NATIONAL QUALITY FORUM

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

September 22, 2011

Committee Members Present: June Lunney, PhD, RN (co-chair); Sean Morrison, MD (co-chair); Robert Fine, MD, FAACP; Richard Goldstein, MD, FAAP; Sarah Hill, MA; 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.

NQF Staff Present: Heidi Bossley, MSN, MBA; Helen Burstin, MD, MPH; Eric Colchamiro, MPA; Angela Franklin, JD; Caren Ginsberg, PhD; Lindsey Tighe, MS.

Others Present:
Dawn Ayalon, National Committee for Quality Assurance (NCQA); Mark Antman, American Medical Association; Maureen Dailey, American Nurses Association; Lori Harmon, Society of Critical Care Medicine; Dale Lupu, American Academy of Hospice; Dena Mendelsohn, Pacific Business Group on Health; Cindy Morgan, The Association of Home and Hospice Care; Tom Murray, the American Society of Critical Oncology; Bob Rehm, NCQA; Carol Roth, RAND; Betty Scott, First Health Hospice and Home Care; Carol Spence, National Hospice and Palliative Care Organization; Latoi Tatum, MD Anderson Cancer Center; Martha Tecca, Deyta; Joan Teno, Brown Medical School; Samantha Tierney, American Medical Association; Becky VanVorst, Deyta; Neil Wenger, RAND.

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

INTRODUCTIONS AND OPENING REMARKS

Dr. Ginsberg welcomed the Steering Committee to the meeting, noting that the purpose of the discussion was to review a pair of potentially competing/related measures, a set of harmonized pain measures, and measures that were updated following the Committee's in-person meeting. Ms. Tighe conducted a roll call.

Before the review of the measures, Dr. Morrison discussed the status of the ASCO measures under maintenance review. He noted that the Committee had asked for specific information regarding the usefulness of the measures for quality improvement and public reporting, including reliability and validity testing information and information on the process-outcome links. He added that the measure developers were given the opportunity to provide that information but that they chose to withdraw them; as such, these measures will not be considered in this project. Dr. Morrison stated that there will be an upcoming NQF project addressing cancer care, and these measures can be submitted to that project. Mr. Murray, who is with ASCO, the steward of these measures, said that he would be willing to work with staff to refine further and resubmit the measures during that project.

REVIEW OF COMPETING/RELATED MEASURES

1641: Hospice and Palliative Care—Treatment Preferences (UNC)

- **Specifications can be viewed below.**

0326: Advance Care Plan (NCQA)

- **Specifications can be viewed here.**

Dr. Burstin prefaced the discussion on harmonization, stating that where possible, NQF endorses one measure addressing a given topic area. When several measures address the same topic area, a best-in-class measure should be selected. If this is not possible, NQF asks for the measures to be harmonized so that the evidence for the focus of the measures and the approaches that the different developers are taking are unified.

The Steering Committee discussion centered on whether measure 0326: *Advance Care Plan* (NCQA) and measure 1641: *Hospice and Palliative Care—Treatment Preferences* (UNC) were intended to capture the same information. The Advance Care Plan measure is not intended to capture a population of patients who are approaching the immediate end of life; rather, it can be seen as a conversation for a healthy person to have with his or her doctor when age or risk factors increase. The measure captures legal documentation via an advance care plan or through a designated surrogate decision maker. Measure 1641, however, captures documentation of life-sustaining preferences when the end of life is imminent, in only the hospice and palliative care settings. The Steering Committee reached consensus that as the measures capture different patient populations at different periods of time when patients seek care, they do not need to be harmonized.

The Committee noted that measure 0326 could be improved by defining "surrogate decision maker"; currently there is little standardization in the use of the term.

Recommendations regarding measure 1641 are highlighted below.

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

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 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: Recommendations While the Committee did not recommend harmonization of this measure, they did encourage the developer to improve it by including the completion of a Physicians Order for Life Sustaining Treatment (POLST) form as a way to document care preferences in the numerator.
1. Importance to Measure and Report: Overall, the criteria for importance were met.

1641: Hospice and Palliative Care-Treatment Preferences
(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) 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.
2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. *(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)* Rationale: • The numerator captures a discussion with the patient, not simply prescribed orders. This is important because it captures the patient's preferences.
3. Usability: H-13; M-5; L-1; I-1 *(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)* 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 Delivery; 4b. Electronic Sources; 4c.Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)* Rationale: • All data elements are available through electronic clinical data. • Concern that the documentation may not be standardized, making it somewhat challenging to reliably extract.

COMMITTEE REVIEW OF HARMONIZED PAIN MEASURES

1628: Patients with advanced cancer assessed for pain at outpatient visits (RAND)
1634: Hospice and Palliative Care- Pain Screening (UNC)

The Steering Committee reviewed the harmonized measure specifications presented by the measure developers for measures 1628 and 1634. Committee members had no concerns regarding the modifications to the measures. Specifications for both measures can be found below; sections where there are changes to the measures have been highlighted.

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: 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. 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 Recommendation: • Codes for the two lowest level office visits should not be included, as they are typically not long enough for a discussion of pain

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

and may or may not include time with a physician.

- Unlikely to be any unintended consequences from removing these codes from the measure specifications.

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) The developer harmonized the numerator, and it met the Committee's approval.

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

(1a. High 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. 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.

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

(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)

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. The measures have been harmonized.

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

(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)

Rationale:

- 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 Delivery; 4b. Electronic Sources; 4c.Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)

Rationale:

- If data are captured in oncology practice EMRs, the measure becomes very feasible.
- Steering Committee members noted that this measure is limited by the study population.

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 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.

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:

1634: Hospice and Palliative Care- Pain Screening
1) Steering Committee members requested harmonization of the numerator of this measure with that of measure 1634. 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) The developer harmonized the numerator, and the Committee approved. 2) These two time intervals were selected after consulting with hospice and palliative care providers about the timeframes for evaluation. The timeframes are 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. High 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 the Committee considered as additional evidence when making its decision.
2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. *(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)* 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 *(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)* Rationale: • Measure is important, prevalent, and easily implemented electronically; this is known 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 Delivery; 4b. Electronic Sources; 4c.Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)* Rationale: • 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.

COMMITTEE REVIEW OF UPDATED MEASURES

The Committee next discussed the group of measures for which it had requested additional information.

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. (Deyta)

For measure 1647, the Committee was presented with a more precisely specified numerator, as well as additional evidence addressing the importance of measuring and reporting the measure results. The developer also provided evidence, captured through a retrospective study, that patients who did have documentation of a conversation of their spiritual or religious concerns demonstrated 63 percent

improvement in overall spiritual distress as opposed to patients who did not have documentation of this conversation.

The measure developer also provided the Steering Committee with reliability testing data collected through the PEACE project.

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.

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: Yes-13; No-5
Rationale:

- The measure will affect a significant number of patients.
- The benefits of assessing spiritual distress and attempting to intervene far outweigh any harms.

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.
3) The Committee considered whether the measure addresses and fully meets the NQF criteria for the quantity, quality, and consistency of evidence.

Developer Response:

1) The data provided were sufficient to ensure that reliability was met.
2) Further specification of the numerator details was sufficient for Steering Committee members.
3) The Steering Committee noted that their 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.

1. Importance to Measure and Report: Overall, the criteria for importance were met.
(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)
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 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 achieved consensus 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. For this reason, the Steering Committee recommended that this measure pass the importance criteria.

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

- The Steering Committee noted that the reliability testing provided by the measure developer was sufficient by common

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.
standards. • The Steering Committee stated that face validity was sufficient for this measure.
3. Usability: H-9; M-6; L-3; I-0 *(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)* Rationale: • 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 *(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c.Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)* Rationale: • Steering Committee members noted that measure information is easily abstracted through chart data.

0208: Family Evaluation of Hospice Care (NHPCO)

For measure 0208, the Steering Committee was provided with updated evidence on importance to measure and report.

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 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. 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 1,000 hospices offers good evidence of its feasibility and utility.
If applicable, Conditions/Questions for Developer: • The Steering Committee asked for more information on disparities and issues related to stratification of the measure.

0208: Family Evaluation of Hospice Care
Response • 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 were unintentionally left out of the original submission. The Committee raised no concerns with this information presented.
1. Importance to Measure and Report: Overall, the criteria for importance were met. *(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)* 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. 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)* 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. • The measure developer did not adequately address disparities and issues related to stratification.
3. Usability: H-10; M-9; L-0; I-0 *(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)* Rationale: • This measure is already in extensive use. • The items of the composite score have good face validity and should be easily understood by the public.
4. Feasibility: H-12; M-6; L-1; 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)* Rationale: • The data elements would not be in an electronic record, but they would be available electronically when using a vendor. • While some data elements may be in use, the measure is a follow-back survey requiring additional, albeit modest, resources for its data collection.

1632: CARE – Consumer Assessments and Reports of End of Life (Center for Gerontology and Health Care Research)

For measure 1632, the Steering Committee was provided with updated evidence on importance to measure and report.

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

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

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.
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 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. The experience with a closely related tool for the hospice setting seems compelling.
- 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.

If Applicable, Conditions/Questions for Developer:

- The measure developer provided the Committee with more detail on the numerator specifications and updated evidence. The Committee raised no concerns with this information presented.

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

(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)

Rationale:

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

1632: CARE- Consumer Assessments and Reports of End of Life
2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. *(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)* Rationale: • The measure elements, although complicated, are unambiguous with reliable data elements and measure score. • The measure will identify racial disparities in care.
3. Usability: H-9; M-9; L-0; I-1 *(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)* 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 measure's usability.
4. Feasibility: H-7; M-10; L-2; 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)* 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.

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

For measure 1617, the Steering Committee was provided with updated evidence on importance to measure and report.

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: The Committee approved the measure, but it also asked for additional information on the evidence for the measure, which the developer provided. The Committee acknowledged that the updates significantly improved the measure.
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) 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.
1. Importance to Measure and Report: Overall, the criteria for importance were met. *(1a. High 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:

1617: Patients Treated with an Opioid who are given a bowel regimen
• Measure demonstrates a high impact—this is an important treatment issue • Evidence provided through literature studies. • Impact on healthcare cost and patient distress is significant. • Though the evidence is limited, measure makes common scientific sense, is easily implemented, and can have significant impact.
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)* Rationale: • Validity testing conducted empirically. • Reliability testing accomplished through ACOVE and ASSIST.
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)* 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 Delivery; 4b. Electronic Sources; 4c.Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)* Rationale: • Data are easily collected.

NQF MEMBER AND PUBLIC COMMENT

The discussion was opened for public comment. No comments were received.

NEXT STEPS

Ms. Tighe reminded the Steering Committee that voting on the measures would be accomplished via Survey Monkey. Committee members were asked to vote to approve the updated measure submissions and measure harmonization information for all the measures discussed on the call, with the exception of measure 1647, which required voting on the complete NQF measure evaluation criteria.

NQF staff will compile a draft report and circulate it to the Committee. The draft report is scheduled to be posted for NQF Member and public comment for a 30-day period. Following that period, a conference call will be scheduled with the Committee to review the comments received.