NATIONAL QUALITY FORUM

IN-PERSON MEETING OF THE PALLIATIVE CARE AND EOL CARE ENDORSEMENT MAINTENANCE STEERING COMMITTEE

July 20-21, 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; Naomi Karp, JD; Mark Leenay, MD; Michael Lepore, PhD; Solomon Liao, MD; Stephen Lutz, MD; Helene Martel, MA; Naomi Naierman, MPA; Douglas Nee, PharmD, MS; Kathleen O'Malley; 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; Ann Hammersmith, JD (Day 1 only); Karen Pace, PhD, RN, (Day 1 only); Caren Ginsberg, PhD; Lindsey Tighe, MS.

Others Present:
Sydney Dy, Johns Hopkins University; Craig Earle, The Ontario Institute for Cancer Research*; Laura Hanson, University of North Carolina Chapel Hill*; Carol Roth, RAND; Martha Tecca, Deyta; Joan Teno, Brown Medical School; Neil Wenger, RAND;

*Participating via teleconference

The full transcripts and audio recordings from the meeting can be found on the project webpage.

INTRODUCTIONS AND DISCLOSURES

Dr. Morrison and Ms. Lunney introduced the project, and welcomed the Steering Committee to the meeting. Dr. Ginsberg, Dr. Burstin and Ms. Bossley, representing the National Quality Forum (NQF), also extended their thanks to the Committee. Following an overview from Ms. Hammersmith, Committee members introduced themselves and announced their Disclosures and Conflicts of Interest.

BACKGROUND

Palliative care generally refers to patient and family-centered care that optimizes quality of life by anticipating, preventing, and alleviating suffering across the continuum of a patient's illness. Historically, palliative care referred to treatment available to patients at home and enrolled in hospice. More recently, palliative care has become available to acutely ill patients and its meaning has evolved to encompass comprehensive care that may be provided along with disease-specific, life-prolonging treatment. End-of-life (EOL) care refers to comprehensive care for a life-limiting illness that meets the patient's medical, physical, psychological, spiritual and social needs. Hospice care is a service delivery system that emphasizes symptom management without life-prolonging treatment, and is intended to enhance the quality of life for both patients with a limited life expectancy and their families. Attention recently has been focused on increasing the quality and availability of hospice and palliative care services, both for acutely ill patients and those at EOL. Studies have found that palliative care programs across the trajectory of a patient's illness, including EOL care can result in improved quality of care, including higher patient satisfaction, improved communication, fewer admissions to intensive care units, emergency departments and acute care hospitals, more referrals to hospice, and reduced costs.

The number of palliative care and EOL care programs has increased rapidly in recent years. Nonetheless, palliative care and EOL care services remain underutilized and more than one million people in the United States die each year of chronic and debilitating illnesses without receiving hospice services. A comprehensive set of performance metrics is needed to gauge our progress in these clinical areas.

The current project will seek to endorse performance measures focusing on:

- assessment and management of relief of symptoms at EOL and for acutely ill patients (e.g., pain, dyspnea, weight loss, weakness, nausea, serious bowel problems, delirium and depression);
- patient- and family-centered palliative and hospice care that address psychosocial needs and care transitions; and
- patient, caregiver and family experiences of care.

These recommended measures include measures that are undergoing the NQF maintenance process, as well as new measures submitted for endorsement consideration in this project.

PROJECT OVERVIEW

Dr. Ginsberg then delivered an overview of the project, and introduced the project's staff. She explained that the purpose of the project is to identify and endorse new and existing measures for quality improvement and public reporting that improve the quality of life for patients that receive palliative care and end-of-life care.

EVALUATION OF PALLIATIVE CARE AND END-OF-LIFE CARE MEASURES

The Palliative Care and End-of-Life Care Steering Committee considered 22 measures, including 9 measures undergoing maintenance review, using NQF's measure evaluation criteria. To facilitate the evaluation, the committee members were assigned specific measures to review prior to the meeting. Ratings for the measure evaluation criteria were collected from each set of reviewers prior to the meeting using a Survey Monkey tool and were provided to the entire Committee during discussion.

Dr. Pace introduced the measure endorsement process, and explained how Committee members should consider the measures against the measure evaluation criteria. They must determine, for each measure, whether it meets the NQF standards for endorsement. She reviewed the protocol for voting, and also looked specifically at measure 0213, to help the Committee understand how these criteria are applied. Dr. Burstin also spoke on the deliberations of NQF's Consensus Standards Advisory Committee, with regard to newer measures, where the evidence might not be as robust. While those discussions are still in their early stages, she asked the Committee to consider the measures as is.

The Measures

Summaries of the reviewed measures' evaluation of measures, along with the Committee's votes and rationale are presented in the tables below. Questions to and answers from the measure developers are also included.

Utilization measures

- 0213 Proportion admitted to the ICU in the last 30 days of life (ASCO) (maintenance)
- 0214 Percentage of patients who died from cancer dying in an acute care setting (ASCO) (maintenance)
- 0215 Proportion not admitted to hospice (ASCO) (maintenance)
- 0210 Proportion receiving chemotherapy in the last 14 days of life (ASCO) (maintenance)
- 0211 Proportion with more than one emergency room visit in the last days of life (ASCO) (maintenance)
- 0212 Proportion with more than one hospitalization in the last 30 days of life (ASCO) (maintenance)
- 0216 Proportion admitted to hospice for less than 3 days (ASCO) (maintenance)

Pain Management measures

- 1634 Hospice and Palliative Care- Pain Screening (UNC)
- 1637 Hospice and Palliative Care – Pain Assessment (UNC)
- 1617 Patients treated with an Opioid who are given a bowel regimen (RAND)
- 1628 Patients with advanced cancer assessed for pain at outpatient visits (RAND)

Dyspnea Management measures

- 1638 Hospice and Palliative Care- Dyspnea Treatment (UNC)
- 1639 Hospice and Palliative Care – Dyspnea Screening (UNC)
- 1630 Hospitalized patients who die an expected death who have dyspnea addressed (RAND)

Care preference measures

- 1626 Patients admitted to the ICU who have care preferences documented (RAND)
- 1641 Hospice and Palliative Care- Treatment Preferences (UNC)
- 1647 Documentation of spiritual/religious concerns (Deyta)
- 0209 Comfortable dying (NHPCO) (maintenance)
- 1625 Hospitalized patients who die an expected death with an ICD that has been deactivated (RAND)

Quality of Care at the End of Life measures

- 0208 Family Evaluation of Hospice Care (NHPCO) (maintenance)
- 1632 CARE- Consumer Assessments and Reports of End of Life (Center for Gerontology and Health Care Research)
- 1623 Bereaved Family Survey (PROMISE Center)

Please note that seven of the endorsement maintenance measures, Measures 0210-0216, all stewarded by the American Society of Clinical Oncology (ASCO) were reviewed by this committee prior to the meeting. The Committee decided to table discussion and voting on these measures, pending more information from the developer. In addition, a final vote was tabled on Measure 1647 also pending further information on reliability testing and numerator details. Committee members will discuss additional information in follow-up phone calls.

Overarching Issues

Several themes and issues emerged from the Steering Committee discussion and evaluation:

Measures for which voting was tabled pending more information:
Related and Competing Measures
The Committee identified several competing and related measures. After considering all measures independently, the Committee then began a discussion to determine if related measures required harmonization or if there were competing measures, whether one measure better met the evaluation criteria. In particular, the Committee considered two measures relating to assessment and screening of pain (1628: Patients with advanced cancer assessed for pain at outpatient visits; and 1637: Hospice and Palliative Care – Pain Assessment). After consideration of the measure specifications, the Steering Committee determined that the measures were related, not competing, as the measures addressed different settings and patient populations. The Committee discussed the need to consider harmonizing the numerators of these measures, in addition to clarifying the definitions of screening and assessment.

The Committee also was asked to consider whether Measure 1641, Hospice and Palliative Care – Treatment Preferences and existing NQF measure 0326, Advanced Care Plan are related or competing. NQF will provide the Committee with updated specifications for Measure 0326 to review concurrently with Measure 1641 to allow the Steering Committee to determine what further action is needed.

Completeness of measure submission forms; Incorporating additional evidence in reviews
The Committee discussed whether they should use their own opinions and knowledge of evidence if the evidence in a measure submission form was missing or limited. It was determined that Committee members are free to use their own expert knowledge in their decisions. Committee members should indicate their use of additional information in their measure evaluations.

Several measure submissions had incomplete evidence, or the evidence presented was not relevant. The votes on Measures 0210-0216 were tabled, in part, because of incomplete or outdated evidence, which will be provided to the Committee prior to vote. Measure 1625: Hospitalized patients who die an Expected Death with an ICD that has been deactivated, had limited documentation of evidence; however, Steering Committee members were able to cite evidence to support the measure based on their individual expertise and clinical knowledge. Measure 1647: Documentation of spiritual/religious concerns, also had limited documentation of evidence; the measure developer will provide more evidence for the Steering Committee to consider.

Unintended consequences of measures
The Committee discussed potential unintended consequences of three measures:

- Measure 0213: Proportion admitted to the ICU in the last 30 days of life, may provide perverse incentives to admit patients to the ICU. The measure developer stated that such unintended consequences of this measure have not been observed.
- Measure 1638: Hospice and Palliative Care – Dyspnea Treatment, may lead to over-treatment of dyspnea as a result of screening. The developer stated that undertreating, rather than over-treating dyspnea was a more pressing concern. They also acknowledged that overtreatment might be problematic in the future as a result of the implementation of this measure.

Process-Outcome Links
The Committee discussed the link between the process of care and desired health outcome in selected measures. In the discussion of Measure 0213, Proportion admitted to the ICU in the last 30 days of life, the Committee reflected on whether admitting a patient to the ICU during this period of time

reflected good or bad care, or accurately reflected patient wishes. The Committee also discussed whether documentation of spiritual concerns (Measure 1647) led to improved patient outcomes.

Further discussion centered around distinguishing a process of care from an outcome. The Committee discussed that many of the ASCO-stewarded measures (although not all were discussed) could be classified as either process or outcome measures.

Measure Gaps

The Committee identified gaps in performance measurement of palliative care and end-of-life care. The following summarizes these identified measure gap areas:

Patient Preferences

- Measures that focus on discussions with patients in an acute care setting and over the course of their illness about patient preferences, within 48 hours and then weekly within the ICU.
- Measures focus on advance care planning and documentation, particularly measures that span the duration of illness and across care settings.
- Measures that address patient decisions to avail themselves of hospice care.
- Measures incorporating the use of Physicians Orders for Life-Sustaining Treatment (POLST) in hospitals; across transitions of care and in reference to care coordination.

Quality of Life

- Measures that assess quality of life for all patients, and not just those seen by palliative care and/or hospice teams.
- Measures that look at quality of life across the continuum of care, including the outpatient setting or nursing homes.
- Outcome measures on end-of-life care that allow for benchmarking.
- Measures that incorporate the use of post-mortem surveys.
- Process measures related to communication of critically ill patients; for example, ICU family meetings.
- Measures addressing children or young adults; for example, minors with decision making capacity; the presence or availability of hospices with expertise to care for children; the availability of functional services such as Occupational Therapy (OT), Physical therapy (PT), and child life educational support services in the community for critically ill children and families.
- Measures of cultural and linguistic competence in delivering palliative and end-of-life care.
- Measures addressing psychosocial and spiritual end-of-life care.

Family/Caregiver Experience of Care

- Measures of after-death care regarding treatment of the body and treatment of the patient's family.
- Measures reflecting education of the patient's family on the signs and symptoms of imminent death.
- Measures about education and support of caregivers, particularly regarding the dying episode.

Process Measures in Palliative and End of Life Care

- Measures of resource use and efficiency in hospice care.
- Measures of artificial hydration and nutrition.
- Communication measures reflecting clarity of prognosis.
- Measures reflecting the interdisciplinary nature and training of the palliative care team, including spiritual and psychosocial care needs.

- Measures of palliative care for chronically ill patients who are not at the end of life.

COMMITTEE MEASURE EVALUATIONS

Utilization Measures

0210: Proportion receiving chemotherapy in the last 14 days of life (maintenance)
0211: Proportion with more than one emergency room visit in the last days of life (maintenance)
0212: Proportion with more than one hospitalization in the last 30 days of life (maintenance)
0213: Proportion admitted to the ICU in the last 30 days of life (maintenance)
0214: Percentage of patients who died from cancer dying in an acute care setting (maintenance)
0215: Proportion not admitted to hospice (maintenance)
0216: Proportion admitted to hospice for less than 3 days (maintenance)

Measures 0210-0216 were reviewed by the Steering Committee en masse and were not voted upon. No recommendations for endorsement were made, as the Steering Committee requested that the measure developer provide more information to allow for thorough review and consideration of the measures. All of the measure submission forms for this group of measures lacked similar information; as such, the Steering Committee discussed the information required for review with the measure developer. The measure developer will provide that information to the Steering Committee for their review on a future conference call.

Steering Committee members requested the following information be provided:

Importance:

- Demonstration of the process-outcome link for each measure. Specifically the Steering Committee requested that the developer demonstrate how each measure is indicative of high or poor quality of care.
- Updated evidence to support the focus of each measure. Steering Committee members noted that much of the evidence provided was weak or did not address the topic directly.
- The Steering Committee requested information on the demonstrated performance gap from the current use of the measures.

Scientific Acceptability:

- Administrative codes and data claims codes are used to specify each measure. Steering Committee members noted that as the measures are in use, such codes should be provided.
- Reliability and validity testing data which utilizes information captured from the current use of the measures.
- Information on whether the variation in measure score is adjusted for case mix, and if not, the rationale behind this decision.

Usability:

- Information on the impact each measure has had in improving quality.

- Information on whether the measures need to be adapted given the increasing use of inpatient palliative care units. Steering Committee members noted that, for example, patients may seek emergency care or be admitted to the ICU close to end-of-life in order to receive palliative care. This trend in increased utilization of hospital services would be indicative of better quality of care; however, how would this be captured with the measures?
- Information on the current use of the measures. The measures have been NQF-endorsed and in use for several years; as such, the Steering Committee requested information on the use and public reporting of the measures.

Feasibility:

- Information on unintended consequences of measurement, as captured through current use of the measures.

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
Description: Percentage of hospice or palliative care patients who were screened for pain during the hospice admission evaluation / palliative care initial encounter Numerator Statement: Patients who are screened for the presence or absence of pain and its severity, if present, during the admission evaluation for hospice / 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: None 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) 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 Developer Response: 1) Awaiting response. 2) These two time intervals were selected after consulting with hospice and palliative care providers about the timeframes for evaluation – and that 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.
1. Importance to Measure and Report: Overall, the criteria for importance were met. *(1a. Impact; 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)* Rationale: • 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 considered by the Committee as additional evidence when making their decision.
2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.

1634: Hospice and Palliative Care- Pain Screening

(2a. Precise specifications; 2b. Reliability testing: H-16, M-4, L-0. I-0; 2c. Validity testing H-17, M-3, L-0, I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-11, M-7, L-2, I-0)

Rationale:

- 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.

3. Usability: H-16, M-3, L-1, I-0

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

- 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.

4. Feasibility: H-19, M-1, L-0, I-0

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- The measure is easily implemented electronically.
- If electronic data is not available, Steering Committee members noted that substantial data collection effort may be required, as data has to be extracted from the patient chart.

1637: Hospice and Palliative Care- Pain Assessment

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.

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.

Denominator Statement: Patients enrolled in hospice OR receiving palliative care who report pain when pain screening is done on the admission evaluation / initial encounter.

Exclusions: Patients with length of stay < 1 day in palliative care or < 7 days in hospice, patients who were not screened for pain.

Adjustment/Stratification: No risk adjustment or stratificationnecessary.

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-16, N-4, A-0

Rationale:

If applicable, Conditions/Questions for Developer:

- Within the denominator details, the measure has a positive screen for hospice patient of "if greater than 0", hospice patient is "greater than 4"?

Developer Response:

- Screening scores were based on clinicians input

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

(1a. Impact; 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)

Rationale:

- 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.

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.

(2a. Precise specifications; 2b. Reliability testing: H-7, M-11, L-2, I-0; 2c. Validity testing H-6, M-11, L-2, I-1; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-5, M-9, L-3, I-3)

1637: Hospice and Palliative Care- Pain Assessment

Rationale:

- 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.

3. Usability: H-7, M-7, L-6, I-0

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

- 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.

4. Feasibility: H-3, M-12, L-5, I-0

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- The measure is easily captured electronically.
- If electronic data is not available, Steering Committee members noted that substantial data collection effort may be required, as data has to be extracted from the patient chart.

1617: Patients Treated with an Opioid who are given a bowel regimen

Description: Percentage of vulnerable adults treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed

Numerator Statement: Patients from the denominator that are given a bowel regimen or there is documentation as to why this was not needed

Denominator Statement: Vulnerable adults who are given a new prescription for an opioid

Exclusions: None

Adjustment/Stratification: No risk adjustment or stratification necessary

Level of Analysis: Clinician : Group/Practice, Clinician : Individual, Facility, Health Plan

Type of Measure: Process

Data Source: Electronic Clinical Data : Electronic Health Record, Paper Records, Patient Reported Data/Survey

Measure Steward: RAND Corporation | 1776 Main Street | Santa Monica | California | 90407

Steering Committee Recommendation for Endorsement: Y-19, N-1, A-0

Rationale:

If applicable, Conditions/Questions for Developer:

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?

Developer Response:

1) Awaiting response
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).

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

(1a. Impact; 1b. Performance gap: H-16, M-3, L-1, I-0; 1c. Outcome or Evidence: Evidence Quantity: H-10, M-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)

Rationale:

- Measure demonstrates a high impact – this is an important treatment issue
- Evidence provided through literature studies
- Impact on health care cost and patient distress is significant
- The measure is easily implemented and can have significant impact.

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.

(2a. Precise specifications; 2b. Reliability testing: H-15, M-5, L-0, I-0; 2c. Validity testing: H-13, M-6, L-1, I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-8, M-6, L-3, I-3)

Rationale:

1617: Patients Treated with an Opioid who are given a bowel regimen

- Reliability testing was measured against current acceptable statistical assessments.
- Validity testing conducted empirically

3. Usability: H-10, M-9, L-1, I-0

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

- The measure is easily understood by the public.

4. Feasibility: H-13, M-7, L-0, I-0

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- Data is easily collected.

1628: Patients with advanced cancer assessed for pain at outpatient visits

Description: Adult patients with advanced cancer who have an assessment of pain with a standardized quantitative tool at each outpatient visit

Numerator Statement: Outpatient visits from the denominator where the patient´s pain was assessed with a quantitative standardized tool

Denominator Statement: Adult patients with advanced cancer who have at least 1 primary care or cancer-related outpatient visit

Exclusions: None

Adjustment/Stratification: No risk adjustment or stratification

Level of Analysis: Facility, Integrated Delivery System

Type of Measure: Process

Data Source: Electronic Clinical Data, Electronic Clinical Data : Registry, Paper Records

Measure Steward: RAND Corporation | 1776 Main Street | Santa Monica | California | 90407

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

Rationale:

If applicable, Conditions/Questions for Developer:

1) Steering Committee members requested harmonization of the numerator of this measure with that of measure 1634

Developer Response:

1) Awaiting response.

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

(1a. Impact; 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)

Rationale:

- 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 health care 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.

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.

(2a. Precise specifications; 2b. Reliability testing: H-10, M-8, L-0, I-2; 2c. Validity testing: H-9, M-11, L-0, I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-5, M-5, L-3, I-7)

Rationale:

- 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.

3. Usability: H-9, M-10, L-1, I-0

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

1628: Patients with advanced cancer assessed for pain at outpatient visits
• This measure is important for public reporting and will be easily understood.
4. Feasibility: H-12, M-7, L-1, I-0 *(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)* Rationale: • As data capture in oncology practice increasingly utilizes EMRs, this measure will become more feasible.

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.
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) Is 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. Impact; 1b. Performance gap: H-20, M-0, L-0, I-0; 1c. Outcome or Evidence: Evidence Quantity: H-11, M-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)* Rationale: • 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.
2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. *(2a. Precise specifications; 2b. Reliability testing: H-18, M-2, L-0, I-0; 2c. Validity testing: H-17, M-3, L-0, I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-7, M-7, L-2, I-4)* Rationale: • 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.
3. Usability: H-18, M-2, L-0, I-0 *(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)* Rationale: • The measure is very clear and straight forward; 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.

1639: Hospice and Palliative Care- Dyspnea Screening.

4. Feasibility: H-16, M-4, L-0, I-0

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- The data is available electronically and can be extracted.
- If electronic data is not available, Steering Committee members noted that substantial data collection effort may be required, as data has to be extracted from the patient chart.

1638: Hospice and Palliative Care- Dyspnea Treatment

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 screened for dyspnea, and/or patients with a negative screening.
Adjustment/Stratification: No risk adjustment
Level of Analysis: Clinician : Group/Practice, Facility
Type of Measure: Process
Data Source: Electronic Clinical Data
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-17, N-3, A-0
Rationale:

If applicable, Conditions/Questions for Developer

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?

Developer Response:

1) There is 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.

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

(1a. Impact; 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)

Rationale:

- 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.

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met

(2a. Precise specifications; 2b. Reliability testing: H-7, M-11, L-2, I-0; 2c. Validity testing: H-10, M-9, L-1, I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-5, M-6, L-4, I-5)

Rationale:

- 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.

3. Usability: H-8, M-11, L-1, I-0

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

- 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.

4. Feasibility: H-2, M-11, L-6, I-1

1638: Hospice and Palliative Care- Dyspnea Treatment

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- The measure is easily implemented electronically;
- If electronic data is not available, Steering Committee members noted that substantial data collection effort may be required, as data has to be extracted from the patient chart.

1630: Hospitalized patients who die an expected death who have dyspnea addressed.

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

Numerator Statement: Percentage of patients with dyspnea from the denominator who on any day(s) during the denominator time window had:

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

b) a reassessment of their dyspnea (response to treatment or reassessment in untreated dyspnea) within 24 hours

Denominator Statement: Hospitalized patients who died an expected death and who had dyspnea in the 7 days prior to death

Exclusions: None

Adjustment/Stratification: No risk adjustment or stratification

Level of Analysis: Facility

Type of Measure: Process

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

Measure Steward: RAND Corporation | 1776 Main Street | Santa Monica | California | 90407

Steering Committee Recommendation for Endorsement: No vote taken – measure did not pass importance criterion

Rationale:

If applicable, Conditions/Questions for Developer:

1) Could this measure be expanded to other settings of care?
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?

Developer Response:

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 time frame simplifies data abstraction.

1. Importance to Measure and Report: The measure did not pass the importance criterion.

(1a. Impact; 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)

Rationale:

- 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.

2. Scientific Acceptability of Measure Properties: No vote taken – measure did not pass importance criterion

(2a. Precise specifications; 2b. Reliability testing; 2c. Validity testing; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities)

Rationale:

- Definition of unexpected death is unclear

3. Usability: No vote taken – measure did not pass importance criterion

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

4. Feasibility: No vote taken – measure did not pass importance criterion

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

1630: Hospitalized patients who die an expected death who have dyspnea addressed.
• Hard to see how this can be implemented with paper medical records.

NQF Member and Public Comment Period

Ms. Tecca spoke to encourage members to consider harmonization beyond Palliative Care and End-of-Life care settings so that measures will be available across settings. She expressed concerns about the pain screening measure, measure 1634, particularly because of the seven day timeframe for pain screening to occur. Dr. Morrison clarified that patients had to have been in hospice for seven days, but must be screened on admission in order to meet the numerator criteria.

Ms. O'Malley said that the Committee should consider other evidence in the field; the Committee should be aware of Medicare requirements in its consideration of measures, as it puts out its recommendations for Palliative Care and End-of-Life Care.

Ms. Lunney noted that measure 0213 -- Proportion Admitted to ICU in the Last 30 Days of Life – was presented from a broad perspective and does not have an established benchmark. The measure is useful for comparison between facilities, but does not set a standard for acceptable performance. Dr. Burstin agreed, and noted that there are concerns about what the right threshold for evidence is, but that it is important to get information overall and to structure the measure to get accountability for the information. Dr. Bruera agreed and said that evidence is not necessarily linked to what occurs in the ICU, and ultimately, information has to be based on evidence.

Care Preference Measures

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

1626: Patients Admitted to ICU who have care preferences documented
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. 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. Denominator Statement: All vulnerable adults admitted to ICU who survive at least 48 hours after ICU admission Exclusions: None Adjustment/Stratification: No risk adjustment or stratification. Level of Analysis: Facility, Health Plan, Integrated Delivery System Type of Measure: Process Data Source: Electronic Clinical Data: Electronic Health Record, Paper Records Measure Steward: RAND Corporation, 1776 Main Street, Santa Monica, California 90407
Steering Committee Recommendation for Endorsement: Y-20; N-0; A-0 Rationale: • 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.
If applicable, Conditions/Questions for Developer:
1. Importance to Measure and Report: Overall, the criteria for importance were met. *(1a. 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)* Rationale: • 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

1626: Patients Admitted to ICU who have care preferences documented

experience of care.
- The evidence is solid, though there are no clinical trials cited.

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.
(2a. Precise specifications; 2b. Reliability testing: H-10; M-9; L-1; I-0; 2c. Validity testing: H-7; M-12; L-1: I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-9; M-7; L-0; I-4)
Rationale:
- Steering Committee members acknowledged that it is difficult to measure whether there was a failure to attempt 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 capturing the intended process.
- However, Steering Committee members noted that there is strong interrater reliability with the measure.
- Steering Committee stated that face validity was acceptable.

3. Usability: H-10; M-8; L-1; I-1
(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)
Rationale:
- The Steering Committee stated that this measure provides important information for those seeking care.

4. Feasibility: H-7; M-8; L-4; I-1
(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)
Rationale:
- Clinical measures are routinely generated during daily patient care. Data is easily obtainable through EMR's or medical record chart documentation.

1641: Hospice and Palliative Care-Treatment Preferences

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

Steering Committee Recommendation for Endorsement: Y-19; N-1; A-0
Rationale:
- The measure impacts 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:

1. Importance to Measure and Report: Overall, the criteria for importance were met.
(1a. 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)
Rationale:
- 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. Important because it captures the patient's preferences.

1641: Hospice and Palliative Care-Treatment Preferences

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.
(2a. Precise specifications; 2b. Reliability testing: H-12; M-8; L-0; I-0; 2c. Validity testing: H-12; M-7; L-1: I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-8; M-6; L-1; I-5)
Rationale:

- Inter-rater reliability is very strong.
- Validity testing for this measure focuses on the target population consistent with research; construct validity is demonstrated.

3. Usability: H-13; M-5; L-1; I-1
(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)
Rationale:

- Data submitted shows that the measure results are meaningful, understandable, and very usable to affect quality outcomes for palliative and hospice patient populations.

4. Feasibility: H-8; M-10; L-2; I-0
(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)
Rationale:

- All data elements are available electronically.
- If electronic data is not available, Steering Committee members noted that substantial data collection effort may be required, as data has to be extracted from the patient chart.
- Concern that the documentation may not be standardized, making it somewhat challenging to reliably extract.

1647: Documentation of spiritual/religious concerns

Description: This measure reflects the percentage of hospice patients with documentation of a discussion of spiritual/religious concerns 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

Steering Committee Recommendation for Endorsement: Final recommendation for endorsement pending future Steering Committee review.
Rationale:

- The Steering Committee will review the measure on a future conference call once the measure developer has addressed the below conditions/questions.

If applicable, Conditions/Questions for Developer:

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.

Developer Response:

1) Awaiting response.
2) Awaiting response.

1. Importance to Measure and Report: Overall, the criteria for importance were met.
(1a. Impact: H-20; M-0; L-0; I-0; 1b. Performance gap: H-12; M-4; L-4; I-0; 1c. Evidence Quantity:H-2; M-11; L-7; I-0; Evidence Quality H-3; M-8; L-8; I-1; Evidence Consistency: H-4; M-9; L-6; I-1)
Rationale:

- 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

1647: Documentation of spiritual/religious concerns
patients who receive services from approximately 5000 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.
2. Scientific Acceptability of Measure Properties: Not voted on. *(2a. Precise specifications; 2b. Reliability testing: H-; M-; L-; I-; 2c. Validity testing: H-; M-; L-: I-; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-; M-; L-; I-)* Rationale: • The Steering Committee has requested the developer provide additional information about reliability testing.
3. Usability: Not voted on. *(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)* Rationale: • The Steering Committee will vote on Usability if the measure passes the Scientific Acceptability criteria.
4. Feasibility: Not voted on. *(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)* Rationale: • The Steering Committee will vote on Feasibility if the measure passes the Scientific Acceptability criteria.

Comprehensive Measures

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

0209: Comfortable Dying
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: 1) The measure impacts many patients. 2) Use of this measure will improve attention to the important practice of documenting preferences for life sustaining treatments.
If applicable, Conditions/Questions for Developer:
1. Importance to Measure and Report: Overall, the criteria for importance were met. *(1a. Impact: H-20; M-0; L-0; I-0; 1b. Performance gap: H-17; M-3; L-0; I-0; 1c. Evidence: Outcome Measure; Evidence criteria were not individually voted on)* Rationale: • Management of pain is a key priority identified by the NPP.
2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. *(2a. Precise specifications; 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.*

0209: Comfortable Dying

Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-9; M-8; L-1; I-2)

Rationale:

- The measure was presented with robust 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 who had their pain relieved.

3. Usability: H-18; M-2; L-0; I-0

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

- The measure captures whether pain was controlled or not based on the patient's own perception, acknowledging that pain scales are not reliable between 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.

4. Feasibility: H-14; M-6; L-0; I-0

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- Data elements are easily accessible through patient self report.

1625: Hospitalized Patients who Die an Expected Death with an ICD that has been deactivated

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 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

Steering Committee Recommendation for Endorsement: Y-13; N-7; A-0

Rationale:

- The measure impacts many patients, and the use of ICDs is becoming much more prevalent. This measure will become more useful as the use of ICDs continues to become more prevalent.
- There is emerging literature about use of ICDs near death.

If applicable, Conditions/Questions for Developer:

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

(1a. 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)

Rationale:

- 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 the prevalence of ICDs in patients is increasing.

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.

(2a. Precise specifications; 2b. Reliability testing: H-5; M-9; L-3; I-3; 2c. Validity testing: H-5; M-7; L-6: I-2; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-7; M-4; L-1; I-8)

Rationale:

- Charts used in reliability testing were for patients 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.

3. Usability: H-11; M-8; L-1; I-0

1625: Hospitalized Patients who Die an Expected Death with an ICD that has been deactivated

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

- The Steering Committee noted that there is no accepted standard of performance for this measure, as there is not yet enough data to establish a benchmark or standard. The measure is not yet used for public reporting.

4. Feasibility: H-7; M-8; L-5; I-0

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- Data elements are accessible through paper records.
- The measure developer is working to implement this measure in EHR, which will make it more feasible to use.

0208: Family Evaluation of Hospice Care

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.
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.
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.
Exclusions: Composite Score: If a survey respondent did not enter a response to more than 3 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.
Adjustment/Stratification: No risk adjustment or stratification.
Level of Analysis: Facility, Population: National
Type of Measure: Process
Data Source: Patient Reported Data/Survey
Measure Steward: National Hospice and Palliative Care Organization, 1731 King Street, Alexandria, Virginia 22314

Steering Committee Recommendation for Endorsement: Y-19; N-0; A-0

Rationale:

- 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.

If applicable, Conditions/Questions for Developer:

- The Steering Committee would like more information on disparities and issues related to stratification of the measure.

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

(1a. 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)

Rationale:

- A significant variance in performance was demonstrated.
- The body of evidence is based on studies, focus groups and professional guidelines that demonstrate 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.

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.

(2a. Precise specifications; 2b. Reliability testing: H-15; M-4; L-0; I-0; 2c. Validity testing: H-15; M-3; L-1: I-0; 2d. Exclusions justified; 2e.

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Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-11; M-6; L-1; I-1)

Rationale:

- The FEHC survey is well defined and precisely specified so it can be implemented consistently within and across Hospice organizations and allow for comparability.
- Disparities and issues related to stratification were not addressed adequately by the measure developer.
- The developer presented evidence that the items of the composite score have good face validity and should be easily understood by the public.

3. Usability: H-10; M-9; L-0; I-0

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

- This measure is already in extensive use.

4. Feasibility: H-12; M-6; L-1; I-0

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- 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.

1632: CARE- Consumer Assessments and Reports of End of Life

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.

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.

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 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.

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.

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. J Pain Symptom Manage-Special Section on Measuring Quality of Care at Life´s End II. 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. J Pain Symptom Manage. 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. JAMA. 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? J Pain Symptom Manage. 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. J Pain Symptom Manage. 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. J Pain Symptom Manage. 2007 Nov 2007;34(5):472-479.

1632: CARE- Consumer Assessments and Reports of End of Life

7. Connor SR, Teno J, Spence C, Smith N. Family Evaluation of Hospice Care: Results from Voluntary Submission of Data Via Website. J Pain Symptom Manage. 2005 Jul 2005;30(1):9-17.

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.

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

Exclusions: We excluded deaths due to accidents, trauma, during surgery, lethal injection, acute overwhelming infections, and from complications of pregnancy.

Adjustment/Stratification: No risk adjustment or stratification.

Level of Analysis: Facility, Population: Community, Population: National, Population: Regional

Type of Measure: Patient Engagement/Experience

Data Source: Other

Measure Steward: Center for Gerontology and Health Care Research, 121 South Main Street, Providence, Rhode Island 02912

Steering Committee Recommendation for Endorsement: Y-19; N-0; A-0

Rationale:

- This post-mortem 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 QI.
- 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 better support patients and families at end of life.

If applicable, Conditions/Questions for Developer:

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

(1a. 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)

Rationale:

- Compelling evidence was presented both for being high impact and there being a demonstrated performance gap.
- The measure is based upon a credible structure-process-outcome relationship with great consensus.

2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met.

(2a. Precise specifications; 2b. Reliability testing: H-11; M-8; L-0; I-0; 2c. Validity testing: H-9; M-10; L-0: I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-10; M-9; L-0; I-0)

Rationale:

- The measure elements, although complicated, are unambiguous with reliable data elements and measure score.

3. Usability: H-9; M-9; L-0; I-1

(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)

Rationale:

- 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

(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)

Rationale:

- 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.

1623: Bereaved Family Survey

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

1623: Bereaved Family Survey

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 he 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 year, 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 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.

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 addditional 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.

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 your 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.

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.

Exclusions: - Veterans for whom a family member knowledgeable about their care cannot be identified (determined by family member´s report)

- 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.

Adjustment/Stratification: No risk adjustment or stratification.

Level of Analysis: Facility, Population: National, Population: Regional

Type of Measure: Outcome

Data Source: Other

Measure Steward: PROMISE Center, 3800 Woodland Avenue, Building 4100, Philadelphia, Pennsylvania 19104

Steering Committee Recommendation for Endorsement: Y-19; N-0; A-0

Rationale:

- 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.

If applicable, Conditions/Questions for Developer:

1623: Bereaved Family Survey
1. Importance to Measure and Report: Overall, the criteria for importance were met. *(1a. 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)* Rationale: • 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.
2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. *(2a. Precise specifications; 2b. Reliability testing: H-7; M-10; L-2; I-0; 2c. Validity testing: H-7; M-11; L-1: I-0; 2d. Exclusions justified; 2e. Risk adjustment/stratification; 2f. Meaningful differences; 2g. Comparability; 2h. Disparities: H-8; M-9; L-0; I-2)* Rationale: • 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.
3. Usability: H-12; M-6; L-0; I-1 *(3a. Meaningful/useful for public reporting and quality improvement; 3b. Harmonized; 3c. Distinctive or additive value to existing measures)* Rationale: • 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 percent 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.
4. Feasibility: H-8; M-11; L-0; I-0 *(4a. Clinical data generated during care process; 4b. Electronic sources; 4c. Exclusions – no additional data source; 4d. Susceptibility to inaccuracies/ unintended consequences identified 4e. Data collection strategy can be implemented)* Rationale: • 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 follow up written survey sent when not reached.

NQF Member and Public Comment Period

No comments were received.

NEXT STEPS

- NQF staff will submit the Committee's questions to the measure developers.
- The Committee will meet via teleconference on August 17, 2011, to continue discussions from the in-person meeting.