of the HVLDL. Unfortunately, the NQF Geriatrics and Palliative Care Committee was not presented with this report or the details of some of the data from the report prior to voting. Specifically, the data shows positive correlation between RN and MSW visits and CAHPS Hospice Survey outcomes although it is a low correlation. The correlation with chaplain and aide visits is also low. Granted, RN and MSW visit correlations are higher, but these visits are in the same correlation category as chaplain and aide visits per the data. None of the visit types had a moderate (0.5-0.7) or strong (0.7-1) correlation with the CAHPS Hospice Survey outcomes. It was mentioned by Committee members during the March 2022 review that the data does not align with the experience of some Committee members in that visits from other disciplines, specifically chaplain, are valued by patients and families. In fact, in the initial review of the measure the Committee suggested that the measure could be further strengthened by expanding the care disciplines covered, conducting a more holistic review of patient and caregiver end of life desires, and including postmortem visits and pediatric palliative care hospice patients. Hospice visit data and its correlation to the CAHPS hospice survey results should be further analyzed, including analysis that incorporates visits in the context of the individualized plan of care and the patient's wishes regarding visits. If warranted based on this data, CMS should expand any visit data utilized in the HQRP to include all core disciplines. • Claims-based visit data, from which the HVLDL is calculated, do not provide a true picture of hospice services delivered to Medicare hospice beneficiaries. This is because they do not include telehealth visits. Some patients and families prefer this type of visit especially in the final days of life. NAHC strongly recommends that telehealth visits be included in the HVLDL as these visits are indicators of care and services provided by the hospice and are

related to and ordered on the plan of care. An identifier for telehealth visits on hospice claims would allow CMS to capture this data, and NAHC and other hospice stakeholders have urged CMS to create a code or other identifier for this purpose. • The Hospice Outcome & Patient Evaluation (HOPE) instrument, currently in the beta testing phase, will capture data as hospice care is being delivered to patients, a gap in the HQRP that CMS sought to close in recent years. The amount of data and information available not only to consumers but also to the measure steward, CMS, and hospice providers from the HQRP is relatively small. The HOPE will bring significantly more data and information to the HQRP that will allow for more robust quality measures. It is anticipated that the HOPE will be in use soon by hospices. NAHC strongly recommends the impact of the measures anticipated from the HOPE on visits in last days of life be considered, to eliminate any possible future duplication. We appreciate the opportunity to submit these comments and strongly urge the Committee to reconsider its vote on NQF #4635 – Hospice Visits in the Last Days of Life. Sincerely, Katie Wehri Director of Home Health & Hospice Regulatory Affairs

Developer Response

Thank you for your comments regarding Hospice Visits in the Last Days of Life (HVLDL). we appreciate your thoughtful and input, and we have prepared response addressing the important issues you raised. We are grateful that the intent of the measure is understood. We were also happy that the measure's performance met all NQF criteria for variability, validity, and reliability, and was recommended for endorsement. We welcome the opportunity to address the issues raised. Visits by professional hospice staff - registered nurses and social workers - have been cited in focus groups as being particular helpful in the last days of life by bereaved family. Such attestations led CMS to incentivize visits by these staff, only (and not the full IDG team) in the Service Intensity Add-On policy implemented in 2016. Subsequently in development of HVLDL, CMS conducted a per-discipline analysis comparing the receipt of visits with the hospices' CAHPS outcome scores. Visits by registered nurses and social workers were the only two disciplines which yielded a meaningful positive correlation. A previously developed measure, Hospice Visits When Death is Imminent (HVWDII), encompassed a broader array of the disciplines of the IDG. This measure, encompassing the full IDG, failed to meet NQF testing standards, directly resulting from poor validity evidence (i.e., no relation to CAHPS scores), as detailed in a report CMS has published on its website since 2020 (https://www.cms.gov/files/document/hqrphospice-visits-when-death-imminent-testing-re-specification-reportoctober-2020.pdf). Based on our data analysis, we believe another measure broadly encompassing the full IDG team would similarly fail as was the case with HVWDII. CMS re-specified HVWDII as HVLDL, which meets testing criteria, and is moreover calculated using claims data, important information already collected by providers; CMS would be negligent to not publicly report this information, which we have shown to provide value to the Hospice Quality Reporting Program. It should be noted the evidence for chaplain visits was mixed - that is, the additional inclusion of chaplain visits may meet NQF testing standards and bring demonstrated value to the HQRP. However, at present chaplain visits are not captured by claims data. CMS believes HVLDL which focuses on RN/SW visits, only, brings meaningful value to the HQRP., and the lack of chaplain visits should not prevent the public receive otherwise useful data. We appreciate the commenter's note to consider the HOPE data as a source of chaplain visits in the future. The commenter notes that end-of-life visits may not occur due to refusals. CMS had

implicitly allowed for refusals during measure design, by specifying the measure to counts visits in two of the last three days or life, instead of visits on each of last three days. Also, CMS believes there is value to a broad, population-based measures. CMS certainly expects that caregiver refusals of visits will occur - and indeed family wishes of privacy near death a of paramount to be respected - and scores are not expected to ever be 100%. But basic analyses demonstrate there is important variation across hospices, more so than could plausibly be explained by differences in patient refusals across hospices. CMS believes this variation reveals meaningful differences in care delivery that could be useful to patients and their families when making a choice about the type of provider from whom they wish to receive care. The commenter raised the issue of telehealth. While we appreciate the comment, the steward at this time intends to keep the measure as specified, with in-person visits being the focus. CMS is proud of the new HOPE instrument currently in development, which will collect more information on hospice quality of care and will greatly enhance what is currently reported in the Hospice Quality Reporting Program. However, HOPE has not yet been nationally implemented, and no data has been collected, so it will be some time before measures from national HOPE data can be publicly reported. CMS has claims data on hand right now and would be remiss to not report this useful information. Patients and families making a difficult decision during an emotional time need assistance now and HVLDL will assist to help healthcare consumers make an informed choice.

NQF Response

N/A

NQF Committee Response

Thank you for your comment. The Standing Committee notes that there is value in monitoring the quality of care provided by registered nurses and social workers during the last-days-of-life. While the Standing Committee recognizes the concern that certain disciplines are excluded from the measure, the Standing Committee maintains that the measure meets NQF criteria as specified and stands by the decision to recommend the measure for endorsement. However, the Standing Committee encourages the developer to monitor data and billing codes, as they become available, to support the inclusion of other interdisciplinary groups (e.g., chaplains, licensed practical nurses) within future iterations of the measure. The Standing Committee also recommended that the developer consider returning for early NQF maintenance review, prior to the designated three years, if including additional disciplines becomes more feasible.

Marian Grant, C-TAC; Submitted by Dr. Marian Grant, DNP, RN

Comment ID#: 7979 (Submitted: 04/27/2022)
Council / Public: CON
Level of Support: N/A

Comment

C-TAC supports this measure

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Mr. George Handzo, Rev., BCC, CSSBB, HealthCare Chaplaincy Network

Comment ID#: 7986 (Submitted: 04/29/2022)
Council / Public: Public
Level of Support: N/A

Comment

The HealthCare Chaplaincy Network appreciates CMS' goal of developing a measure that seeks to improve the quality of care currently being provided to beneficiaries and their families at the end-of-life. We welcome the opportunity to comment on this measure. There is clear evidence that the last days of life for a hospice patient can be times of high symptom burden. Both patients and family caregivers can have high needs in all domains of care. If the patient and family desire a visit from hospice staff, it is certainly within the hospice's responsibility to deliver it. The evidence suggests that many hospices may not be meeting this goal reliably and there appears justification for a quality measure to help improve this situation. However, the measure itself should be of high quality and patient-centered. The Meaningful Measure area for the Hospice Visits in Last Days of Life measure is "Person Centered Care" and the Healthcare Priority is "Strengthen Person & Family Engagement as Partners in their Care". We believe that, as currently constructed and without modification, the proposed measure does not fit within this priority and NQF should not endorse it. Arguably, the central tenet of the patient and family-centered care that CMS promises to deliver to all beneficiaries is to enable the care that the patient and family want when they want it and not impose care on patients that they do not desire. This measure as currently constructed incentivizes hospices to impose RN and social worker visits on patients and families who may not want them and where a visit from a different member of the hospice interdisciplinary group may be more appropriate. Furthermore, the HVLDL measures does not allow the virtual telehealth visits that some families prefer and discourages hospices from meeting the end-of-life spiritual and religious needs of patients and families by focusing heavily on only the medical portion of the interdisciplinary team. This measure does not serve the Meaningful Measure or Healthcare Priority as intended. It is our strong belief that analysis utilizing data that includes whether the patient/family desired a visit from the disciplines that are part of a measure or exclusion criteria that removes patients/caregivers who refuse visits offered by these various disciplines in the last days of life from the measure denominator would better reflect quality of care and better serve the Meaningful Measure and Healthcare Priority. Collecting and monitoring data of visits in the last days of life is understandable, and the Coalition strongly urges CMS to consider visit data in the context of an individualized plan of care reflective of patient and family wishes. Furthermore, we suggest a clear claims-based indicator that outlines spiritual care visits. This provision will accurately serve the purpose of reducing administrative and reporting burden that this measure seems to bring forward. The literature is clear that spiritual needs are prevalent at the end of life

and rise in importance as death approaches. There are indications that spiritual well-being buffers the potential impact of end-of-life despair. Most religious traditions also have important end-of-life rituals. The National Consensus Project Clinical Guidelines for Quality Palliative Care propose that maximizing the benefits of supporting spiritual and religious needs requires a trained professional health care chaplain-a spiritual care specialist. The current measure is effectively a barrier to the delivery of that spiritual/religious care by not permitting chaplain visits to be included in this measure, even if this is what the family chooses and desires at the end of life. There seems to be a major disconnect between the stated goal of the measure and the research used to describe it. The developer states the goal of the measure as follows: "Collecting information about hospice staff visits for measuring quality of care will encourage hospices to visit patients and caregivers and provide services that will address their care needs and improve quality of life during the patients' last days of life." It would seem that the goal is to have as many patients as possible and caregivers who want a visit to be visited so that their needs can be addressed. We completely agree with this goal. However, there is no discussion here of the quality of the visits-only the fact that those visits were made. The developers justify the measure based on patient satisfaction scores on the CAHPS. In the process they limit the hospice's incentive to deliver visits by limiting the disciplines (RN and social workers only) whose visits count (excluding physicians, LPNs, aides and chaplains) and excluding virtual visits which many patients might prefer. It seems that the developers have conflated two different goals-increasing the number of patients visited and meeting patient needs on one hand and measuring family satisfaction with the visits that are made on the other. We suggest they focus on the former and remove all restrictions on the members of the hospice staff whose visits count for the purposes of this measure. The 2020 Abt Associates report, Hospice Quality Reporting Program Quality Measures and Assessment Instruments Development, Modification and Maintenance, and Quality Reporting Oversight Support, provides background information on the development of the HVLDL. Unfortunately, the NQF Geriatrics and Palliative Care Committee was not presented with this report or the details of some of the data from the report prior to voting. Specifically, the data shows positive correlation between RN and MSW visits and CAHPS Hospice Survey outcomes although it is a low correlation. The correlation with chaplain and aide visits is also low. Granted, RN and MSW visit correlations are higher, but these visits are in the same correlation category as chaplain and aide visits per the data. None of the visit types had a moderate (0.5-0.7) or strong (0.7-1) correlation with the CAHPS Hospice Survey outcomes. It was mentioned by Committee members during the March 2022 review that the data does not align with the experience of some Committee members in that visits from other disciplines, specifically chaplain, are valued by patients and families. In fact, in the initial review of the measure the Committee suggested that the measure could be further strengthened by expanding the care disciplines covered, conducting a more holistic review of patient and caregiver end of life desires, and including postmortem visits and pediatric palliative care hospice patients. The Hospice Outcome & Patient Evaluation (HOPE) instrument, currently in the beta testing phase, will capture data as hospice care is being delivered to patients, a gap in the HQRP that CMS sought to close in recent years. The amount of data and information available not only to consumers but also to CMS and hospice providers from the HQRP is relatively small. The HOPE will bring significantly more data and information to the HQRP that will allow for more robust quality measures. It is anticipated that the HOPE will be in use soon by hospices. The Coalition urges CMS to consider the impact of the

measures anticipated from the HOPE on visits in last days of life, to eliminate any possible future duplication. In sum, this measure is much needed however, it must be of the highest quality itself. The measure can reach that status with three simple changes: 1) Removing the restrictions on the disciplines of the staff whose visits count, 2) allowing virtual visits, and 3) inserting an exception to the denominator for patients and families who are documented to not want a visit of any kind at end of life (last 3 days). Therefore, until such time as appropriate changes can be made, HCCN recommends the Committee reconsider its vote to endorse the HVLDL measure. HealthCare Chaplaincy Network Since its founding in 1961, HealthCare Chaplaincy Network (HCCN) has led the way in the integration of spiritual care in health care through clinical practice, education, research, and advocacy. The organization has grown from a small program providing hospital chaplaincy in the New York metropolitan area into an internationally recognized model for multi-faith spiritual care, education, and research. The parent company of the Spiritual Care Association (SCA) and the SCA University of Theology and Spirituality (UTS), HCCN has catalyzed spiritual care research through a grant from the John Templeton Foundation, which has resulted in ground-breaking studies that provide an evidence base for the effectiveness of spiritual care in health care. Through the publication of several key white papers, and the annual Caring for the Human Spirit Conference, HCCN's outreach and advocacy is now felt throughout the field of chaplaincy, nationally and internationally. Balboni TA, Paulk ME, Balboni MJ, Phelps AC, Loggers ET, Wright AA, Block SD, Lewis EF, Peteet JR, Prigerson HG. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. J Clin Oncol. 2010 Jan 20;28(3):445-52. doi: 10.1200/JCO.2009.24.8005. McClain, C. S., Rosenfeld, B., & Breitbart, W. (2003). Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. The lancet, 361(9369), 1603-1607. Chen, J., Lin, Y., Yan, J., Wu, Y., & Hu, R. (2018). The effects of spiritual care on quality of life and spiritual well-being among patients with terminal illness: a systematic review. Palliative medicine, 32(7), 1167-1179. Murray, S. A., Kendall, M., Grant, E., Boyd, K., Barclay, S., & Sheikh, A. (2007). Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. Journal of pain and symptom management, 34(4), 393-402.

Developer Response

Thank you for your comments regarding Hospice Visits in the Last Days of Life (HVLDL). we appreciate your thoughtful and input, and we have prepared response addressing the important issues you raised. We are grateful that the intent of the measure is understood. We were also happy that the measure's performance met all NQF criteria for variability, validity, and reliability, and was recommended for endorsement. We welcome the opportunity to address the issues raised. Visits by professional hospice staff - registered nurses and social workers - have been cited in focus groups as being particular helpful in the last days of life by bereaved family. Such attestations led CMS to incentivize visits by these staff, only (and not the full IDG team) in the Service Intensity Add-On policy implemented in 2016. Subsequently in development of HVLDL, CMS conducted a per-discipline analysis comparing the receipt of visits with the hospices' CAHPS outcome scores. Visits by registered nurses and social workers were the only two disciplines which yielded a meaningful positive correlation. A previously developed measure, Hospice Visits When Death is Imminent (HVWDII), encompassed a broader array of the disciplines of the IDG. This

measure, encompassing the full IDG, failed to meet NQF testing standards, directly resulting from poor validity evidence (i.e., no relation to CAHPS scores), as detailed in a report CMS has published on its website since 2020 (https://www.cms.gov/files/document/hqrphospice-visits-when-death-imminent-testing-re-specification-reportoctober-2020.pdf). Based on our data analysis, we believe another measure broadly encompassing the full IDG team would similarly fail as was the case with HVWDII. CMS re-specified HVWDII as HVLDL, which meets testing criteria, and is moreover calculated using claims data, important information already collected by providers; CMS would be negligent to not publicly report this information, which we have shown to provide value to the Hospice Quality Reporting Program. It should be noted the evidence for chaplain visits was mixed - that is, the additional inclusion of chaplain visits may meet NQF testing standards and bring demonstrated value to the HQRP. However, at present chaplain visits are not captured by claims data. CMS believes HVLDL which focuses on RN/SW visits, only, brings meaningful value to the HQRP., and the lack of chaplain visits should not prevent the public receive otherwise useful data. We appreciate the commenter's note to consider the HOPE data as a source of chaplain visits in the future. The commenter notes that end-of-life visits may not occur due to refusals. CMS had implicitly allowed for refusals during measure design, by specifying the measure to counts visits in two of the last three days or life, instead of visits on each of last three days. Also, CMS believes there is value to a broad, population-based measures. CMS certainly expects that caregiver refusals of visits will occur - and indeed family wishes of privacy near death a of paramount to be respected - and scores are not expected to ever be 100%. But basic analyses demonstrate there is important variation across hospices, more so than could plausibly be explained by differences in patient refusals across hospices. CMS believes this variation reveals meaningful differences in care delivery that could be useful to patients and their families when making a choice about the type of provider from whom they wish to receive care. The commenter raised the issue of telehealth. While we appreciate the comment, the steward at this time intends to keep the measure as specified, with in-person visits being the focus. CMS is proud of the new HOPE instrument currently in development, which will collect more information on hospice quality of care and will greatly enhance what is currently reported in the Hospice Quality Reporting Program. However, HOPE has not yet been nationally implemented, and no data has been collected, so it will be some time before measures from national HOPE data can be publicly reported. CMS has claims data on hand right now and would be remiss to not report this useful information. Patients and families making a difficult decision during an emotional time need assistance now and HVLDL will assist to help healthcare consumers make an informed choice.

NQF Response

N/A

NQF Committee Response

Thank you for your comment. The Standing Committee notes that there is value in monitoring the quality of care provided by registered nurses and social workers during the last-days-of-life. While the Standing Committee recognizes the concern that certain disciplines are excluded from the measure, the Standing Committee maintains that the measure meets NQF criteria as specified and stands by the decision to recommend the measure for endorsement. However, the Standing

Committee encourages the developer to monitor data and billing codes, as they become available, to support the inclusion of other interdisciplinary groups (e.g., chaplains, licensed practical nurses) within future iterations of the measure. The Standing Committee also recommended that the developer consider returning for early NQF maintenance review, prior to the designated three years, if including additional disciplines becomes more feasible.

Ms. Amy Melnick, MPA, National Coalition for Hospice and Palliative Care

Comment ID#: 7980 (Submitted: 04/29/2022)
Council / Public: QMRI
Level of Support: Member Does NOT Support

Comment

The National Coalition for Hospice and Palliative Care appreciates CMS' goal of developing a measure that seeks to improve the quality of care currently being provided to beneficiaries and their families at the end-of-life. We welcome the opportunity to comment on #3645 Hospice Visits in the Last Days of Life. The Coalition is comprised of 13 national organizations working together so that all patients, families and caregivers will have equitable access to quality hospice and palliative care. There is clear evidence that the last days of life for a hospice patient can be times of high symptom burden. Both patients and family caregivers can have high needs in all domains of care. If the patient and family desire a visit from hospice staff, it is the hospice's responsibility to deliver it. The evidence suggests that many hospices may not be meeting this goal reliably and there appears justification for a quality measure to help improve this situation. However, the measure itself should be of high quality and patient centered. The Meaningful Measure area for the Hospice Visits in Last Days of Life measure is "Person Centered Care" and the Healthcare Priority is "Strengthen Person & Family Engagement as Partners in their Care". We believe that, as currently constructed and without modification, the proposed measure does not fit within this priority and NQF should not endorse it. The central tenet of the patient and family-centered care that CMS promises to deliver to all beneficiaries is to enable the care that the patient and family want when they want it and not impose care on patients that they do not desire. This measure, as currently constructed incentivizes hospices to impose RN and social worker visits on patients and families who may not want them and where a visit from a different member of the hospice interdisciplinary group may be more appropriate. Furthermore, the HVLDL measures does not allow the virtual telehealth visits that some families prefer and discourages hospices from meeting the end-of-life spiritual and religious needs of patients and families by focusing heavily on only the medical portion of the interdisciplinary team. This measure does not serve the Meaningful Measure or Healthcare Priority as intended. It is our strong belief that analysis utilizing data that includes whether the patient/family desired a visit from the disciplines that are part of a measure or exclusion criteria that removes patients/caregivers who refuse visits offered by these various disciplines in the last days of life from the measure denominator would better reflect quality of care and better serve the Meaningful Measure and Healthcare Priority. Collecting and monitoring data of visits in the last days of life is highly desirable and needed, however, the Coalition strongly urges CMS to consider visit data in the context of an individualized plan of care reflective of patient and family wishes. The literature is clear that spiritual needs are prevalent at the end of life and rise in importance as death approaches. There are indications that spiritual well-being buffers the potential impact of

end-of-life despair. Most religious traditions also have important end-of-life rituals. The National Consensus Project Clinical Guidelines for Quality Palliative Care propose that maximizing the benefits of supporting spiritual and religious needs requires a trained professional health care chaplain-a spiritual care specialist. The current measure is effectively a barrier to the delivery of that spiritual/religious care by not permitting chaplain visits to be included in this measure, even if this is what the family chooses and desires at the end of life. There seems to be a major disconnect between the stated goal of the measure and the research used to describe it. The developer states the goal of the measure as follows: "Collecting information about hospice staff visits for measuring quality of care will encourage hospices to visit patients and caregivers and provide services that will address their care needs and improve quality of life during the patients' last days of life." The Coalition supports the overarching goal of members of the interdisciplinary hospice team visiting patients and families during the last three days of life (unless of course the patient and family declines a visit). However, there is no discussion here of the quality of the visits-only the fact that those visits were made. The developers justify the measure based on patient satisfaction scores on the CAHPS. In the process they limit the hospice's incentive to deliver visits by limiting the disciplines (RN and social workers only) whose visits count (excluding physicians, LPNs, aides and chaplains) and excluding virtual visits which many patients might prefer. It seems that the developers have conflated two different goals-increasing the number of patients visited and meeting patient needs on one hand and measuring family satisfaction with the visits that are made on the other. We strongly recommend restrictions on the members of the hospice staff whose visits count for the purposes of this measure. The 2020 Abt Associates report, Hospice Quality Reporting Program Quality Measures and Assessment Instruments Development, Modification and Maintenance, and Quality Reporting Oversight Support, provides background information on the development of the HVLDL. Unfortunately, the NQF Geriatrics and Palliative Care Committee was not presented with this report or the details of some of the data from the report prior to voting. Specifically, the data shows positive correlation between RN and MSW visits and CAHPS Hospice Survey outcomes although it is a low correlation. The correlation with chaplain and aide visits is also low. Granted, RN and MSW visit correlations are higher, but these visits are in the same correlation category as chaplain and aide visits per the data. None of the visit types had a moderate (0.5-0.7) or strong (0.7-1) correlation with the CAHPS Hospice Survey outcomes. In the initial review of the measure, the Committee suggested that the measure could be further strengthened by expanding the care disciplines covered, conducting a more holistic review of patient and caregiver end of life desires, and including postmortem visits and pediatric palliative care hospice patients. The Hospice Outcome & Patient Evaluation (HOPE) instrument, currently in the beta testing phase, will capture data as hospice care is being delivered to patients, a gap in the HQRP that CMS sought to close in recent years. The amount of data and information available not only to consumers, but also to CMS and hospice providers from the HQRP is relatively small. The HOPE will bring significantly more data and information to the HQRP that will allow for more robust quality measures. It is anticipated that the HOPE will be in use soon by hospices. The Coalition urges CMS to consider the impact of the measures anticipated from the HOPE on visits in last days of life, to eliminate any possible future duplication. In sum, this measure is much needed however, it must be of the highest quality itself. The measure can reach that status with three simple changes: 1) Removing the restrictions on the disciplines of the staff whose visits count, 2) allowing virtual visits,

and 3) inserting an exception to the denominator for patients and families who are documented to not want a visit of any kind at end of life (last 3 days). Therefore, until such time as appropriate changes can be made, the Coalition recommends the Committee reconsider its vote to endorse the HVLDL measure. Balboni T, Balboni M, Paulk ME, Phelps A, Wright A, Peteet J, Block S, Lathan C, Vanderweele T, Prigerson H. Support of cancer patients' spiritual needs and associations with medical care costs at the end of life. Cancer. 2011 Dec 1;117(23):5383-91. doi: 10.1002/cncr.26221. Balboni TA, Paulk ME, Balboni MJ, Phelps AC, Loggers ET, Wright AA, Block SD, Lewis EF, Peteet JR, Prigerson HG. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. J Clin Oncol. 2010 Jan 20;28(3):445-52. doi: 10.1200/JCO.2009.24.8005. McClain, C. S., Rosenfeld, B., & Breitbart, W. (2003). Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. The lancet, 361(9369), 1603-1607. Chen, J., Lin, Y., Yan, J., Wu, Y., & Hu, R. (2018). The effects of spiritual care on quality of life and spiritual well-being among patients with terminal illness: a systematic review. Palliative medicine, 32(7), 1167-1179. Murray, S. A., Kendall, M., Grant, E., Boyd, K., Barclay, S., & Sheikh, A. (2007). Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. Journal of pain and symptom management, 34(4), 393-402.

Developer Response

Thank you for your comments regarding Hospice Visits in the Last Days of Life (HVLDL). we appreciate your thoughtful and input, and we have prepared response addressing the important issues you raised. We are grateful that the intent of the measure is understood. We were also happy that the measure's performance met all NQF criteria for variability, validity, and reliability, and was recommended for endorsement. We welcome the opportunity to address the issues raised. Visits by professional hospice staff - registered nurses and social workers - have been cited in focus groups as being particular helpful in the last days of life by bereaved family. Such attestations led CMS to incentivize visits by these staff, only (and not the full IDG team) in the Service Intensity Add-On policy implemented in 2016. Subsequently in development of HVLDL, CMS conducted a per-discipline analysis comparing the receipt of visits with the hospices' CAHPS outcome scores. Visits by registered nurses and social workers were the only two disciplines which yielded a meaningful positive correlation. A previously developed measure, Hospice Visits When Death is Imminent (HVWDII), encompassed a broader array of the disciplines of the IDG. This measure, encompassing the full IDG, failed to meet NQF testing standards, directly resulting from poor validity evidence (i.e., no relation to CAHPS scores), as detailed in a report CMS has published on its website since 2020 (https://www.cms.gov/files/document/hqrphospice-visits-when-death-imminent-testing-re-specification-reportoctober-2020.pdf). Based on our data analysis, we believe another measure broadly encompassing the full IDG team would similarly fail as was the case with HVWDII. CMS re-specified HVWDII as HVLDL, which meets testing criteria, and is moreover calculated using claims data, important information already collected by providers; CMS would be negligent to not publicly report this information, which we have shown to provide value to the Hospice Quality Reporting Program. It should be noted the evidence for chaplain visits was mixed - that is, the additional inclusion of chaplain visits may meet NQF testing standards and bring demonstrated value to the HQRP. However, at present chaplain visits are not captured by claims data. CMS believes HVLDL which focuses on RN/SW visits, only, brings meaningful value to the

HQRP., and the lack of chaplain visits should not prevent the public receive otherwise useful data. We appreciate the commenter's note to consider the HOPE data as a source of chaplain visits in the future. The commenter notes that end-of-life visits may not occur due to refusals. CMS had implicitly allowed for refusals during measure design, by specifying the measure to counts visits in two of the last three days or life, instead of visits on each of last three days. Also, CMS believes there is value to a broad, population-based measures. CMS certainly expects that caregiver refusals of visits will occur - and indeed family wishes of privacy near death a of paramount to be respected - and scores are not expected to ever be 100%. But basic analyses demonstrate there is important variation across hospices, more so than could plausibly be explained by differences in patient refusals across hospices. CMS believes this variation reveals meaningful differences in care delivery that could be useful to patients and their families when making a choice about the type of provider from whom they wish to receive care. The commenter raised the issue of telehealth. While we appreciate the comment, the steward at this time intends to keep the measure as specified, with in-person visits being the focus. CMS is proud of the new HOPE instrument currently in development, which will collect more information on hospice quality of care and will greatly enhance what is currently reported in the Hospice Quality Reporting Program. However, HOPE has not yet been nationally implemented, and no data has been collected, so it will be some time before measures from national HOPE data can be publicly reported. CMS has claims data on hand right now and would be remiss to not report this useful information. Patients and families making a difficult decision during an emotional time need assistance now and HVLDL will assist to help healthcare consumers make an informed choice.

NQF Response

N/A

NQF Committee Response

Thank you for your comment. The Standing Committee notes that there is value in monitoring the quality of care provided by registered nurses and social workers during the last-days-of-life. While the Standing Committee recognizes the concern that certain disciplines are excluded from the measure, the Standing Committee maintains that the measure meets NQF criteria as specified and stands by the decision to recommend the measure for endorsement. However, the Standing Committee encourages the developer to monitor data and billing codes, as they become available, to support the inclusion of other interdisciplinary groups (e.g., chaplains, licensed practical nurses) within future iterations of the measure. The Standing Committee also recommended that the developer consider returning for early NQF maintenance review, prior to the designated three years, if including additional disciplines becomes more feasible.

Stephanie Collingwood, UnityPoint Health; Submitted by Stephanie Collingwood

Comment ID#: 7964 (Submitted: 04/25/2022)
Council / Public: PRO
Level of Support: N/A

Comment

UnityPoint Health respectfully offers comments in support of measure 3645. UnityPoint Health is one of the nation's most integrated health care systems. Through more than 32,000 employees and our relationships with more than 480 physician clinics, 40 hospitals in urban and rural communities and 14 home health agencies throughout our 9 regions, UnityPoint Health provides care throughout Iowa, central Illinois, and southern Wisconsin. On an annual basis, UnityPoint Health hospitals, clinics and home health provide a full range of coordinated care to patients and families through more than 8.4 million patient visits. While this measure may result in additional operational burden, its important and meaningful for patients to have direct care in the last few days prior to their death. This allows providers to deliver additional support to family/loved ones on medication and treatment plans to reduce pain and suffering. Direct care providers are trained to identify the signs of an impending death, which family/loved ones are not. Those instructions and preparation for the patient's passing allow for a more peaceful dying process. As a health care organization, we understand family members may not always have the knowledge to recognize clinical rationale for direct care provided within the few days prior to their loved one's death, and therefore, it would not be captured on the Hospice CAHPS survey. UnityPoint Health is supportive of this measure.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

NQF #3665 Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood (Recommended)

Anna Kim, American Geriatrics Society; Submitted by Anna Kim

Comment ID#: 7960 (Submitted: 04/25/2022)
Council / Public: HPR
Level of Support: Member Does Support

Comment

The AGS supports patients' experience of feeling heard and understood as a key goal and benefit of palliative care. Patients want to be treated as an individual and have their symptoms and goals of care managed effectively, which may be challenging at times given provider time constraints.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Marian Grant, C-TAC; Submitted by Dr. Marian Grant, DNP, RN

Comment ID#: 7977 (Submitted: 04/27/2022)
Council / Public: CON
Level of Support: N/A

Comment

C-TAC strongly supports NQF endorsement of this measure. It is unique in capturing the patient's experience of communication with a health care provider and team and is thus an important way to incorporate the patient's voice. Although it was tested in palliative care programs, we strongly feel it should be considered for use in all quality programs as a core measure. C-TAC has been supportive of its development and validation and will now advocate for its use with our health system and payer members and in our policy advocacy with the Centers for Medicare and Medicaid and the Innovation Center there as well.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Ms. Amy Melnick, MPA, National Coalition for Hospice and Palliative Care

Comment ID#: 7981 (Submitted: 04/29/2022)
Council / Public: QMRI
Level of Support: Member Does Support

Comment

The National Coalition for Hospice and Palliative Care strongly supports NQF endorsement of this measure, #3665. The Coalition praises NQF for recognizing the utility and suitability of Feeling Heard and Understood measure to help measure quality care from the patient's perspective. This measure is a patient reported measures and was developed with patients and caregivers at the table from the very beginning including in each phase of measure development. The Coalition notes and appreciates that the Standing Committee and draft report recognize that this measure is demonstratively meaningful directly to patients. Although the issue of survey fatigue was raised in the report, we would like to remind NQF that 87% of patient and caregiver respondents during the

robust public comment period reported that they would be likely to complete a survey of their experience with their health care provider. We look forward to working with the measure steward, AAHPM at broadening this measure to other patient populations and settings.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Polly Friend

Comment ID#: 7973 (Submitted: 04/26/2022)
Council / Public: Public
Level of Support: N/A

Comment

WiserCare offers support for measure 3665. As a company, WiserCare respects the voice of the patient and the need for comprehensive discussions with a focus on understanding the patient's goals and preferences for care. We support this measure which helps to identify the extent the patient feels heard and understood, as well as to determine what is important in their life.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Stephanie Collingwood, UnityPoint Health; Submitted by Stephanie Collingwood

Comment ID#: 7963 (Submitted: 04/25/2022)
Council / Public: PRO
Level of Support: N/A

Comment

UnityPoint Health respectfully offers comments in support of measure 3665. UnityPoint Health is one of the nation's most integrated health care systems. Through more than 32,000 employees and our relationships with more than 480 physician clinics, 40 hospitals in urban and rural communities and 14 home health agencies throughout our 9 regions, UnityPoint Health provides care

throughout Iowa, central Illinois, and southern Wisconsin. On an annual basis, UnityPoint Health hospitals, clinics and home health provide a full range of coordinated care to patients and families through more than 8.4 million patient visits. The Center to Advance Palliative Care (CAPC) standards for quality palliative care support the importance and value of comprehensive provider and interdisciplinary team discussions focused on understanding, advocating, and incorporating the patient's goals into their care plan. Therefore, a measurement capturing the patient's experience with feeling understood, their best interests advocated, and goals reflected in their care as a unique person is meaningful data to support an evidenced based intervention. From an operational perspective, new information capture mechanisms would have to be introduced through patient experience survey. Today, this is supported in a variety of methods with the majority of home care surveys captured through paper mail. Overall, UnityPoint Health is supportive of this measure.

Developer Response

Thank you for your support of the measure. We agree that understanding the patient's experience of feeling heard and understood is meaningful information to drive improvements in care.

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

NQF #3666 Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain (Recommended)

Anna Kim, American Geriatrics Society; Submitted by Anna Kim

Comment ID#: 7961 (Submitted: 04/25/2022)
Council / Public: HPR
Level of Support: Member Does Support

Comment

The AGS supports Measure #3666: Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain and believes patients' experience of receiving desired help for pain is also a key goal and benefit of palliative care. The interdisciplinary team structure of palliative care offers patients a more holistic mechanism of addressing their pain and with appropriate follow-up. Multiple modalities may also help with improved pain management.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Dr. Marian Grant, DNP, RN, Coalition to Transform Advanced Care (C-TAC)

Comment ID#: 7978 (Submitted: 04/27/2022)
Council / Public: CON
Level of Support: N/A

Comment

C-TAC supports this measure and appreciate that it incorporates the patient's perspective regarding what their goal for pain management is. As with NQF# 3665 Patients' Experience of Feeling Heard and Understood, once this is endorsed C-TAC will advocate for its use with our health system and payer members and in our policy advocacy with the Centers for Medicare and Medicaid and the Innovation Center there as well.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Ms. Amy Melnick, MPA, National Coalition for Hospice and Palliative Care

Comment ID#: 7985 (Submitted: 04/29/2022)
Council / Public: QMRI
Level of Support: Member Does Support

Comment

The National Coalition for Hospice and Palliative Care strongly supports NQF endorsement of this measure, #3666. The Coalition praises NQF for recognizing the utility and suitability of Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain. This measure is from the patient's perspective of getting help they desired for pain, and pain is broadly defined to include spiritual and other non-physical sources of pain. As a patient reported measure, it was developed with patients and caregivers at the table from the very beginning including in each phase of measure development. Importantly, the Receiving Desired Help for Pain measure assesses whether patients are getting the kind of care that they want. This is very different from surveying whether standardized clinical outcomes have been met. Assessment of pain-related clinical outcomes (e.g., asking how bad pain is, on a scale of 1 to 10) is already possible through existing performance measures, yet this is a one-size-fits-all approach that does not incorporate the patient's goals of care. Asking patients to report on their experience of the care they received, and whether they feel their problem was addressed as they wished, is the only way to reflect the patient's perspective.

We look forward to working with the measure steward, AAHPM, at broadening this measure to other patient populations and settings.

Developer Response

N/A

NQF Response

Thank you for your comment. It has been shared with the Standing Committee and the measure developer.

NQF Committee Response

N/A

Stephanie Collingwood

Comment ID#: 7962 (Submitted: 04/25/2022)
Council / Public: PRO
Level of Support: N/A

Comment

3666- Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain UnityPoint Health respectfully offers comments in opposition of measure 3666 as outlined below. UnityPoint Health is one of the nation's most integrated health care systems. Through more than 32,000 employees and our relationships with more than 480 physician clinics, 40 hospitals in urban and rural communities and 14 home health agencies throughout our 9 regions, UnityPoint Health provides care throughout Iowa, central Illinois, and southern Wisconsin. On an annual basis, UnityPoint Health hospitals, clinics and home health provide a full range of coordinated care to patients and families through more than 8.4 million patient visits. The Center to Advance Palliative Care (CAPC) Serious Illness Model priorities include symptom management, however, is not limited to pain management. Serious illness management is aligned with a broader definition of symptom management. The unique and limited focus on only pain is an archaic lens on mature palliative care practice. If this measure were to broaden the focus to include serious illness symptom management versus the limited lens of pain, it would align with best known practice. As reflected in measure 3665, the palliative care practice symptom management priorities should align with the patient's unique needs assessment and aligned with the patient's goals of care. Example: "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 [serious illness symptoms] from their palliative care provider and team within 6 months of the ambulatory palliative care visit". From an operational perspective, new information capture mechanisms would have to be introduced through patient experience survey. Today, this is supported in a variety of methods with the majority of home care surveys captured through paper mail. UnityPoint Health opposes this measure as currently drafted and would recommend changing the language from "pain" to "serious illness symptoms".

Developer Response

Thank you for your comment. We agree that palliative care practice prioritizes serious illness symptom management broadly and not limited to pain. We limited the current measure development effort to pain management because it is a symptom commonly encountered in serious illness and was rated as a high priority for patients during our information gathering phase. Our measure was developed with input from a 30-member TECUPP which included patients and caregivers. The TECUPP discussed and ultimately decided against adding additional symptoms to the measure, in part due to concerns about measurement issues and difficulty comparing providers, since the measure was created for use in MIPS. Future work should expand on this to include other symptoms that may have different lookback periods, require additional cognitive testing to ensure appropriate wording and item structure, and as noted, require different information capture mechanisms.

NQF Response

N/A

NQF Committee Response

Thank you for your comment. The Standing Committee found that this measure meets NQF criteria as specified and maintained its decision to recommend the measure for endorsement.

National Quality Forum
1099 14th Street NW, Suite 500
Washington, DC 20005
https://www.qualityforum.org