

NATIONAL QUALITY FORUM

CONFERENCE CALL OF THE PALLIATIVE CARE AND EOL CARE ENDORSEMENT MAINTENANCE STEERING COMMITTEE

November 22, 2011

Committee Members Present: June Lunney, PhD, RN (co-chair); Sean Morrison, MD (co-chair); Russell Acevedo, MD; Eduardo Bruera, MD, FAAHPM; David Casarett, MD, MA; Robert Fine, MD, FAACP, Richard Goldstein, MD, FAAP; Sarah Hill, MA; Pamela Kalen; Mark Leenay, MD; Helene Martel, MA; Tina Picchi, MA, BCC; Tracy Schroepfer, PhD; Douglas White, MD, MAS.

NQF Staff Present: Heidi Bossley, MSN, MBA; Helen Burstin, MD, MPH; Eric Colchamiro, MPA; Lindsey Tighe, MS.

Others Present:

Laura Hanson, University of North Carolina; Hien Lu, Department of Veterans Affairs; Dale Lupu, American Academy of Hospice; Liz Silva, Deyta; Carol Spence, National Hospice and Palliative Care Organization; Martha Tecca, Deyta;

*The audio recordings from this discussion can be found on the project webpage.

WELCOME AND INTRODUCTIONS

Dr. Morrison welcomed the Steering Committee and provided a brief overview of the agenda. The purpose of this call was:

- for the Palliative and End-of-Life Care Steering Committee to review and discuss the comments received during the NQF Public and Member Comment period;
- determine the course of action for the submitted comments; and
- continue reviewing the measure developers' response to the Committee's suggested modifications for the measures.

The measure developers/stewards were available on the call to respond to questions from the Committee as needed.

PUBLIC AND MEMBER COMMENTS

The Palliative Care and End-of-Life Care Public and Member Comment period closed on November 15, 2011. A total of 121 comments from 33 individuals or organizations were received on measures both recommended and not recommended for endorsement as well as some general comments.

Please see the Palliative Care and End-of-Life Care project page for a spreadsheet of all of the comments received, including final responses from the Steering Committee. In addition, comments were referred to the measure developers and their responses have been included along with the Committee's responses.

Several dominant themes were identified in the comments received and were addressed by the Steering Committee as described below.

General Comments

NQF DOCUMENT – DO NOT CITE, QUOTE, REPRODUCE, OR DISTRIBUTE

NATIONAL QUALITY FORUM

Concerns with the underlying evidence and relationship to the outcome

Commenters suggested that several measures lacked a supportive evidence base for the topic of measurement. The Steering Committee had discussed this issue during its deliberations and determined that Steering Committee members were to utilize their expert judgment or apply additional evidence based on their own knowledge or expertise during the evaluation process, which is consistent with the NQF measure evaluation criteria and guidance outlined in the Evidence Testing Task Force. In some instances when the evidence presented for a particular measure in the measure submission form by a measure developer did not meet the NQF subcriteria of the quantity, quality, and consistency of the evidence, it was determined that the Committee's collective judgment was acceptable for those measures whose benefits far outweigh any potential risks associated with it.

Concern with the lack of outcome measures

Multiple comments were submitted noting that many of the measures evaluated were process, not outcome measures. The Steering Committee had noted this issue during its discussions, adding the need for development of outcome measures to the list of gap areas to be addressed in future work on palliative care and end-of-life care.

Comments on Measures Recommended for Endorsement

Request for harmonization of measures 1626 and 1641

Several comments received called for harmonization of Measures #1626 and #1641 since they believed that care preferences and treatment preferences were similar. The Committee reviewed the measures and agreed that the intended focus of the two measures differed in that most if not all patients have care preferences but many patients often do not have treatment preferences (e.g., life-sustaining treatments).

Request for pairing of measures 1634 & 1637 as well as 1638 & 1639

Several comments received questioned the necessity of the Pain Screening (measure #1634) and Dyspnea Screening (measure #1639) measures, as the Pain Assessment (measure #1637) and Dyspnea Treatment (measure #1638) measures are more proximal to the outcome. The Committee reasoned that screening leads to assessment or treatment and one cannot be accomplished without the other. To further strengthen the link between the two sets of measures, 1634 and 1637, and 1638 and 1639 are recommended as paired measures.

EVALUATION SUMMARY TABLES

Evaluation Summary—Candidate Consensus Standards Recommended for Endorsement

The summary of the comments and subsequent actions for each measure are highlighted in the evaluation summary tables below.

PAIN MANAGEMENT MEASURES

LEGEND: Y = Yes; N = No; C = Completely; P = Partially; M = Minimally; N = Not at all

1634: Hospice and Palliative Care- Pain Screening (measure specifications) (developer materials and meeting summaries)
--

Description: Percentage of hospice or palliative care patients who were screened for pain during the hospice admission evaluation /

NATIONAL QUALITY FORUM

<p>1634: Hospice and Palliative Care- Pain Screening (measure specifications) (developer materials and meeting summaries)</p> <p>palliative care initial encounter</p> <p>Numerator Statement: Patients who are screened for the presence or absence of pain (and if present, rating of its severity) using a standardized quantitative tool during the admission evaluation for hospice / initial encounter for hospital-based palliative care. Screening may be completed using verbal, numeric, visual analog, rating scales designed for use the non-verbal patients, or other standardized tools.</p> <p>Denominator Statement: Patients enrolled in hospice for 7 or more days OR patients receiving hospital-based palliative care for 1 or more days.</p> <p>Exclusions: Patients with length of stay < 7 days in hospice, or < 1 day in palliative care.</p> <p>Adjustment/Stratification: None</p> <p>Level of Analysis: Clinician : Group/Practice, Facility</p> <p>Type of Measure: Process</p> <p>Data Source: Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record</p> <p>Measure Steward: University of North Carolina- Chapel Hill 725 Martin Luther King Jr Blvd, CB 7590 Chapel Hill North Carolina 27599-7590</p>
<p>Steering Committee Recommendation for Endorsement: <u>Y-20, N-0, A-0</u></p> <p>Rationale:</p>
<p>If Applicable, Conditions/Questions for Developer:</p> <ol style="list-style-type: none"> 1) Steering Committee members requested harmonization of the numerator of this measure with that of measure 1628 2) Please explain the rationale for the denominator being limited to 1 day for palliative care and 7 days for hospice care <p>Developer Response:</p> <ol style="list-style-type: none"> 1) The developer harmonized the numerator with measure 1628: Patients with advanced cancer assessed for pain at outpatient visits (RAND), and it met the Committee's approval. 2) These two time intervals were selected after consulting with hospice and palliative care providers about the timeframes for evaluation. The aim was to allow for the timeframes be generalizable and realistic (in duration) for the scope of the initial evaluation. The measure, as tested, did not specify a definition of the initial evaluation.
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-12, M-7, L-1, I-0; 1c. Evidence Quantity H-14, M-6, L-0, I-0; Evidence Quality H-16, M-4, L-0, I-0; Evidence Consistency H-17, M-2, L-1; I-0)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The Steering Committee stated that the measure is important, particularly because it prompts treatment when pain screening is positive; however, it was noted that the supplied evidence is more directly related to a gap in pain assessment rather than screening. • This assessment, therefore, is triggered by the screening; a factor the Committee considered as additional evidence when making its decision.
<p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met.</u> <i>(2a. Reliability Testing: H-16, M-4, L-0, I-0; 2b. Validity Testing H-17, M-3, L-0, I-0; 2c. Disparities: H-11, M-7, L-2, I-0)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The Steering Committee noted that the specifications requiring that patients be enrolled in palliative care for 7 or more days OR hospice care for 1 or more days will exclude a significant percentage of patients. Steering Committee members would prefer to see the measure without these constraints. Ultimately, the Steering Committee recommended the measure as there is no testing or evidence for the measure with any other specifications.
<p>3. Usability: <u>H-16, M-3, L-1, I-0</u> <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Measure is important and prevalent. • From its use in the University of North Carolina's PEACE project, an effort that aimed to develop quality measures for hospice and palliative care. In this project, it was found to be useful for those seeking care and quality improvement.
<p>4. Feasibility: <u>H-19, M-1, L-0, I-0</u> <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p>

NATIONAL QUALITY FORUM

<p>1634: Hospice and Palliative Care- Pain Screening (measure specifications) (developer materials and meeting summaries)</p> <ul style="list-style-type: none"> The measure is easily implemented electronically. If electronic data are not available, Steering Committee members noted that substantial data collection effort may be required, as data must be extracted from the patient chart.
<p>5. Public & Member Comments:</p> <ul style="list-style-type: none"> A comment was received suggesting that this measure should not, in its denominator, exclude those patients with a shortened length of stay. The measure developer was in agreement with the concern expressed, but noted that, while they may consider expanding it in the future, this exclusion was recommended by the Technical Expert Panel during quality measure development. As such, the measure will not be changed, but the Committee agreed that it should be looked at in the future. Multiple comments were received suggesting that this measure was duplicative with measure 1637. The measure developer responded that developers continue to see the need for Pain Screening (which applies to all patients admitted to hospice or palliative care) as separate from Pain Assessment (which applies only to the subset of patients who report having pain as a symptom). The Steering Committee agreed with the developer's comments; noting the need for both measures, the Committee recommended them for endorsement as paired measures.

<p>1637: Hospice and Palliative Care- Pain Assessment (measure specifications) (developer materials and meeting summaries)</p> <p>Description: This quality measure is defined as: Percentage of hospice or palliative care patients who screened positive for pain and who received a clinical assessment of pain within 24 hours of screening.</p> <p>Numerator Statement: Patients who received a comprehensive clinical assessment to determine the severity, etiology and impact of their pain within 24 hours of screening positive for pain.</p> <p>Denominator Statement: Patients enrolled in hospice OR receiving palliative care who report pain when pain screening is done on the admission evaluation / initial encounter.</p> <p>Exclusions: Patients with length of stay < 1 day in palliative care or < 7 days in hospice, patients who were not screened for pain. Patients who screen negative for pain are excluded from the denominator.</p> <p>Adjustment/Stratification: No risk adjustment or stratification necessary.</p> <p>Level of Analysis: Clinician : Group/Practice, Facility</p> <p>Type of Measure: Process</p> <p>Data Source: Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record</p> <p>Measure Steward: University of North Carolina- Chapel Hill 725 Martin Luther King Jr Blvd, CB 7590 Chapel Hill North Carolina 27599-7590</p>
<p>Steering Committee Recommendation for Endorsement: <u>Y-16, N-4, A-0</u></p> <p>Rationale:</p>
<p>If Applicable, Conditions/Questions for Developer:</p> <ul style="list-style-type: none"> Within the denominator details, the measure has a positive screen for hospice patient of "if greater than 0," hospice patient is "greater than 4"? <p>Developer Response:</p> <ul style="list-style-type: none"> Screening scores were based on clinicians' input
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-14, M-5, L-0, I-1; 1c. Outcome or Evidence: Evidence Quantity H-11, M-6, L-2, I-1; Evidence Quality H-10, M-8, L-2, I-0; Evidence Consistency H-10, M-6, L-1, I-3)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> The Steering Committee noted that there is uncertainty as to what degree these components are associated with better outcomes if you measure them; however, given the demonstrated performance gap in assessment, the Steering Committee voted that this measure met the criteria for importance. Steering Committee members noted that consistent follow-up assessments may have more therapeutic value than an initial assessment alone, but this may be difficult to capture through measurement currently.
<p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met.</u> <i>(2a. Reliability Testing: H-7, M-11, L-2, I-0; 2b. Validity Testing H-6, M-11, L-2, I-1; 2c. Disparities: H-5, M-9, L-3, I-3)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> The Steering Committee noted that the reliability testing was conducted with appropriate method and scope. The measure has good face validity and the endorsement of both an expert panel and several consensus statements.

NATIONAL QUALITY FORUM

<p>1637: Hospice and Palliative Care- Pain Assessment (measure specifications) (developer materials and meeting summaries)</p> <p>3. Usability: <u>H-7, M-7, L-6, I-0</u> <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure seems to be easily understandable to the public. • The measure will allow hospices and palliative care units to lay the foundation for the next steps to reduce and manage pain. • From its use in the University of North Carolina's PEACE project, an effort that aimed to develop quality measures for hospice and palliative care. In this project, it was found to be useful for those seeking care and quality improvement.
<p>4. Feasibility: <u>H-3, M-12, L-5, I-0</u> <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure is easily captured electronically. • If electronic data are not available, Steering Committee members noted that substantial data collection effort may be required, as data must be extracted from the patient chart.
<p>5. Public & Member Comments:</p> <ul style="list-style-type: none"> • A comment was received suggesting that this measure was duplicative with measure 1634 – <i>Hospice and Palliative Care – Pain Screening</i>. The measure developer responded that developers continue to see the need for Pain Screening (which applies to all patients admitted to hospice or palliative care) as separate from Pain Assessment (which applies only to the subset of patients who report having pain as a symptom). The Steering Committee agreed with the developer's comments; noting the need for both measures, the Committee recommended them for endorsement as paired measures. • A comment was received suggesting that this measure should contain an exclusion for patients with negative screening for pain, and not to include them in the patient population receiving an assessment. The measure developer agreed, and will revise the denominator statement to reflect that this denominator excludes patients who screen negatively for pain. The Steering Committee agreed with this change.

<p>1617: Patients Treated with an Opioid who are given a bowel regimen (measure specifications) (developer materials and meeting summaries)</p>
<p>Description: Percentage of vulnerable adults treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed</p> <p>Numerator Statement: Patients from the denominator that are given a bowel regimen or there is documentation as to why this was not needed</p> <p>Denominator Statement: Vulnerable adults who are given a new prescription for an opioid</p> <p>Exclusions: None</p> <p>Adjustment/Stratification: No risk adjustment or stratification necessary</p> <p>Level of Analysis: Clinician : Group/Practice, Clinician : Individual, Facility, Health Plan</p> <p>Type of Measure: Process</p> <p>Data Source: Electronic Clinical Data : Electronic Health Record, Paper Records, Patient Reported Data/Survey</p> <p>Measure Steward: RAND Corporation 1776 Main Street Santa Monica California 90407</p>
<p>Steering Committee Recommendation for Endorsement: <u>Y-19, N-1, A-0</u></p> <p>Rationale:</p> <p>If Applicable, Conditions/Questions for Developer:</p> <ol style="list-style-type: none"> 1) Why is a bulk agent being considered as a bowel regimen? 2) Why is this particular population being considered? And could it (has there been testing) be considered more broadly as a measure for all elders, not just vulnerable elders? <p>Developer Response:</p> <ol style="list-style-type: none"> 1) The developer provided information that bulk agents are used in treating constipation. 2) Population being considered is not just vulnerable elders but has been expanded to vulnerable adults. Measure has been tested but does not have reliability testing (only prevalence).
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-16, M-3, L-1, I-0; 1c. Outcome or Evidence: Evidence Quantity: H-10, M-</i></p>

NATIONAL QUALITY FORUM

<p>1617: Patients Treated with an Opioid who are given a bowel regimen (measure specifications) (developer materials and meeting summaries)</p> <p>10, L-0, I-0; Evidence Quality: H-16, M-4, L-0, I-0; Evidence Consistency: H-17, M-3, L-0, I-0)</p> <p>Rationale:</p> <ul style="list-style-type: none"> • Measure demonstrates a high impact—this is an important treatment issue. • Evidence is provided through literature studies. • Impact on healthcare cost and patient distress is significant. • The measure is easily implemented and can have significant impact.
<p>2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. (2a. Reliability Testing: H-15, M-5, L-0, I-0; 2b. Validity Testing: H-13, M-6, L-1, I-0; 2c. Disparities: H-8, M-6, L-3, I-3)</p> <p>Rationale:</p> <ul style="list-style-type: none"> • Reliability testing was measured against current acceptable statistical assessments. • Validity testing was conducted empirically.
<p>3. Usability: H-10, M-9, L-1, I-0 (Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure is easily understood by the public.
<p>4. Feasibility: H-13, M-7, L-0, I-0 (4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</p> <p>Rationale:</p> <ul style="list-style-type: none"> • Data are easily collected.
<p>5. Public & Member Comments:</p> <ul style="list-style-type: none"> • Multiple comments were received about the denominator term “vulnerable adult”. The measure developer responded that the vulnerable adults definition includes patients >74 years of age, VES-13 score >2, poor prognosis/terminal illness defined as life expectancy <6 months, or Stage IV cancer. Additionally, the measure 1626 - <i>Patients Admitted to ICU who have care preferences documented</i>, which also looks at “vulnerable adults”, was harmonized so that these denominators are the same. • A comment was received suggesting that it will be difficult to capture the patients treated with an opioid who are given a bowel regimen. The measure developer responded that this measure does not rely on any patient reports, but rather requires that the healthcare provider document (at the time of prescription) that a bowel regimen has been recommended or the reason why it was not needed. The Steering Committee agreed with this comment. • A comment was received suggesting that the measure represents a “care plan” standard of care and a “low bar”. The Committee responded that agreed that in an ideal setting, this would be a standard of care; however, given the studies demonstrating low performance in meeting this measure, the Committee recommended it for endorsement as improvement in measure performance would lead to significant improvement in patient comfort and pain reduction. • A comment was received suggesting that the measure lacked a sound evidence base linking the process to outcomes, and that the measure had a significant burden to overcome in data collection. The measure developer responded that consensus concurs that prevention/management of opioid-related constipation is important for patient comfort and for deriving maximal benefit from medications. While data collection via chart abstraction is laborious, it is a requirement for many quality measures. The Committee concurred, and added that in cases where there is a sparse body of evidence, the Committee can rely on its own expert opinion. With respect to burden of data collection, the Steering Committee acknowledged that the implementation of EHR will decrease the burden of data collection for many of the measures.
<p>1628: Patients with advanced cancer assessed for pain at outpatient visits (measure specifications) (developer materials and meeting summaries)</p> <p>Description: Adult patients with advanced cancer who have an assessment of pain with a standardized quantitative tool at each outpatient visit</p> <p>Numerator Statement: Patients who are screened for the presence or absence of pain (and if present, rating of its severity) using a standardized quantitative tool during the admission evaluation for hospice / initial encounter for hospital-based palliative care. Screening may be completed using verbal, numeric, visual analog, rating scales designed for use the non-verbal patients, or other standardized</p>

NATIONAL QUALITY FORUM

<p>1628: Patients with advanced cancer assessed for pain at outpatient visits (measure specifications) (developer materials and meeting summaries)</p>
<p>tools.</p> <p>Denominator Statement: Adult patients with advanced cancer who have at least 1 primary care or cancer-related outpatient visit</p> <p>Exclusions: None</p> <p>Adjustment/Stratification: No risk adjustment or stratification</p> <p>Level of Analysis: Facility, Integrated Delivery System</p> <p>Type of Measure: Process</p> <p>Data Source: Electronic Clinical Data, Electronic Clinical Data : Registry, Paper Records</p> <p>Measure Steward: RAND Corporation 1776 Main Street Santa Monica California 90407</p>
<p>Steering Committee Recommendation for Endorsement: Y-20, N-0, A-0</p> <p>Rationale:</p>
<p>If Applicable, Conditions/Questions for Developer:</p> <p>1) Steering Committee members requested harmonization of the numerator of this measure with that of measure 1634.</p> <p>Developer Response:</p> <p>1) The developer harmonized the numerator with measure 1634: Hospice and Palliative Care- Pain Screening (UNC), and it met the Committee's approval.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Codes for the two lowest level office visits should not be included, as they are typically not long enough for a discussion of pain and may or may not include time with a physician. • Unlikely to be any unintended consequences from removing these codes from the measure specifications.
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-16, M-4, L-0, I-0; 1c. Outcome or Evidence: Evidence Quantity: H-8, M-8, L-4, I-0; Evidence Quality: H-10, M-10, L-0, I-0; Evidence Consistency: H-10, M-10, L-0, I-0)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Pain assessment is standard of care and well documented. The Steering Committee noted that inadequate management as an outpatient is more likely to lead to increased healthcare costs than poor management as an inpatient. • There is a demonstrated performance gap in pain assessment. • Steering Committee members noted that this measure is limited by the study population.
<p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met.</u> <i>(2a. Reliability Testing: H-10, M-8, L-0, I-2; 2b. Validity Testing: H-9, M-11, L-0, I-0; 2c. Disparities: H-5, M-5, L-3, I-7)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Reliability testing was well documented. • Validity testing was accomplished through an expert panel using a modified Delphi. • The Steering Committee noted that it is unclear why this would be limited to only Stage 4 cancer patients; however, given that there is no testing in other populations and the Steering Committee acknowledged the importance of this assessment, the measure was voted as meeting the criteria for Scientific acceptability. • Steering Committee members noted the relationship of this measure to measure 1634 and asked the measure developers to harmonize the numerators.
<p>3. Usability: H-9, M-10, L-1, I-0 <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • This measure is important for public reporting and will be easily understood.
<p>4. Feasibility: H-12, M-7, L-1, I-0 <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • As data capture in oncology practice increasingly uses EMRs, this measure will become more feasible.
<p>5. Public & Member Comments:</p> <ul style="list-style-type: none"> • Multiple comments were received suggesting that the measure would be difficult to report and collect data on, as a result of the

NATIONAL QUALITY FORUM

1628: Patients with advanced cancer assessed for pain at outpatient visits ([measure specifications](#)) ([developer materials and meeting summaries](#))

variety of settings in which a patient might be assessed, along with HIPPA restrictions. The measure developer responded that the definition of screening for this measure requires the use of a quantitative standardized tool which is becoming more and more commonly utilized in varied healthcare settings, and that the measure could also be extracted via EHR data. In addition, it is safe to assume that this measure would lead to the expectation that the advanced cancer patient was screened for pain during primary care visits. The Steering Committee Agreed with measure developer response, as it was consistent with Committee deliberations.

- A comment was received recommending that the committee consider severe cancers other than specifically Stage IV. The measure developer and the Committee responded in agreement; measures capturing broader patient populations was noted as a gap area for future measure development.
- Multiple comments were received suggesting that this measure could be reconciled with other measures (1634 and 1637). The measure developer responded that they have worked with the developer of measure #1634 and have changed the term "assessment" in measure #1628 to "screening" and have harmonized the definition of screening to match that of measure #1634. With respect to measure #1637, it requires a comprehensive assessment of pain factors (in a patient who has screened positive for pain) at the time of admission to hospice or palliative care. There is no overlap between these 2 measures, as #1628 is a screening measure only. The Committee agreed with this comment, and added that as screening leads to assessment or treatment, one cannot be accomplished without the other. To further strengthen the link between the two measures, the Committee recommended 1634 and 1637 as paired measures.
- A comment was received suggesting that the measure lacked a sound evidence base linking the process to outcomes, and that the measure had a significant burden to overcome in data collection. The measure developer responded that regular assessment of pain is vital to the successful management of chronic/advanced cancer pain over time. The Committee concurred, and added that in cases where there is a sparse body of evidence, the Committee can rely on its own expert opinion. With respect to burden of data collection, the Steering Committee acknowledged that the implementation of EHR will decrease the burden of data collection for many of the measures..

DYSPNEA MANAGEMENT MEASURES

LEGEND: Y = Yes; N = No; C = Completely; P = Partially; M = Minimally; N = Not at all

1639: Hospice and Palliative Care- Dyspnea Screening ([measure specifications](#)) ([developer materials and meeting summaries](#))

Description: Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation / palliative care initial encounter.

Numerator Statement: Patients who are screened for the presence or absence of dyspnea and its severity during the hospice admission evaluation / initial encounter for palliative care.

Denominator Statement: Patients enrolled in hospice for 7 or more days OR patients receiving hospital-based palliative care for 1 or more days.

Exclusions: Patients with length of stay < 7 days in hospice, or < 1 day in palliative care.

Adjustment/Stratification: No risk adjustment

Level of Analysis: Clinician: Group/Practice, Facility

Type of Measure: Process

Data Source: Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record

Measure Steward: University of North Carolina- Chapel Hill | 725 Martin Luther King Jr Blvd, CB 7590 | Chapel Hill | North Carolina | 27599-7590

Steering Committee Recommendation for Endorsement: Y-20, N-0, A-0

Rationale:

If Applicable, Conditions/Questions for Developer:

- 1) Are there disparities data for this measure?

Developer Response:

- 1) No data currently available

1. Importance to Measure and Report: Overall, the criteria for importance were met.

(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-20, M-0, L-0, I-0; 1c. Outcome or Evidence: Evidence Quantity: H-11, M-

NATIONAL QUALITY FORUM

<p>1639: Hospice and Palliative Care- Dyspnea Screening (measure specifications) (developer materials and meeting summaries) <i>9, L-0, I-0; Evidence Quality: H-14, M-6, L-0, I-0; Evidence Consistency: H-18, M-2, L-0, I-0</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • This is a prevalent problem. • There is not demonstrated evidence that solely screening for dyspnea leads to better outcomes, but it is a necessary step leading to treatment. For this reason, the Steering Committee believes it meets importance criteria given the vulnerable population addressed by this measure. • There is an opportunity for improvement.
<p>2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. <i>(2a. Reliability Testing: H-18, M-2, L-0, I-0; 2b. Validity Testing: H-17, M-3, L-0, I-0; 2c. Disparities: H-7, M-7, L-2, I-4)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Initially, Steering Committee members raised concerns that the numerator data may not be consistently documented. • The testing results signified that the measure is clearly specified. • The reliability testing used appropriate data elements and demonstrated high reliability. • Validity evidence for the measure is within acceptable statistical norms.
<p>3. Usability: <i>H-18, M-2, L-0, I-0</i> <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure is very clear and straightforward; quality improvement action may be taken to improve opportunities for treatment of patients with dyspnea. • Steering Committee members raised concerns that the numerator data may not be consistently documented.
<p>4. Feasibility: <i>H-16, M-4, L-0, I-0</i> <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy can be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The data are available electronically and can be extracted. • If electronic data are not available, Steering Committee members noted that substantial data collection effort may be required, as data must be extracted from the patient chart.
<p>5. Public & Member Comments:</p> <ul style="list-style-type: none"> • Multiple comments were received suggesting measures 1638 and 1639 be harmonized as one composite measure. The measure developer responded that Dyspnea Screening (1639) and Dyspnea Treatment (1639) were designed and tested as paired quality measures, in order to ensure that all patients entering hospice are screened for dyspnea. Screening is included in order to ensure that all patients with dyspnea are identified for treatment. The Steering Committee agreed with the developer's comments; noting the need for both measures, the Committee recommended them for endorsement as paired measures. • A comment was received suggesting that the description of the measure be expanded to capture the severity of the dyspnea the patient is experiencing, and that the patient that reports dyspnea. The measure developer responded that the operational definition for this quality measure did not expressly define a cut-off for dyspnea severity, because there are few standardized clinical instruments validated for recording severity. As a result of this lack of standardization, the developer included all dyspnea regardless of severity, but permitted in Dyspnea Treatment that all modalities. The Steering Committee agreed with measure developer's response, as it was consistent with Committee deliberations.

<p>1638: Hospice and Palliative Care- Dyspnea Treatment (measure specifications) (developer materials and meeting summaries)</p> <p>Description: Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening. Numerator Statement: Patients who screened positive for dyspnea who received treatment within 24 hours of screening. Denominator Statement: Patients enrolled in hospice for 7 or more days OR patients receiving palliative care who report dyspnea when dyspnea screening is done on the admission evaluation / initial encounter. Exclusions: Palliative care patients with length of stay < 1 day or hospice patients with length of stay < 7 days, patients who were not</p>
--

NATIONAL QUALITY FORUM

<p>1638: Hospice and Palliative Care- Dyspnea Treatment (measure specifications) (developer materials and meeting summaries)</p> <p>screened for dyspnea, and/or patients with a negative screening.</p> <p>Adjustment/Stratification: No risk adjustment</p> <p>Level of Analysis: Clinician : Group/Practice, Facility</p> <p>Type of Measure: Process</p> <p>Data Source: Electronic Clinical Data</p> <p>Measure Steward: University of North Carolina- Chapel Hill 725 Martin Luther King Jr Blvd, CB 7590 Chapel Hill North Carolina 27599-7590</p>
<p>Steering Committee Recommendation for Endorsement: <u>Y-17, N-3, A-0</u></p> <p>Rationale:</p>
<p>If Applicable, Conditions/Questions for Developer</p> <ol style="list-style-type: none"> 1) Is what constitutes treatment too broad to be clear to raters of the measure? 2) Did chart abstracters rely on narrative data to catch non-pharmacological interventions? 3) Is there an expectation that anyone, with any level of dyspnea, would get treatment? 4) How was 24 hours chosen for screening? <p>Developer Response:</p> <ol style="list-style-type: none"> 1) There are separate reliability and validity data for this measure and measure 1639, which was not submitted, as these are paired measures. There was very good ability for independent raters to identify presence of treatment—kappa of 0.89. 2) Abstracters relied on physicians, nursing notes, MARs. 3) That is correct. The measure developer could not find good, well-validated instruments for consistent measurement of dyspnea. Unlike pain, there is not a broad array of well-accepted severity standards 4) Comparable to other measures in set—given different settings—the consensus for the response time was 24 hours.
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u></p> <p><i>(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-15, M-4, L-1, I-0; 1c. Outcome or Evidence: Evidence Quantity: H-12, M-7, L-1, I-0; Evidence Quality: H-8, M-11, L-1, I-0; Evidence Consistency: H-7, M-12, L-1, I-0)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • As with screening, treatment of dyspnea remains problematic for a large number of patients. The Steering Committee stated that this measure would likely benefit these patients.
<p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met</u></p> <p><i>(2a. Reliability Testing: H-7, M-11, L-2, I-0; 2b. Validity Testing: H-10, M-9, L-1, I-0; 2c. Disparities: H-5, M-6, L-4, I-5)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Reliability and validity data are strong. Steering Committee members noted that the range of what constitutes treatment is large, from opioids to non-pharmacological interventions.
<p>3. Usability: <u>H-8, M-11, L-1, I-0</u></p> <p><i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Information produced for dyspnea treatment is meaningful and understandable such that quality improvement action may be taken to improve opportunities for treatment and improved patient outcomes of dyspnea.
<p>4. Feasibility: <u>H-2, M-11, L-6, I-1</u></p> <p><i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure is easily implemented electronically. • If electronic data are not available, Steering Committee members noted that substantial data collection effort may be required, as data must be extracted from the patient chart.
<p>5. Public & Member Comments:</p> <ul style="list-style-type: none"> • A comment was received suggesting that this measure should not, in its denominator, exclude those patients with a shortened length of stay. The measure developer noted that the investigators who have developed and tested this quality measure are in agreement with the concern expressed in this comment, but note that all current data available on the Dyspnea Screening measure was collected using this operational definition. The measure has been submitted as it was tested, but the developers endorse the need to collect data and consider expansion in the future to include short-stay patients. The Committee agreed

NATIONAL QUALITY FORUM

<p>1638: Hospice and Palliative Care- Dyspnea Treatment (measure specifications) (developer materials and meeting summaries)</p> <p>with the concern presented, but recognizes that the measure was presented as tested. The Committee believed that the measure should be revisited in the future, and that future versions of it should be expanded to capture the patients currently excluded by the denominator.</p> <ul style="list-style-type: none"> • A comment was received suggesting that the measure should distinguish specifically between "mild" and "moderate-to-severe" dyspnea to be more useful. The measure developer responded that they chose to include all dyspnea because ratings of severity are not yet well developed for nonverbal patients. The Committee added that there are no standard tools supported by current evidence for assessment of dyspnea, making it difficult to determine a severity cut-off when screening. • A comment was received recommending that any measurements related to symptom management consider the patient's acceptable level along with their desire to engage in a treatment plan. The measure developer responded that this measure addresses the need to treat dyspnea promptly when present, but does not include in its operational definition any standard for treating to a particular level of dyspnea severity; this does not limit care in any manner. The Steering Committee agreed with this response, as it was consistent with Committee deliberations. • A comment was received requesting clarification on which dyspnea screening tool was recommended by the measure steward, and that the measure should allow for more treatment strategies. The Steering Committee and the measure developer agreed; the developer noted that no one dyspnea screening instrument has proven to be the optimal approach. As such, the measure operational definition does not require the use of a specific clinical screening instrument for this reason. • Multiple comments were received suggesting that, because this measure includes both screening and treatment, measures 1638 and 1639 should be combined as a composite. The measure developer responded that screening is included in order to ensure that all patients with dyspnea are identified for treatment; patients with dyspnea should first be identified, and then treated. The Steering Committee agreed with the developer's comments; noting the need for both measures, the Committee recommended them for endorsement as paired measures.
--

CARE PREFERENCE MEASURES

LEGEND: Y = Yes; N = No; C = Completely; P = Partially; M = Minimally; N = Not at all

<p>1626: Patients Admitted to ICU who have care preferences documented (measure specifications) (developer materials and meeting summaries)</p> <p>Description: Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done.</p> <p>Numerator Statement: Patients in the denominator who had their care preferences documents within 48 hours of ICU admission or have documentation of why this was not done.</p> <p>Denominator Statement: All vulnerable adults admitted to ICU who survive at least 48 hours after ICU admission</p> <p>Exclusions: None</p> <p>Adjustment/Stratification: No risk adjustment or stratification.</p> <p>Level of Analysis: Facility, Health Plan, Integrated Delivery System</p> <p>Type of Measure: Process</p> <p>Data Source: Electronic Clinical Data: Electronic Health Record, Paper Records</p> <p>Measure Steward: RAND Corporation, 1776 Main Street, Santa Monica, California 90407</p> <p>Steering Committee Recommendation for Endorsement: <u>Y-20; N-0; A-0</u></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure impacts many patients. • Determination of patient wishes at the end of life is crucial to patient care for both the patients and their families/caregivers. <p>If Applicable, Conditions/Questions for Developer:</p> <p>1. Importance to Measure and Report: Overall, the criteria for importance were met. <i>(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-19; M-1; L-0; I-0; 1c. Evidence Quantity:H-11; M-9; L-0; I-0; Evidence Quality H-12; M-8; L-0; I-0; Evidence Consistency: H-15; M-5; L-0; I-0)</i></p>
--

NATIONAL QUALITY FORUM

<p>1626: Patients Admitted to ICU who have care preferences documented (measure specifications) (developer materials and meeting summaries)</p>
<p>Rationale:</p> <ul style="list-style-type: none">• Performance gap is well documented.• The measure is important for all ICU patients, including, but not limited to, vulnerable adults.• The Steering Committee noted that ensuring documentation of care preferences is linked to improved quality of life and experience of care.• The evidence is solid, though there are no clinical trials cited.
<p>2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. <i>(2a. Reliability Testing: H-10; M-9; L-1; I-0; 2b. Validity Testing: H-7; M-12; L-1; I-0; 2c. Disparities: H-9; M-7; L-0; I-4)</i></p> <p>Rationale:</p> <ul style="list-style-type: none">• Steering Committee members acknowledged that it is difficult to measure whether there was a failure to attempt to meet patient preferences.• Concern that chart data may not always be present and that definitions are too broad for implementation.• Concern that many patients may not be communicative in the first 48 hours in the ICU; as such, this measure may not be usable.• Concern that this measure is an ICU documentation issue rather than one that captures the intended process.• However, Steering Committee members noted that there is strong inter-rater reliability with the measure.• Steering Committee stated that face validity was acceptable.
<p>3. Usability: H-10; M-8; L-1; I-1 <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none">• The Steering Committee stated that this measure provides important information for those seeking care.
<p>4. Feasibility: H-7; M-8; L-4; I-1 <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none">• Clinical measures are routinely generated during daily patient care. Data are easily obtainable through EMRs or medical record chart documentation.
<p>5. Public & Member Comments:</p> <ul style="list-style-type: none">• Multiple comments were received about the “vulnerable adults” denominator in this measure. Commenters raised issue with: singling out a specific population; that it is unworkable – a target of 100% of ICU patients is not only appropriate for every patient; and the need to harmonize this definition with that in measure 1617. The measure developer responded that the different definition was an oversight; they will revise to add “VES-13 score >2” to the definition of the vulnerable adult in #1626. The Steering Committee added that the measure could address a broader population, but that it is a good first step for achieving high standards of care.• A comment was received suggesting that the measure lacked evidence, a clear link to outcomes, and was burdensome for data collection. The measure developer responded that expert consensus concurs that elicitation of care preferences at the time of ICU admission is vital to the provision of care that matches the wishes of the patient. The increase in use of EHR documentation would further facilitate the abstraction and access of these data in the future. The Steering Committee added that its members were able to utilize their expert judgment or apply additional evidence based on their own knowledge or expertise during the evaluation process, a decision consistent with the NQF measure evaluation criteria and guidance outlined in the Evidence Testing Task Force.• A comment was received suggesting that the measure should not be recommended for endorsement due to it not meeting the scientific acceptability criterion. The Steering Committee noted that the measure had been rigorously tested, and that the Committee had voted to approve it under the measure evaluation criteria. The Committee thoroughly reviewed the testing data for the measure, and noted that interrater reliability for chart abstraction was high. Additionally, the measure developer provided testing information on the process-outcome link for the measure, demonstrating a positive relationship between quality score and patient function and survival. Further, face validity of the measure was reviewed in the ACOVE, ACOVE3 and ASSIST panels, with experts panels reviewing the relevant literature and using a modified Delphi panel to vote on the

NATIONAL QUALITY FORUM

<p>1626: Patients Admitted to ICU who have care preferences documented (measure specifications) (developer materials and meeting summaries)</p> <p>validity of the measure.</p> <ul style="list-style-type: none"> • A comment was received suggesting that there could be modifications to improve this measure, including revisions to the numerator, and tying this conversation to a quality measure in health care facilities. The measure developer responded that the measure requirement is not designed to reflect optimal care, but rather ensure that a reasonable effort has been made to address the patient's care preferences. The Steering Committee agreed with this response, as it was consistent with Committee deliberations. • A comment was received questioning the measure, and noting that most patients have their care preferences documented, but they are often ignored. The measure developer responded that it is unlikely that any measure could enforce providers' attention to patient care preferences if that intent is lacking. The expectation of regular documentation of these preferences on ICU admission as indicated in this measure would work in the direction of emphasizing the need to elicit preferences and direct care that is compatible with them. The Steering Committee agreed with this response, as it was consistent with Committee deliberations. • A comment was received concerning the 48 hour measurement window in the measure, and requesting that it be significantly shortened. The measure developer responded that the goal is to ensure that adequate time is allowed for healthcare providers to address the care preference issue along with other care priorities. Forty-eight hours provides for a reasonable time to pass prior to judging the care to be inadequate. The Steering Committee agreed with this response, as it was consistent with Committee deliberations. • A comment was received requesting harmonization of the definition of "care preferences" with that of "treatment preferences" used in measure 1641. The Committee believed that it was important to make a clear distinction between care preferences (which are universally desired), and treatment preferences (which not every individual has). As such, the Steering Committee views the measures as being related, but intrinsically different.

<p>1641: Hospice and Palliative Care-Treatment Preferences (measure specifications) (developer materials and meeting summaries)</p> <p>Description: Percentage of patients with chart documentation of preferences for life sustaining treatments. Numerator Statement: Patients whose medical record includes documentation of life sustaining preferences. Denominator Statement: Seriously ill patients enrolled in hospice OR receiving specialty palliative care in an acute hospital setting. Exclusions: Patients with length of stay < 1 day in palliative care or < 7 days in hospice Adjustment/Stratification: No risk adjustment or stratification. Level of Analysis: Clinician: Group/Practice, Facility Type of Measure: Process Data Source: Electronic Clinical Data, Electronic Clinical Data: Electronic Health Record Measure Steward: University of North Carolina-Chapel Hill, 725 Martin Luther King Jr Blvd, CB 7590, Chapel Hill, North Carolina 27599-7590</p>
<p>Steering Committee Recommendation for Endorsement: <u>Y-19; N-1; A-0</u></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure affects many patients. • Use of this measure will improve attention to the important practice of documenting preferences for life-sustaining treatments.
<p>If Applicable, Conditions/Questions for Developer:</p> <p>Recommendations While the Committee did not recommend harmonization of this measure with NQF-endorsed measure 0326: <i>Advance Care Plan (NQQA/PCPI)</i>, it did encourage the developer to improve it by including the completion of a Physicians Order for Life Sustaining Treatment (POLST) or POLST paradigm forms as ways to document care preferences in the numerator.</p>
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> (1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-16; M-3; L-1; I-0; 1c. Evidence Quantity:H-16; M-4; L-0; I-0; Evidence Quality H-13; M-7; L-0; I-0; Evidence Consistency: H-19; M-1; L-0; I-0)</p> <p>Rationale:</p>

NATIONAL QUALITY FORUM

<p>1641: Hospice and Palliative Care-Treatment Preferences (measure specifications) (developer materials and meeting summaries)</p> <ul style="list-style-type: none"> • Performance gap is well documented. • There is a large number of both palliative care and end-of-life care patients who are affected. • There is evidence demonstrating a need for a discussion of life-sustaining treatment preferences with the patient, and poor communication about patient preferences has been identified as a major quality concern in palliative and end-of-life care. • The numerator captures a discussion with the patient, not simply prescribed orders. This is important because it captures the patient's preferences.
<p>2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. <i>(2a. Reliability Testing: H-12; M-8; L-0; I-0; 2b. Validity Testing: H-12; M-7; L-1; I-0; 2c. Disparities: H-8; M-6; L-1; I-5)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Inter-rater reliability is very strong. • Validity testing for this measure focuses on the target population consistent with research; construct validity is demonstrated.
<p>3. Usability: H-13; M-5; L-1; I-1 <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Data submitted shows that the measure results are meaningful, understandable, and very usable to affect quality outcomes for palliative and hospice patient populations.
<p>4. Feasibility: H-8; M-10; L-2; I-0 <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • All data elements are available electronically. • If electronic data are not available, Steering Committee members noted that substantial data collection effort may be required, as data must be extracted from the patient chart. • Concern that the documentation may not be standardized, making it somewhat challenging to extract reliably.
<p>Public & Member Comments:</p> <ul style="list-style-type: none"> • Commenters suggested that the numerator be modified to allow various state versions of the Physicians Order for Life Sustaining Treatment (POLST) to count toward the numerator. The measure developer has modified the numerator to capture "POLST paradigm" forms, which the Steering Committee agreed adequately addressed the comment. • Several comments suggested that the patient population captured by the measure be broadened. While both the Steering Committee and the measure developer agreed that other patient populations would benefit from the measure, the measure was only tested in the specified patient population. This has been noted by the Steering Committee as an opportunity for future measure development. • A comment was received requesting harmonization of the definition of "care preferences" with that of "treatment preferences" used in measure 1641. The Committee believed that it was important to make a clear distinction between care preferences (which are universally desired), and treatment preferences (which not every individual has). As such, the Steering Committee views the measures as being related, but intrinsically different. • A comment was received questioning the process outcome link, the evidence base for the measure, and the feasibility of implementing the measure. The Steering Committee noted that measure evaluation criteria was strictly applied when evaluating this measure, and that the measure met all criteria including being reasonably linked to the desired outcome and having a supportive evidence base for the focus of the measure. With respect to feasibility of implementation, the Steering Committee acknowledged that implementation of EHR will decrease the burden of data collection; however, testing provided with the measure demonstrated that the measure is feasible as specified.

<p>1647: Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss (measure specifications) (developer materials and meeting summaries)</p>
<p>Description: This measure reflects the percentage of hospice patients with documentation of a discussion of spiritual/religious concerns</p>

NATIONAL QUALITY FORUM

<p>1647: Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss (measure specifications) (developer materials and meeting summaries)</p>
<p>or documentation that the patient/caregiver/family did not want to discuss. Numerator Statement: Number of patient with clinical record documentation of spiritual/religious concerns or documentation that the patient/family did not want to discuss Denominator Statement: Total number of patient's discharged from hospice care during the designated reporting period. Exclusions: Testing has only been done with the adult population, but there is no reason to believe that this wouldn't be applicable to all hospice patients. Adjustment/Stratification: No risk adjustment or stratification. Level of Analysis: Facility Type of Measure: Process Data Source: Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record, Paper Records Measure Steward: Deyta, LLC, 7400 New LaGrange Road, Suite 200, Louisville, Kentucky 40222</p>
<p>Steering Committee Recommendation for Endorsement: <u>Yes-13; No-5</u> Rationale:</p> <ul style="list-style-type: none"> • The measure will affect a significant number of patients. • The benefits of assessing spiritual distress and attempting to intervene far outweigh any harms.
<p>If Applicable, Conditions/Questions for Developer:</p> <ol style="list-style-type: none"> 1) Steering Committee members have requested data on reliability testing be provided. 2) The Steering Committee has requested that the measure developer address the lack of a use of a standardized instrument to measure spiritual distress or religious concerns. 3) The Committee considered whether the measure addresses and fully meets the NQF criteria for the quantity, quality, and consistency of evidence. <p>Developer Response:</p> <ol style="list-style-type: none"> 1) The data provided were sufficient for the Steering Committee members. 2) Further specification of the numerator details was sufficient for Steering Committee members. 3) The Steering Committee noted that its own expert opinion on the importance of the measure to report is sufficient for the measure to pass the NQF importance criteria even though the measure may not meet the guidelines for quantity, quality, and consistency of evidence.
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-9; M-7; L-1; I-1; 1b. Performance Gap: H-4; M-8; L-5; I-0; 1c. Evidence Quantity: H-0; M-4; L-10; I-2; Evidence Quality H-0; M-6; L-10; I-1; Evidence Consistency: H-1; M-6; L-5; I-4)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Consumers are interested in this measure. • There has been variation demonstrated in performance across hospices using the measure. • Spiritual care has been shown to be a critical element of quality of life at the end of life and is of significance to the 1.5 million patients who receive services from approximately 5,000 hospices throughout the United States. • Steering Committee members noted that there may not be effective interventions to address the issues faced by patients reporting spiritual distress. It is difficult to link this process to outcomes, but it is still important to the quality of life for these individuals. • Steering Committee members noted that though the body of evidence for this measure does not yet exist, the benefits to this measure far outweigh any potential risks associated with it. Consensus from the Steering Committee was that though the evidence does not meet the importance criteria, the measure should pass on importance based on the Committee's collective expertise.
<p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met.</u> <i>(2a. Reliability Testing: H-3; M-10; L-3; I-2; 2b. Validity Testing: H-2; M-9; L-4; I-3; 2c. Disparities: H-1; M-5; L-2; I-9)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The Steering Committee noted that the reliability testing the measure developer provided was sufficient by common standards. • The Steering Committee stated that face validity was sufficient for this measure.
<p>3. Usability: <u>H-9; M-6; L-3; I-0</u> <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p>

NATIONAL QUALITY FORUM

1647: Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss (measure specifications) (developer materials and meeting summaries)
<ul style="list-style-type: none"> The Steering Committee stated that the measure will be useful for encouraging assessments of spiritual distress, the first step in ensuring that patients are treated for spiritual distress.
4. Feasibility: H-9; M-7; L-2; I-0 <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i>
Rationale: <ul style="list-style-type: none"> Steering Committee members noted that measure information is easily abstracted through chart data.
Public & Member Comments: <ul style="list-style-type: none"> Several comments were received questioning the process outcome link, the evidence base for the measure, and the feasibility of implementing the measure. The Steering Committee noted that measure evaluation criteria was strictly applied when evaluating this measure, and that the measure met all criteria including being reasonably linked to the desired outcome and having a supportive evidence base for the focus of the measure. With respect to feasibility of implementation, the Steering Committee acknowledged that implementation of EHR will decrease the burden of data collection; however, testing provided with the measure demonstrated that the measure is feasible as specified. Several comments indicated that an outcome measure addressing patient spiritual needs may be stronger than the submitted process measure. The Steering Committee acknowledges that this measure is a first step in assessing a patient's spiritual needs; evidence from the measure developer's testing demonstrates that having this conversation leads to an improved outcome in the patient's reported levels of spiritual distress. Several comments suggested that the measure should address palliative care patients in addition to hospice patients. Both the Steering Committee and the measure developer agreed with this notion; however, this measure has only been tested in the hospice population and thus can only be evaluated for this population. The Steering Committee has noted this area as a gap area for future measure development.

QUALITY OF CARE AT THE END OF LIFE MEASURES

LEGEND: Y = Yes; N = No; C = Completely; P = Partially; M = Minimally; N = Not at all

0209: Comfortable Dying (measure specifications) (developer materials and meeting summaries)
Description: Number of patients who report being uncomfortable because of pain at the initial assessment (after admission to hospice services) who report pain was brought to a comfortable level within 48 hours. Numerator Statement: Patients whose pain was brought to a comfortable level (as defined by patient) within 48 hours of initial assessment (after admission to hospice services). Denominator Statement: Patients who replied "yes" when asked if they were uncomfortable because of pain at the initial assessment (after admission to hospice services). Exclusions: Inclusions: Patients are eligible if they: Report they are uncomfortable because of pain at the initial assessment (after admission to hospice services); Are able to communicate and understand the language of the person asking the question; Are able to self-report; and, Are at least 18 years of age or older. Adjustment/Stratification: No risk adjustment or stratification. Level of Analysis: Facility, Population: National Type of Measure: Outcome Data Source: Patient Reported Data/Survey Measure Steward: National Hospice and Palliative Care Organization, 1731 King Street, Suite 100, Alexandria, Virginia 22314
Steering Committee Recommendation for Endorsement: Y-20; N-0; A-0 Rationale: <ol style="list-style-type: none"> The measure affects many patients. Use of this measure will improve attention to the important practice of documenting preferences for life-sustaining treatments.
If Applicable, Conditions/Questions for Developer:

NATIONAL QUALITY FORUM

<p>0209: Comfortable Dying (measure specifications) (developer materials and meeting summaries)</p> <p>1. Importance to Measure and Report: Overall, the criteria for importance were met. <i>(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-17; M-3; L-0; I-0; 1c. Evidence: This measure is an outcome measure; as such, evidence criteria were not individually voted on)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Management of pain is a key priority identified by NPP.
<p>2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. <i>(2b. Reliability Testing: H-12; M-8; L-0; I-0; 2c. Validity Testing: H-13; M-7; L-0; I-0; 2d. Exclusions Justified; 2e. Risk Adjustment/Stratification; 2f. Meaningful Differences; 2g. Comparability; 2h. Disparities: H-9; M-8; L-1; I-2)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure was presented with strong data on scientific acceptability. • Some information on disparities was presented indicating no difference in the ethnic distribution of patients whose pain was not brought to a comfortable level to those whose pain was relieved.
<p>3. Usability: H-18; M-2; L-0; I-0 <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The measure captures whether pain was controlled or not based on the patient's own perception, acknowledging that pain scales are not reliable across patients. It is usable for that purpose currently. However, the measure does not capture pain relief for patients who are in obvious pain yet unable to answer questions related to their pain, or patients who are unconscious.
<p>4. Feasibility: H-14; M-6; L-0; I-0 <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Data elements are easily accessible through patient self-report.
<p>Public & Member Comments:</p> <ul style="list-style-type: none"> • Several commenters expressed concern that many patients are able to self-report their pain at the time of admission, but then are unable to self-report pain at the time of follow-up. This could significantly lower the measure score for hospices if a large number of patients are unable to self-report at the time of follow-up. The measure developer appreciated the concern and noted that NHPCO provides a Problem Score as a complement to the basic measure score. The Problem Score is calculated by dividing the number of patients whose pain was NOT brought to a comfortable level within 48 hours after the initial assessment by the number of patients who were uncomfortable on admission. This number is multiplied by 100 to get the hospice's score as a percent. A lower score/percentile = better performance. The Problem Score offsets negative bias introduced by inclusion of patients unable to respond at follow up and provides additional context and insight for setting performance improvement goals. The Steering Committee agreed that this addressed the concern expressed in the comments. • A comment was received questioning the process outcome link, the evidence base for the measure, and the feasibility of implementing the measure. The Steering Committee noted that measure evaluation criteria was strictly applied when evaluating this measure, and that the measure met all criteria including being reasonably linked to the desired outcome and having a supportive evidence base for the focus of the measure. With respect to feasibility of implementation, the measure developer noted that the actions needed to generate data for the measure (determining patient goals for comfort on initial assessment, putting interventions in place consistent with those goals, and timely assessment of the effectiveness of the interventions - plus documentation of those actions) are all elements inherent in good pain management practice. The Steering Committee agreed with this rationale.

<p>1625: Hospitalized Patients who Die an Expected Death with an ICD that has been deactivated (measure specifications) (developer materials and meeting summaries)</p> <p>Description: Percentage of hospitalized patients who die an expected death from cancer or other terminal illness and who have an implantable cardioverter-defibrillator (ICD) in place at the time of death that was deactivated prior to death or there is documentation why</p>
--

NATIONAL QUALITY FORUM

<p>1625: Hospitalized Patients who Die an Expected Death with an ICD that has been deactivated (measure specifications) (developer materials and meeting summaries)</p>
<p>it was not deactivated Numerator Statement: Patients from the denominator who have their ICDs deactivated prior to death or have documentation of why this was not done Denominator Statement: Patients who die an expected death who have an ICD in place Exclusions: None Adjustment/Stratification: No risk adjustment or stratification. Level of Analysis: Facility Type of Measure: Process Data Source: Paper Records Measure Steward: RAND Corporation, 1776 Main Street, Santa Monica, California 90407</p>
<p>Steering Committee Recommendation for Endorsement: <u>Y-13; N-7; A-0</u> Rationale:</p> <ul style="list-style-type: none"> • The measure affects many patients, and ICD use is becoming much more prevalent. This measure will become more useful as ICD use continues to grow. • There is emerging literature about ICS use near death.
<p>If Applicable, Conditions/Questions for Developer:</p>
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-10; M-10; L-0; I-0; 1c. Evidence Quantity: H-3; M-6; L-9; I-2; Evidence Quality H-5; M-9; L-3; I-3; Evidence Consistency: H-10; M-7; L-0; I-3)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Steering Committee noted that processes and the evidence base have not caught up with information coming from research and clinical trials dealing with the issue of ICDs left in place at the time of death. • This is a painful and serious event when it occurs, and use of ICDs in patients is increasing.
<p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met.</u> <i>(2a. Reliability Testing: H-5; M-9; L-3; I-3; 2b. Validity Testing: H-5; M-7; L-6; I-2; 2c. Disparities: H-7; M-4; L-1; I-8)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Charts used in reliability testing were for patients who did not have an ICD in place at the time of death. Strong inter-rater reliability of the presence on an ICD was demonstrated. • Face validity and expert panel review were accepted for scientific acceptability criteria.
<p>3. Usability: <u>H-11; M-8; L-1; I-0</u> <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The Steering Committee noted that there is no accepted standard of performance for this measure, as there are not yet enough data to establish a benchmark or standard. The measure is not yet used for public reporting.
<p>4. Feasibility: <u>H-7; M-8; L-5; I-0</u> <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Data elements are accessible through paper records. • The measure developer is working to implement this measure in EHRs, which will make it more feasible to use.
<p>Public & Member Comments:</p> <ul style="list-style-type: none"> • Several commenters expressed concern that the number of patients affected by this measure is relatively small. The measure developer acknowledged this concern; however, both the Steering Committee and the measure developer stated that the negative consequences of patients who experience this at the end of life make this an important care measure. • A comment was received questioning whether a gap in performance of this measure exists. The measure developer noted that in literature cited in the measure submission, of 900 randomly selected hospices, 97% admit patients with ICDs and 58% report that a patient had been shocked in the past year. Additionally, other literature and the developer's own study evidence were cited for ICDs' only being addressed prior to the expected death of the patient in 25-27% of cases. The Steering

NATIONAL QUALITY FORUM

<p>1625: Hospitalized Patients who Die an Expected Death with an ICD that has been deactivated (measure specifications) (developer materials and meeting summaries)</p> <p>Committee acknowledged that this was a significant gap in performance of this measure.</p>
<p>0208: Family Evaluation of Hospice Care (measure specifications) (developer materials and meeting summaries)</p> <p>Description: Composite Score: Derived from responses to 17 items on the Family Evaluation of Hospice Care (FEHC) survey presented as a single score ranging from 0 to 100. Global Score: Percentage of best possible response (Excellent) to the overall rating question on the FEHC survey. Target Population: The FEHC survey is an after-death survey administered to bereaved family caregivers of individuals who died while enrolled in hospice. Timeframe: The survey measures family members perception of the quality of hospice care for the entire enrollment period, regardless of length of service.</p> <p>Numerator Statement: Composite Score: Numerator is the hospice’s composite score, which is the weighted incidence of problem scores derived from responses from 17 items on the FEHC survey. The 17 questions focus on the following aspects of hospice care: symptom management, communication, provision of information, emotional support, and care coordination. Global Score: Numerator is the number of best possible responses (excellent) to the overall rating question on the FEHC survey.</p> <p>Denominator Statement: Composite Score: 100 (100 is the best possible composite score which indicates 0% incidence of problem scores). Global Score: Total number of responses to the overall rating of care quality on the FEHC survey, question G1.</p> <p>Exclusions: Composite Score: If a survey respondent did not enter a response to more than 14 of the 17 FEHC survey questions included in calculation of the composite score then a composite score will not be calculated for that survey and the survey will not be included in the calculation of a composite score for the hospice. Global Score: If survey respondent has not entered a response to overall rating question (G1), the question is not included in the denominator.</p> <p>Adjustment/Stratification: No risk adjustment or stratification.</p> <p>Level of Analysis: Facility, Population: National</p> <p>Type of Measure: Process</p> <p>Data Source: Patient Reported Data/Survey</p> <p>Measure Steward: National Hospice and Palliative Care Organization, 1731 King Street, Alexandria, Virginia 22314</p> <p>Steering Committee Recommendation for Endorsement: <u>Y-19; N-0; A-0</u></p> <p>Rationale:</p> <ul style="list-style-type: none"> • This measure is straightforward and highly usable. Its focus, by and large, will likely demonstrate important differences in the quality of care offered by different hospices. • The FEHC has considerable experience to support its use, and its voluntary adoption by more than 1000 hospices offers good evidence of its feasibility and utility. <p>If Applicable, Conditions/Questions for Developer:</p> <ol style="list-style-type: none"> 1) The Steering Committee would like more information on disparities and issues related to stratification of the measure. <p>Response:</p> <ol style="list-style-type: none"> 1) The developer provided the Committee with additional information on the numerator specifications and updated evidence. The updates also included the composite score and information on importance. Additional information was provided on reliability and validity, along with added data on disparities that was unintentionally left out of the original submission. The Committee raised no concerns with this information being presented. <p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-19; M-0; L-0; I-0; 1b. Performance Gap: H-17; M-1; L-1; I-0; 1c. Evidence Quantity: H-12; M-6; L-0; I-1; Evidence Quality H-13; M-6; L-0; I-0; Evidence Consistency: H-14; M-4; L-1; I-0)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • A significant variance in performance was demonstrated. • The body of evidence is based on studies, focus groups, and professional guidelines demonstrating that the measured aspects of care are those valued by patients and for which the patients (or in this case, the bereaved family members surveyed) are the best and only source of information. <p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met.</u> <i>(2a. Reliability Testing: H-15; M-4; L-0; I-0; 2b. Validity Testing: H-15; M-3; L-1; I-0; 2c. Disparities: H-11; M-6; L-1; I-1)</i></p>

NATIONAL QUALITY FORUM

<p>0208: Family Evaluation of Hospice Care (measure specifications) (developer materials and meeting summaries)</p> <p>Rationale:</p> <ul style="list-style-type: none"> • The FEHC survey is well defined and precisely specified so it can be implemented consistently within and across hospice organizations and allow for comparability. • The measure developer did not adequately address disparities and issues related to stratification. • The developer presented evidence that the items of the composite score have good face validity and should be easily understood by the public.
<p>3. Usability: H-10; M-9; L-0; I-0 <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • This measure is already in extensive use.
<p>4. Feasibility: H-12; M-6; L-1; I-0 <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The data elements would not be in an electronic record, but they would be available electronically when using a vendor. • This survey process is not a part of normal hospital or office routine, and it requires additional resources to obtain responses.
<p>Public & Member Comments:</p> <ul style="list-style-type: none"> • A comment was received suggesting that while important for institutions to collect this information, it is not a topic for performance measurement. The Steering Committee and the measure developer respectfully disagreed, noting that it is very important to measure and report patient's experience with care at the end of life and that the measure as proposed met the measure evaluation criteria. • A comment was received questioning the need for measures 0208, 1632, and 1623 as all address similar topic areas. The Committee believed that these measures address related but not competing questions on the quality of life and patient experience with care. Each serve a different patient population or purpose and they determined it was appropriate to recommend the three measures for endorsement. • A comment was received expressing concern over the time window for administration of the survey impacting measure data. The measure developer noted that in testing, the timing of administration of the survey had no impact on the responses received from the bereaved family. The Steering Committee agreed that this addressed the concern expressed in the comments.

<p>1632: CARE- Consumer Assessments and Reports of End of Life (measure specifications) (developer materials and meeting summaries)</p>
<p>Description: The CARE survey is mortality follow back survey that is administered to the bereaved family members of adult persons (age 18 and older) who died of a chronic progressive illness receiving services for at least 48 hours from a home health agency, nursing homes, hospice, or acute care hospital. The survey measures perceptions of the quality of care either in terms of unmet needs, family reports of concerns with the quality of care, and overall rating of the quality of care. The time frame is the last 2 days of life up to last week of life spent in a hospice, home health agency, hospital, or nursing home.</p> <p>The survey is based on structured literature review,(1) cognitive testing,(2) pre-test,(2) and national survey of the quality of end of life care.(3) The conceptual model is patient focused, family centered care(1) that posits that high quality care at the end of life is obtained when health care institutions: 1) provide the desired level of symptom palliation and emotional support; 2) treat the patient with respect; 3) promote shared decision making; 4) attend to the needs of caregivers for information and skills in providing care for the patient; 5) provide emotional support to the family before and after the patient's death; and 6) coordinates care across settings of care and health care providers.</p> <p>This is the "parent" survey of the Family Evaluation of Hospice Care Survey (4-7) that my colleagues and I have collaborated with the National Hospice and Palliative Care Organization to create a self-administered survey that is used widely by hospices in the USA and other nations. With the proposed development of accountable care organizations and other potential innovations in health care financing, we recognized the need for an instrument that would allow the comparisons across place of care when there is one entity coordinating and/or financing the care for population of decedents. We have decided to submit the telephone based survey for NQF consideration based on the void of validated measures to capture consumer perceptions (i.e, bereaved family members) of the quality of</p>

NATIONAL QUALITY FORUM

<p>1632: CARE- Consumer Assessments and Reports of End of Life (measure specifications) (developer materials and meeting summaries)</p> <p>care at the end of life across place of care. This submission is not meant to be competitive with the existing NQF endorsed Family Evaluation of Hospice Care survey.</p> <p>This new proposed measure for NQF consideration consists of the survey which has six domains and the new creation of 0-100 composite score that is composed of 14 of 17 core items.</p> <ol style="list-style-type: none"> 1. Teno JM, Casey VA, Welch L, Edgman-Levitan S. Patient-Focused, Family-Centered End-of-Life Medical Care: Views of the Guidelines and Bereaved Family Members. <i>J Pain Symptom Manage-Special Section on Measuring Quality of Care at Life's End II</i>. 2001 Sep 2001;22(3):738-751. 2. Teno JM, Clarridge B, Casey V, Edgman-Levitan S, Fowler J. Validation of Toolkit After-Death Bereaved Family Member Interview. <i>J Pain Symptom Manage</i>. 2001 Sep 2001;22(3):752-758. 3. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. <i>JAMA</i>. 2004 Jan 7 2004;291(1):88-93. 4. Rhodes RL, Mitchell SL, Miller SC, Connor SR, Teno JM. Bereaved family members' evaluation of hospice care: what factors influence overall satisfaction with services? <i>J Pain Symptom Manage</i>. 2008 Apr 2008;35(4):365-371. 5. Mitchell SL, Kiely DK, Miller SC, Connor SR, Spence C, Teno JM. Hospice care for patients with dementia. <i>J Pain Symptom Manage</i>. 2007 Jul 2007;34(1):7-16. 6. Rhodes RL, Teno JM, Connor SR. African American bereaved family members' perceptions of the quality of hospice care: lessened disparities, but opportunities to improve remain. <i>J Pain Symptom Manage</i>. 2007 Nov 2007;34(5):472-479. 7. Connor SR, Teno J, Spence C, Smith N. Family Evaluation of Hospice Care: Results from Voluntary Submission of Data Via Website. <i>J Pain Symptom Manage</i>. 2005 Jul 2005;30(1):9-17. <p>Numerator Statement: Respondent reports of concerns with the quality of care, their self-efficacy in basic tasks of caregiving, or unmet needs that indicate an opportunity to improved end of life care provided by either a nursing home, hospital, hospice, or home health agency.</p> <p>Denominator Statement: Non-traumatic deaths and deaths from chronic progressive illnesses based on ICD 9/10 codes are included. A list will be provided as technical appendix to the proposed survey. Note the survey is for only persons that died with the following services or location of care: nursing home, hospital, hospice, or home health agency</p> <p>Exclusions: We excluded deaths due to accidents, trauma, during surgery, lethal injection, acute overwhelming infections, and from complications of pregnancy.</p> <p>Adjustment/Stratification: No risk adjustment or stratification.</p> <p>Level of Analysis: Facility, Population: Community, Population: National, Population: Regional</p> <p>Type of Measure: Patient Engagement/Experience</p> <p>Data Source: Other</p> <p>Measure Steward: Center for Gerontology and Health Care Research, 121 South Main Street, Providence, Rhode Island 02912</p>
<p>Steering Committee Recommendation for Endorsement: <u>Y-19; N-0; A-0</u></p> <p>Rationale:</p> <ul style="list-style-type: none"> • This mortality follow-back survey measure fills a need to obtain feedback from family members or others closest to the patient during the last days of life and can be an invaluable source for public reporting as well as quality improvement. • This measure assesses aspects of end-of-life care considered crucial to patients, families, practitioners, and payers. Its suitability for use in most of the possible end-of-life settings has the potential to inform practice, educate consumers, demonstrate the importance of end-of-life care, and lead to the development of care structures and incentives to support patients and families better at end of life.
<p>If Applicable, Conditions/Questions for Developer:</p> <ul style="list-style-type: none"> • The measure developer provided the Committee with additional detail on the numerator specifications and updated evidence. The Committee raised no concerns with the information presented.
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-19; M-0; L-0; I-0; 1b. Performance Gap: H-14; M-5; L-0; I-0; 1c. Evidence Quantity: H-9; M-9; L-1; I-0; Evidence Quality H-8; M-10; L-0; I-0; Evidence Consistency: H-10; M-9; L-0; I-0)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Compelling evidence was presented both for being high impact and demonstrating a performance gap. • The measure is based upon a credible structure-process-outcome relationship with great consensus.
<p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met.</u> <i>(2a. Reliability Testing: H-11; M-8; L-0; I-0; 2b. Validity Testing: H-9; M-10; L-0; I-0; 2c. Disparities: H-10; M-9; L-0; I-0)</i></p>

NATIONAL QUALITY FORUM

1632: CARE- Consumer Assessments and Reports of End of Life (measure specifications) (developer materials and meeting summaries)
Rationale: <ul style="list-style-type: none">The measure elements, although complicated, are unambiguous with reliable data elements and measure score.
3. Usability: H-9; M-9; L-0; I-1 <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i>
Rationale: <ul style="list-style-type: none">The Steering Committee noted that the FEHC is a good proxy for the CARE instrument; as such, the developer has presented relatively strong evidence of the usability of the measure.
4. Feasibility: H-7; M-10; L-2; I-0 <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</i>
Rationale: <ul style="list-style-type: none">The data are not routinely generated as part of care and would require a follow-back survey.As this is a survey, electronic data collection is not possible. The ease of surveying should be similar to the "offspring" survey and thus is feasible.
Public & Member Comments: <ul style="list-style-type: none">A comment was received suggesting that while important for institutions to collect this information, it is not a topic for performance measurement. The Steering Committee and the measure developer respectfully disagreed, noting that it is very important to measure and report patient's experience with care at the end of life and that the measure as proposed met the measure evaluation criteria.A comment was received questioning the need for measures 0208, 1632, and 1623 as all address similar topic areas. The Committee believed that these measures address related but not competing questions on the quality of life and patient experience with care. Each serve a different patient population or purpose and they determined it was appropriate to recommend the three measures for endorsement.A comment was received expressing concern over the feasibility of implementation for this measure. The Committee did consider the feasibility of the measure ("the extent to which the required data are readily available or could be captured without undue burden and can be implemented for performance measurement"), and determined that the measure passed this criteria.

1623: Bereaved Family Survey (measure specifications) (developer materials and meeting summaries)
Description: The purpose of this measure is to assess families' perceptions of the quality of care that Veterans received from the VA in the last month of life. The BFS consists of 19 items (17 structured and 2 open-ended). The BFS items were selected from a longer survey that was developed and validated with the support of a VA HSR&D Merit Award and have been approved for use by the Office of Management and Budget. Seventeen items in the survey have predefined response options and ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support. Two additional items are open-ended and give family members the opportunity to provide comments regarding the care the patient received. A growing body of research has underscored the degree to which end-of-life care in the United States needs to be improved. The challenges of end-of-life care are particularly significant in the U.S. Department of Veterans Affairs Health Care system because the VA provides care for an increasingly older population with multiple comorbid conditions. In FY2000, approximately 104,000 enrolled Veterans died in the U.S., and approximately 27,200 Veterans died in VA facilities. At least 30% of the Veterans are over age 65 now, and 46% will be over 65 by 2030. Therefore, it is clear that the number of deaths in VA facilities will increase substantially as the World War II and Korean War Veterans age. These demographic trends mean that, like other healthcare systems, the VA will face substantial challenges of providing care to Veterans near the end-of-life. The VA has addressed this challenge aggressively in the last 5 years, however the VA has not yet developed and implemented measures of the quality of end-of-life care it provides to Veterans. There are at least 3 reasons why adoption of a quality measurement tool is essential. First, it would make it possible to define and compare the quality of end-of-life care at each VA facility and to identify opportunities for improvement. Second, facilities and VISNs (geographic service divisions within the VA system) would be able to monitor the effectiveness of efforts to improve care locally and nationally, and would enable monitoring of the impact of the

NATIONAL QUALITY FORUM

<p>1623: Bereaved Family Survey (measure specifications) (developer materials and meeting summaries)</p> <p>Comprehensive End of Life Care Initiative, ensuring that expenditures are producing improvements in care. Third, it will help the VA to recognize those facilities that provide outstanding end-of-life care, so that successful processes and structures of care can be identified and disseminated throughout the VA.</p> <p>The BFS's 17 close-ended items ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support, pain management and personal care needs. Two additional items (not used in scoring) are open-ended and give family members the opportunity to provide comments regarding the care the patient received. The BFS has undergone extensive development and has been pilot-tested for all inpatient deaths in Q4FY2008 in seven VISNs (1,2,4,5,8,11, and 22). As of October 1, 2009, Q1FY2010, all inpatient deaths in all VISNs were included in the project.</p> <p>Numerator Statement: The numerator is comprised of completed surveys (at least 12 of 17 structured items completed), where the global item question has an optimal response. The global item question asks "Overall, how would you rate the care that [Veteran] received in the last month of life" and the possible answer choices are: Excellent, Very good, Good, Fair, or Poor. The optimal response is Excellent.</p> <p>Denominator Statement: The denominator consists of all inpatient deaths for which a survey was completed (at least 12 of 17 structured items completed), excluding: 1) deaths within 24 hours of admission (unless the Veteran had a previous hospitalization in the last month of life); 2) deaths that occur in the Emergency Department; 3) deaths that occur in the operating room; and 4) deaths due to suicide or accidents. Additional exclusion criteria include: 1) Veterans for whom a family member knowledgeable about their care cannot be identified (determined by the family member's report); or contacted (no current contacts listed or no valid addresses on file); 2) absence of a working telephone available to the family member.</p> <p>Exclusions: - Veterans for whom a family member knowledgeable about their care cannot be identified (determined by family member's report)</p> <ul style="list-style-type: none"> - Absence of a current address and/or working telephone number for a family member or emergency contact. - Deaths within in 24 hours of admission without a prior hospitalization of last least 24 hours in the last 31 days of life. - Deaths that occur in the operating room during an outpatient procedure. - Deaths due to a suicide or accident - Surveys in which less than 12 items were answered. <p>Adjustment/Stratification: No risk adjustment or stratification.</p> <p>Level of Analysis: Facility, Population: National, Population: Regional</p> <p>Type of Measure: Outcome</p> <p>Data Source: Other</p> <p>Measure Steward: PROMISE Center, 3800 Woodland Avenue, Building 4100, Philadelphia, Pennsylvania 19104</p>
<p>Steering Committee Recommendation for Endorsement: <u>Y-19; N-0; A-0</u></p> <p>Rationale:</p> <ul style="list-style-type: none"> • This is a straightforward measure with clear and feasible implementation, based upon evidence, that will be useful as it was intended. • This measure captures a unique population in the VA system, which differs from traditional healthcare settings and is not captured in the other surveys under consideration.
<p>If Applicable, Conditions/Questions for Developer:</p>
<p>1. Importance to Measure and Report: <u>Overall, the criteria for importance were met.</u> <i>(1a. High Impact: H-19; M-0; L-0; I-0; 1b. Performance Gap: H-15; M-4; L-0; I-0; 1c. Evidence Quantity: H-8; M-10; L-1; I-0; Evidence Quality H-6; M-12; L-1; I-0; Evidence Consistency: H-7; M-11; L-1; I-0)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • Demographic characteristics in a VA population are atypical of the larger US population, and the survey relies on family perceptions of care. However, this survey offers a way to assess the quality of care that is provided to the family before, during, and after a patient's death.
<p>2. Scientific Acceptability of Measure Properties: <u>Overall, the criteria for scientific acceptability were met.</u> <i>(2a. Reliability Testing: H-7; M-10; L-2; I-0; 2b. Validity Testing: H-7; M-11; L-1; I-0; 2c. Disparities: H-8; M-9; L-0; I-2)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • This is a straightforward, easily accessible survey tool that is well defined and specified with sufficient reliability statistics for administration and scoring. • It is worth noting that the measure fails to address the quality of the care that veterans without family at end of life are receiving.

NATIONAL QUALITY FORUM

<p>1623: Bereaved Family Survey (measure specifications) (developer materials and meeting summaries)</p>
<p>3. Usability: H-12; M-6; L-0; I-1 <i>(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The BFS is currently an optional performance measure as part of the VA's nationwide Comprehensive End of Life Care Initiative. The BFS assesses the initiative's impact on the care that VA facilities provide to veterans and their families. As noted earlier, it is limited in its usability for a broad population, as only a smaller percentage of veterans receive their end-of-life care in VA facilities. • The Steering Committee believes that the BFS measure results will be meaningful and understandable to the public.
<p>4. Feasibility: H-8; M-11; L-0; I-0 <i>(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended consequences identified; 4d. Data Collection Strategy Can Be Implemented)</i></p> <p>Rationale:</p> <ul style="list-style-type: none"> • The data are not routinely generated as part of care and would require a follow-back survey. • As this is a survey, electronic data collection is not possible. This survey process is not a part of normal hospital or office routine, and it requires additional resources to make three attempts to contact next of kin by phone, with a follow-up written survey sent when not reached.
<p>Public & Member Comments:</p> <ul style="list-style-type: none"> • A comment was received suggesting that while important for institutions to collect this information, it is not a topic for performance measurement. The Steering Committee and the measure developer respectfully disagreed, noting that it is very important to measure and report patient's experience with care at the end of life and that the measure as proposed met the measure evaluation criteria. • A comment was received questioning the need for measures 0208, 1632, and 1623 as all address similar topic areas. The Committee believed that these measures address related but not competing questions on the quality of life and patient experience with care. Each serve a different patient population or purpose and they determined it was appropriate to recommend the three measures for endorsement. • A comment was received expressing concern over the feasibility of implementation for this measure. The Committee did consider the feasibility of the measure ("the extent to which the required data are readily available or could be captured without undue burden and can be implemented for performance measurement"), and determined that the measure passed this criteria.

Evaluation Summary—Candidate Consensus Standards Not Recommended for Endorsement

<p>1630: Hospitalized patients who die an expected death who have dyspnea addressed (measure specifications) (developer materials and meeting summaries)</p>
<p>Description: Percentage of hospitalized patients who died an expected death who had dyspnea in the last 7 days of life and who had documentation that they received dyspnea care and follow up</p> <p>Numerator Statement: Percentage of patients with dyspnea from the denominator who on any day(s) during the denominator time window had:</p> <p>a) their dyspnea treated within 24 hours OR had documentation that the dyspnea had improved OR reason why it was not/could not be treated</p> <p>b) a reassessment of their dyspnea (response to treatment or reassessment in untreated dyspnea) within 24 hours</p> <p>Denominator Statement: Hospitalized patients who died an expected death and who had dyspnea in the 7 days prior to death</p> <p>Exclusions: None</p> <p>Adjustment/Stratification: No risk adjustment or stratification</p> <p>Level of Analysis: Facility</p> <p>Type of Measure: Process</p> <p>Data Source: Electronic Clinical Data : Electronic Health Record, Paper Records</p> <p>Measure Steward: RAND Corporation 1776 Main Street Santa Monica California 90407</p>
<p>Steering Committee Recommendation for Endorsement: <u>No vote taken</u>—measure did not pass importance criterion</p>
<p>Rationale:</p>
<p>If Applicable, Conditions/Questions for Developer:</p> <p>1) Could this measure be expanded to other settings of care?</p>

NATIONAL QUALITY FORUM

<p>1630: Hospitalized patients who die an expected death who have dyspnea addressed (measure specifications) (developer materials and meeting summaries)</p> <ol style="list-style-type: none">2) Unexpected death and “addressing dyspnea” are unclear.3) Feasibility concerns regarding collection of data and identification of dyspnea.4) How was 24 hours selected as a timeframe for addressing/intervention for dyspnea? <p>Developer Response:</p> <ol style="list-style-type: none">1) The measure has not been tested in other settings of care.2) These terms are defined in the measure specifications.3) Identifying dyspnea is not as easy as pain, but it is identifiable and can be reliably abstracted, although it does take time.4) This timeframe simplifies data abstraction.
<p>1. Importance to Measure and Report: <u>The measure did not pass the importance criterion.</u> (1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-4, M-10, L-5, I-1; 1c. Outcome or Evidence: Evidence Quantity: H-1, M-5, L-12, I-2; Evidence Quality: H-0, M-7, L-11, I-2; Evidence Consistency: H-1, M-5, L-7, I-7)</p> <p>Rationale:</p> <ul style="list-style-type: none">• Lack of a strong evidence base cited by multiple committee members.• Significant gaps in information.• Would favor one major dyspnea measure and not a smaller subset like this.
<p>2. Scientific Acceptability of Measure Properties: <u>No vote taken—measure did not pass importance criterion</u> (2a. Reliability Testing; 2b. Validity Testing; 2c. Disparities)</p> <p>Rationale:</p> <ul style="list-style-type: none">• Definition of unexpected death is unclear
<p>3. Usability: <u>No vote taken—measure did not pass importance criterion</u> (Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)</p> <p>Rationale:</p>
<p>4. Feasibility: <u>No vote taken—measure did not pass importance criterion</u> (4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c. Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)</p> <p>Rationale:</p> <ul style="list-style-type: none">• Hard to see how this can be implemented with paper medical records.
<p>Public and Member Comments:</p> <ul style="list-style-type: none">• No comments were received on this measure.

NQF MEMBER AND PUBLIC COMMENT

In response to a comment suggesting that reporting of the measure data be stratified by palliative care units and hospice facilities, Martha Tecca (Deyta) stated that in all likelihood reporting of the measure data will be stratified even though the measures were not specified in that way. Reporters of measure data typically stratify measure data by whether facilities are CMS certified; the end result of this would be separation of palliative care unit data and hospice data.

NEXT STEPS

NQF staff will make revisions to the draft report consistent with Steering Committee recommendations. The draft report will be circulated to the Committee via email and will be posted for NQF Member Voting on December 5th.