NATIONAL QUALITY FORUM

TO: NQF Members and Public

FR: NQF Staff

RE: Voting draft report for *National Voluntary Consensus Standards: Palliative Care and End-of-Life Care: A Consensus Report*

DA: December 5, 2011

BACKGROUND

The number of palliative care and EOL care programs has increased rapidly in recent years. Nonetheless, palliative care and EOL care services remain underused, and more than one million people in the United States die each year of chronic and debilitating illnesses without receiving hospice services. Measuring quality of care across the many and varied locations in which palliative care and end-of-life care takes place is important to ensure safe, cost-effective care consistent with the current evidence base. The recommended measures include measures endorsed before 2009 that have undergone maintenance. The majority of measures considered focus on pain management, dyspnea management, care preference, and quality of care at the end of life.

A 21-member Steering Committee representing a range of stakeholder perspectives was appointed to review a total of 22 candidate and endorsement maintenance standards for quality performance in palliative care and end-of-life care. The Steering Committee is recommending 14 measures.

Comments and Revised Voting Report

NQF received 121 comments from 33 organizations and individuals pertaining to the general draft report and to each of the 14 measures recommended for endorsement. The distribution of individual comments by Member Council follows:

- Consumers: 15 comments
- Health Professionals: 28 comments
- Purchasers: 4 comments
- Public Health/Community: 0 comments
- Health Plans: 19 comments
- Quality Measurement, Research, and Improvement: 9 comments
- Providers: 10 comments
- Supplier and Industry: 0 comments
- Non-members: 36

A table of complete comments submitted during the comment period, with the responses to each comment and the actions taken by the Steering Committee and measure developers, is posted to the Palliative Care and End-of-Life Care project page under the Public and Member Comments section.

The revised draft document, *National Voluntary Consensus Standards: Palliative Care and End-of-Life Care: A Consensus Report*, is posted on the Palliative Care and End-of-Life Care project page on the NQF website along with the following additional information:

- Measure submission forms
- Meeting and call summaries from the Steering Committee's discussions.

Revisions to the draft report and the accompanying measure specifications are identified as red-lined changes. (Note: Typographical errors and grammatical changes have not been red-lined to assist in reading).

COMMENTS AND THEIR DISPOSITION

Comments about specific measure specifications were forwarded to the developers, who were invited to respond.

At its review of all comments, the Steering Committee had the benefit of developer responses. Committee members focused their discussion on recurring concerns and specific measures and topic areas that were most controversial or that questioned positions they had taken. The Committee made no changes to its measure recommendations.

Several themes emerged in the comments including:

- concerns with the underlying evidence and relationship to the outcome;
- concerns specific to the focus of the measures, feasibility and usability;
- concern with the lack of outcome measures;
- harmonization requests; and
- recommendations on additions to the report and gaps discussion.

General Comments

Concerns with the underlying evidence and relationship to the outcome

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

Concern with the lack of outcome measures

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

Comments on Measures Recommended for Endorsement

Request for harmonization of measures 1626 and 1641

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

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

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

NQF MEMBER VOTING

Effective July 1, 2011, the voting cycle has changed from 30 days to **15 days** for NQF members to submit their votes. Information for electronic voting has been sent to NQF Member organization primary contacts. Accompanying comments must be submitted via the online voting tool.

NATIONAL QUALITY FORUM

NATIONAL VOLUNTARY CONSENSUS STANDARDS: PALLIATIVE CARE AND END-OF-LIFE CARE—A CONSENSUS REPORT

DRAFT REPORT FOR VOTING

DECEMBER 5, 2011

NATIONAL VOLUNTARY CONSENSUS STANDARDS: PALLIATIVE CARE AND END-OF-LIFE CARE: A CONSENSUS REPORT

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NATIONAL QUALITY FORUM

NATIONAL VOLUNTARY CONSENSUS STANDARDS: PALLIATIVE CARE AND END-OF-LIFE CARE: A CONSENSUS REPORT

EXECUTIVE SUMMARY

Assessing the quality of palliative care and end-of-life care programs by using measures that reflect the current evidence base is crucial to ensure safe, cost-effective care. Palliative care programs in US hospitals have grown by 125 percent in the last decade; by 2030, there will be 72.1 million older persons in the United States, more than twice the number as 2000.[1,2] The need for high-quality and safe palliative care and end-of-life care services will only continue to grow as the population ages.

Attention recently has been focused on increasing the quality and availability of palliative care and end-of-life care services, both for acutely ill patients and those with life-limiting illnesses. Studies have found that palliative care programs across the trajectory of a patient's illness, including end-of-life 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 overall reduced costs.

This report presents the results of the evaluation of 22 measures considered under the National Quality Forum's Consensus Development Process (CDP) version 1.9, nine of which were undergoing endorsement maintenance. Fourteen measures are recommended for endorsement as voluntary consensus standards suitable for accountability and quality improvement, and one measure is not recommended for endorsement. In addition, seven measures that were undergoing endorsement maintenance were withdrawn by the developer during the review process. These measures are not discussed in the report.

NOTES

[1] Center to Advance Palliative Care (CAPC), *Palliative Care Programs Continue Rapid Growth in U.S. Hospitals*, New York, NY:CAPC;2010. Available at www.capc.org/news-and-events/releases/04-05-10. Last accessed October 2011.

[2] Department of Health and Human Services (HHS), Administration on Aging (AOA), *Aging Statistics*, Washington, DC:AOA;2011. Available at www.aoa.gov/aoaroot/aging_statistics/index.aspx. Last accessed October 2011.

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.

The number of palliative care and EOL care programs has increased rapidly in recent years. Nonetheless, palliative care and EOL care services remain underused, 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. Efforts by organizations such as the Joint Commission and Commission on Cancer have recognized their importance through the accreditation programs.

The current project sought 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.

The recommended measures add to the 38 National Quality Forum (NQF)-endorsed® preferred practices, which were endorsed in 2006 for implementation by palliative care and hospice programs and provide a foundation for quality measurement and reporting systems in these areas.

STRATEGIC DIRECTIONS FOR NQF

NQF's mission includes three parts: 1) setting national priorities and goals for performance improvement, 2) endorsing national consensus standards for measuring and publicly reporting on performance, and 3) promoting the attainment of national goals through education and outreach programs. As greater numbers of quality measures are developed and brought to NQF for consideration of endorsement, NQF must assist stakeholders in measuring "what makes a difference" and addressing what is important to achieve the best outcomes for patients and populations.

Several strategic issues have been identified to guide consideration of candidate consensus standards:

DRIVE TOWARD HIGH PERFORMANCE. Over time, the bar of performance expectations should be raised to encourage achievement of higher levels of system performance.

EMPHASIZE COMPOSITES. Composite measures provide much-needed summary information pertaining to multiple dimensions of performance and are more comprehensible to patients and consumers.

MOVE TOWARD OUTCOME MEASUREMENT. Outcome measures provide information of keen interest to consumers and purchasers, and when coupled with healthcare process measures, they provide useful and actionable information to providers. Outcome measures also focus attention on much-needed system-level improvements because achieving the best patient outcomes often requires carefully designed care process, teamwork, and coordinated action on the part of many providers.

CONSIDER DISPARITIES IN ALL WE DO. Some of the greatest performance gaps relate to care of minority populations. Particular attention should be focused in identifying disparities-sensitive performance measures and on identifying the most relevant race/ethnicity/language/socioeconomic strata for reporting purposes.

NATIONAL PRIORITIES PARTNERSHIP

The National Priorities Partnership, a multi-stakeholder collaborative of 48 organizations convened by NQF, plays a key role in identifying strategies for achieving national goals for quality healthcare and facilitating coordinated, multi-stakeholder action. The Department of Health and Human Services has asked the Partnership for its collective, multi-stakeholder input on the National Quality Strategy (NQS) framework, which includes three inextricably linked domains—better care, affordable care, and healthy people/healthy communities—around which priorities, goals, measures, and strategic opportunities for improvement are to be identified and refined.

The NQS, released in March 2011, identified six national priorities, two of which are closely aligned with objectives of the Palliative Care and End-of-Life Care project. These two priorities, "ensuring person- and family-centered care" and "promoting effective communication and coordination of care" emphasize goals to improve patient family and caregiver experience of care, encourage shared decision-making, and improve quality of life for patients with chronic illness and disability with care plans that address pain, symptom management, and psychosocial needs. Many of the measures considered for endorsement in this project address these goals and their related measure concepts and could be used to track performance and monitor improvement of both palliative care and end-of-life care. Such measures include those documenting treatment preferences and spiritual care, family experience of care, and pain and other symptom management. Additionally, NPP identified inappropriate/unwanted non-palliative services at EOL as one of the areas under the overuse goal in the affordability priority area.

RELATED NQF WORK

In 2006, NQF endorsed 38 preferred practices for palliative and hospice care, under the National Framework and Preferred Practices for Hospice and Palliative Care project, as part of an effort

that created a foundation for which a quality measurement and reporting system could be built. The preferred practices were derived from the eight domains of quality palliative and hospice care as established by the National Consensus Project for Quality Palliative Care: structures and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious, and existential aspects of care; cultural aspects of care; care of the imminently dying patient; and ethical and legal aspects of care.

Before 2008, NQF endorsed nine national voluntary consensus standards for addressing symptom management and EOL care for cancer patients within the National Voluntary Consensus Standards for the Quality of Cancer Care project. These endorsed measures included: the National Hospice and Palliative Care Organization survey instrument, components of the Family Evaluation of Hospice Care, and measures addressing healthcare utilization at the EOL.

NQF'S CONSENSUS DEVELOPMENT PROCESS

NQF's National Voluntary Consensus Standards for Palliative Care and End-of-Life Care seeks to endorse additional measures for quality improvement and accountability. Candidate consensus standards were solicited through a Call for Measures that closed on May 18, 2011. Additionally, relevant measures endorsed previously through previous projects were brought into the Palliative Care and End-of-Life Care project as part of NQF's endorsement maintenance process. Twenty-two measures were submitted in response to this project's Call for Measures. Fifteen measures were evaluated for suitability as voluntary consensus standards for quality improvement and accountability using NQF's standard evaluation criteria. Seven measures were withdrawn from consideration by the measure developer as a result of Steering Committee discussions questioning the utility of the measures for public reporting. Steering Committee subgroups rated each measure's strengths and weaknesses using the criteria and subcriteria to assist the Committee in making recommendations. The 21-member, multi-stakeholder Committee provided final evaluations of the four main criteria—importance to measure and report, scientific acceptability of the measure properties, usability, and feasibility – and made endorsement recommendations. Most measure developers were available during Committee discussions to respond to questions and clarify any issues or concerns.

Defining Palliative Care and End-of-Life Care

Distinguishing when EOL care should be initiated has been challenging with many individuals and organizations offering their own perspectives. Most measure developers were unable to offer a defined definition but for the purposes of the Steering Committee discussions, it was thought that if you would not be surprised if the patient dies in the next few months or year and they need support for symptom management, then they should be referred for EOL care. In addition, several comments recommended that the measure results be stratified by palliative care and hospice care. Most of the measures under consideration were specific either in the applicable settings or in the type of program. While all would agree that stratification of the results by setting may be preferable, it is indeed challenging at this time. Future measure development should focus on ways to enable the reporting of care provided across these settings.

One additional comment raised the issue that there is a lack of a common denominator to identify palliative care patients in different settings. The Committee agreed that one is needed and should be considered in the future.

Overarching Measure Evaluation Issues

The Steering Committee encountered several overarching issues during its discussions and evaluations of the measures. These issues were factored into the Committee's ratings and recommendations for measures and are described below, as well as for each individual measure in the evaluation summary table.

Use of Expert Judgment or Additional Evidence in Reviews

While reviewing the evidence provided to support several of the measures, the Steering Committee noted that the evidence provided in the forms did not directly address the measure's focus. In those instances, the Steering Committee members discussed their role regarding using their expert judgment or applying additional evidence based on their own knowledge or expertise during the evaluation process. It was determined that committee members could use their own expert knowledge in their decisions and ratings of the subcriteria but that additional research on the evidence would not be conducted.

Measure #1625: *Hospitalized patients who die an Expected Death with an ICD that has been deactivated* serves as an example of how the Committee applied additional evidence based on its knowledge and expertise. This measure had limited documentation on the underlying evidence. However, Steering Committee members were able to cite evidence to support the measure based on their individual expertise and clinical knowledge, which has not yet been incorporated into clinical guidelines.

In other instances when the evidence presented for a particular measure did not meet the NQF subcriteria of the quantity, quality, and consistency of the evidence, it was determined that the Committee's collective judgment was acceptable for those measures whose benefits far outweigh any potential risks associated with it. Measure #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* serves as a good example of applying expert judgment. The Committee was presented with data from a retrospective study showing that patients whose records documented a conversation of their spiritual or religious concerns demonstrated improvement in overall spiritual distress as opposed to those whose records did not document this conversation. In this discussion, the Steering Committee raised concerns that the evidence presented, though compelling given the topic area addressed by the measure, does not meet the NQF criteria for the quantity, quality, and consistency of evidence. However, the Steering Committee's expert consensus of the measure's importance related to the quality of care provided to a patient and the potential benefits patients will experience based on this assessment was deemed acceptable.

Process-Outcome Links

The Committee discussed the link between the process of care and desired health outcome in selected measures. Several measures presented to the Committee did not have a clear process-outcome link, and data on how these measures lead to better outcomes were presented. For example, the Committee discussed to what degree assessments for pain led to better outcomes (Measure #1637: *Hospice and Palliative Care - Pain Assessment*); but given the performance gap in this area, with only 60 percent of hospice patients and 67 percent of palliative patients having a pain assessment, the Committee supported the measure's importance to measure and

report. In addition, the Committee reasoned that screening leads to assessment and one cannot be accomplished without the other. To further strengthen the link between the two measures, 1634 and 1637, they are recommended as paired. Regarding measure #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*, the Steering Committee noted that effective interventions to address the issues faced by patients reporting spiritual distress might not exist. However, the Committee was presented with data to show that having this conversation resulted in 63 percent of patients reporting improvement in their spiritual distress scores. Comments from several organizations questioned the link between the process measure and desired outcome but the Committee continued to believe that the links presented by the measures were reasonable.

Unintended Consequences of Measures

The Committee discussed potential unintended consequences following the use of a measure. In particular, the Steering Committee questioned whether emphasizing screening for a condition or symptom might result in overtreatment. The Steering Committee suggested that an unintended consequence of Measure #1638: *Hospice and Palliative Care - Dyspnea Treatment* is the potential for overtreating dyspnea. The developer suggested that at this time the more pressing concern the measure addresses is undertreatment rather than overtreatment of dyspnea.

Related and Competing Measures

For those measures that are determined to be competing or related, additional guidance was provided to the Committee requesting them to see if harmonization should be sought for related measures or if one measure could be recommended if more than one competing measure were identified. Competing measures are those that essentially address the same concepts for the target process, condition, and event outcome, as well as the same target patient population. Related measures are those that have the same concepts either for measure focus or target population, but not both. Each measure must meet the measure evaluation criteria before this additional discussion. No measures were determined to be competing, but several measures were determined to be related, and opportunities for harmonization were considered. For example, measure #1641: *Hospice and Palliative Care – Treatment Preferences* and the previously

endorsed measure #326: *Advanced Care Plan* were reviewed to determine if they were competing measures. The measures address populations that were overlapping but differed in focus and intent. Measure #1641 captures documentation of life-sustaining preferences when the end of life is imminent (hospice/specialty palliative care setting) and addresses a different set of questions. Measure #326 captures legal documentation via an advance care plan or through a designated surrogate decision maker. The patient population is over age 65, but the measure is not intended to capture a population of patients who are approaching the immediate end of life. Rather, the measure is intended to encourage a discussion in advance. For these reasons, the Steering Committee did not recommend further action toward harmonization but did make recommendations to improve both measures further. Several comments received called for harmonization of Measures #1626 and #1641 since they believed that care preferences and treatment preferences were similar. The Committee reviewed the measures and agreed that there are distinct differences between the two in that most if not all patients have care preferences but many patients often do not have treatment preferences (e.g., life-sustaining treatments).

In addition, the Steering Committee requested that the measure developers harmonize the numerators of two measures: #1634: *Hospice and Palliative Care – Pain Screening* and #1628: *Patients with advanced cancer assessed for pain at outpatient visits*. These measures both specify pain screening, but for different populations, thus making them related and not competing measures. However, the measures specified different screening tools within the numerators. At the Committee's request, developers harmonized the numerators of these measures so both specify screening for presence or absence of pain, rating pain if available and using a standardized quantitative tool (with examples of pain screening tools provided).

RECOMMENDATIONS FOR ENDORSEMENT

This report presents the results of the evaluation of 15 measures considered under the NQF Consensus Development Process (CDP).

Candidate Consensus Standards Recommended for Endorsement

Fourteen measures are recommended for endorsement as voluntary consensus standards suitable for public reporting and accountability. Evaluation summary tables follow the list of

measures and summarize the results of the Steering Committee's recommendation for endorsement and subsequent public and NQF member comments. Hyperlinks are provided:

- from each listed measure to the evaluation summary table;
- from each summary table to the detailed measure specifications;
- from each summary table to the web page where all materials submitted by the developer or steward are posted; and
- from each summary table to the web page where the meeting and call summaries, transcripts, and recordings can be assessed.

The Steering Committee recommended the following candidate consensus standards for endorsement:

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)

Care Preference Measures

1626: Patients admitted to the ICU who have care preferences documented (RAND)

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

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)

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)

Candidate Consensus Standards Not Recommended for Endorsement

The Steering Committee recommended that the following candidate consensus standard not be endorsed:

1630: Hospitalized patients who die an expected death who have dyspnea addressed (RAND)

PAIN MANAGEMENT MEASURES

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

1634: Hospice and Palliative Care- Pain Screening (measure specifications) (developer materials and meeting summaries) *Paired with measure 1637: Hospice and Palliative Care- Pain Assessment
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: 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) The developer harmonized the numerator with measure 1628: Patients with advanced cancer assessed for pain at outpatient visits (RAND), and it met the Committee's approval. 2) These two time intervals were selected after consulting with hospice and palliative care providers about the timeframes for evaluation. The aim was to allow for the timeframes be generalizable and realistic (in duration) for the scope of the initial evaluation. The measure, as tested, did not specify a definition of the initial evaluation.

1634: Hospice and Palliative Care- Pain Screening (measure specifications) (developer materials and meeting summaries)
*Paired with measure 1637: Hospice and Palliative Care- Pain Assessment

1. Importance to Measure and Report: Overall, the criteria for importance were met.
(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-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 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 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.

5. Public & Member Comments:

- A comment was received suggesting that this measure should not, in its denominator, exclude those patients with a shortened length of stay. The measure developer was in agreement with the concern expressed, but noted that, while they may consider expanding it in the future, this exclusion was recommended by the Technical Expert Panel during quality measure development. As such, the measure will not be changed, but the Committee agreed that it should be looked at in the future.
- Multiple comments were received suggesting that this measure was duplicative with measure 1637. The measure developer responded that developers continue to see the need for Pain Screening (which applies to all patients admitted to hospice or palliative care) as separate from Pain Assessment (which applies only to the subset of patients who report having pain as a symptom). The Steering Committee agreed with the developer's comments; noting the need for both measures, the Committee recommended them for endorsement as paired measures.

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1637: Hospice and Palliative Care- Pain Assessment (measure specifications) (developer materials and meeting summaries)
*Paired with measure 1634: Hospice and Palliative Care- Pain Screening

Description: This quality measure is defined as: Percentage of hospice or palliative care patients who screened positive for pain and

1637: Hospice and Palliative Care- Pain Assessment (measure specifications) (developer materials and meeting summaries)
*Paired with measure 1634: Hospice and Palliative Care- Pain Screening

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. Patients who screen negative for pain are excluded from the denominator.
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. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-14, M-5, L-0, I-1; 1c. Outcome or Evidence: Evidence Quantity H-11, M-6, L-2, I-1; Evidence Quality H-10, M-8, L-2, I-0; Evidence Consistency H-10, M-6, L-1, I-3)

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. Reliability Testing: H-7, M-11, L-2, I-0; 2b. Validity Testing H-6, M-11, L-2, I-1; 2c. Disparities: H-5, M-9, L-3, I-3)

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

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

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

Rationale:

1637: Hospice and Palliative Care- Pain Assessment (measure specifications) (developer materials and meeting summaries)
*Paired with measure 1634: Hospice and Palliative Care- Pain Screening

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

5. Public & Member Comments:

- A comment was received suggesting that this measure was duplicative with measure 1634 – *Hospice and Palliative Care – Pain Screening.* The measure developer responded that developers continue to see the need for Pain Screening (which applies to all patients admitted to hospice or palliative care) as separate from Pain Assessment (which applies only to the subset of patients who report having pain as a symptom). The Steering Committee agreed with the developer's comments; noting the need for both measures, the Committee recommended them for endorsement as paired measures.
- A comment was received suggesting that this measure should contain an exclusion for patients with negative screening for pain, and not to include them in the patient population receiving an assessment. The measure developer agreed, and will revise the denominator statement to reflect that this denominator excludes patients who screen negatively for pain. The Steering Committee agreed with this change.

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1617: Patients Treated with an Opioid who are given a bowel regimen (measure specifications) (developer materials and meeting summaries)

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) The developer provided information that bulk agents are used in treating constipation.
2) Population being considered is not just vulnerable elders but has been expanded to vulnerable adults. Measure has been tested but does not have reliability testing (only prevalence).

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

(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-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 is provided through literature studies.
- Impact on healthcare 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. 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)

1617: Patients Treated with an Opioid who are given a bowel regimen (measure specifications) (developer materials and meeting summaries)

Rationale:

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

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.

5. Public & Member Comments:

- Multiple comments were received about the denominator term "vulnerable adult". The measure developer responded that the vulnerable adults definition includes patients >74 years of age, VES-13 score >2, poor prognosis/terminal illness defined as life expectancy <6 months, or Stage IV cancer. Additionally, the measure 1626 - *Patients Admitted to ICU who have care preferences documented*, which also looks at "vulnerable adults", was harmonized so that these denominators are the same.
- A comment was received suggesting that it will be difficult to capture the patients treated with an opioid who are given a bowel regimen. The measure developer responded that this measure does not rely on any patient reports, but rather requires that the healthcare provider document (at the time of prescription) that a bowel regimen has been recommended or the reason why it was not needed. The Steering Committee agreed with this comment.
- A comment was received suggesting that the measure represents a "care plan" standard of care and a "low bar". The Committee responded that agreed that in an ideal setting, this would be a standard of care; however, given the studies demonstrating low performance in meeting this measure, the Committee recommended it for endorsement as improvement in measure performance would lead to significant improvement in patient comfort and pain reduction.
- A comment was received suggesting that the measure lacked a sound evidence base linking the process to outcomes, and that the measure had a significant burden to overcome in data collection. The measure developer responded that consensus concurs that prevention/management of opioid-related constipation is important for patient comfort and for deriving maximal benefit from medications. While data collection via chart abstraction is laborious, it is a requirement for many quality measures. The Committee concurred, and added that in cases where there is a sparse body of evidence, the Committee can rely on its own expert opinion. With respect to burden of data collection, the Steering Committee acknowledged that the implementation of EHR will decrease the burden of data collection for many of the measures.

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

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

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

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) The developer harmonized the numerator with measure 1634: Hospice and Palliative Care- Pain Screening (UNC), and it met the Committee's approval.

Recommendations:

- Codes for the two lowest level office visits should not be included, as they are typically not long enough for a discussion of pain and may or may not include time with a physician.
- Unlikely to be any unintended consequences from removing these codes from the measure specifications.

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

(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-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 healthcare costs than poor management as an inpatient.
- There is a demonstrated performance gap in pain assessment.
- Steering Committee members noted that this measure is limited by the study population.

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 Ssientific 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

(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:

- As data capture in oncology practice increasingly uses EMRs, this measure will become more feasible.

5. Public & Member Comments:

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

- Multiple comments were received suggesting that the measure would be difficult to report and collect data on, as a result of the variety of settings in which a patient might be assessed, along with HIPPA restrictions. The measure developer responded that the definition of screening for this measure requires the use of a quantitative standardized tool which is becoming more and more commonly utilized in varied healthcare settings, and that the measure could also be extracted via EHR data. In addition, it is safe to assume that this measure would lead to the expectation that the advanced cancer patient was screened for pain during primary care visits. The Steering Committee Agreed with measure developer response, as it was consistent with Committee deliberations.
- A comment was received recommending that the committee consider severe cancers other than specifically Stage IV. The measure developer and the Committee responded in agreement; measures capturing broader patient populations was noted as a gap area for future measure development.
- Multiple comments were received suggesting that this measure could be reconciled with other measures (1634 and 1637). The measure developer responded that they have worked with the developer of measure #1634 and have changed the term "assessment" in measure #1628 to "screening" and have harmonized the definition of screening to match that of measure #1634. With respect to measure #1637, it requires a comprehensive assessment of pain factors (in a patient who has screened positive for pain) at the time of admission to hospice or palliative care. There is no overlap between these 2 measures, as #1628 is a screening measure only. The Committee agreed with this comment, and added that as screening leads to assessment or treatment, one cannot be accomplished without the other. To further strengthen the link between the two measures, the Committee recommended 1634 and 1637 as paired measures.
- A comment was received suggesting that the measure lacked a sound evidence base linking the process to outcomes, and that the measure had a significant burden to overcome in data collection. The measure developer responded that regular assessment of pain is vital to the successful management of chronic/advanced cancer pain over time. The Committee concurred, and added that in cases where there is a sparse body of evidence, the Committee can rely on its own expert opinion. With respect to burden of data collection, the Steering Committee acknowledged that the implementation of EHR will decrease the burden of data collection for many of the measures..

DYSPNEA MANAGEMENT MEASURES

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

1639: Hospice and Palliative Care- Dyspnea Screening (measure specifications) (developer materials and meeting summaries)
*Paired with measure 1638: Hospice and Palliative Care- Dyspnea Treatment

Description: Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation / palliative care initial encounter.
Numerator Statement: Patients who are screened for the presence or absence of dyspnea and its severity during the hospice admission evaluation / initial encounter for palliative care.
Denominator Statement: Patients enrolled in hospice for 7 or more days OR patients receiving hospital-based palliative care for 1 or more days.
Exclusions: Patients with length of stay < 7 days in hospice, or < 1 day in palliative care.
Adjustment/Stratification: No risk adjustment
Level of Analysis: Clinician: Group/Practice, Facility
Type of Measure: Process
Data Source: Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record
Measure Steward: University of North Carolina- Chapel Hill | 725 Martin Luther King Jr Blvd, CB 7590 | Chapel Hill | North Carolina | 27599-7590

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

If Applicable, Conditions/Questions for Developer:
1) Are there disparities data for this measure?
Developer Response:

1639: Hospice and Palliative Care- Dyspnea Screening (measure specifications) (developer materials and meeting summaries)
*Paired with measure 1638: Hospice and Palliative Care- Dyspnea Treatment

1) No data currently available

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

(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-20, M-0, L-0, I-0; 1c. Outcome or Evidence: Evidence Quantity: H-11, M-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. Reliability Testing: H-18, M-2, L-0, I-0; 2b. Validity Testing: H-17, M-3, L-0, I-0; 2c. Disparities: H-7, M-7, L-2, I-4)

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

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

Rationale:

- The measure is very clear and straightforward; quality improvement action may be taken to improve opportunities for treatment of patients with dyspnea.
- Steering Committee members raised concerns that the numerator data may not be consistently documented.

4. Feasibility: H-16, M-4, 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 data are available electronically and can be extracted.
- If electronic data are not available, Steering Committee members noted that substantial data collection effort may be required, as data must be extracted from the patient chart.

5. Public & Member Comments:

- Multiple comments were received suggesting measures 1638 and 1639 be harmonized as one composite measure. The measure developer responded that Dyspnea Screening (1639) and Dyspnea Treatment (1639) were designed and tested as paired quality measures, in order to ensure that all patients entering hospice are screened for dyspnea. Screening is included in order to ensure that all patients with dyspnea are identified for treatment. The Steering Committee agreed with the developer's comments; noting the need for both measures, the Committee recommended them for endorsement as paired measures.
- A comment was received suggesting that the description of the measure be expanded to capture the severity of the dyspnea the patient is experiencing, and that the patient that reports dyspnea. The measure developer responded that the operational definition for this quality measure did not expressly define a cut-off for dyspnea severity, because there are few standardized clinical instruments validated for recording severity. As a result of this lack of standardization, the developer included all dyspnea regardless of severity, but permitted in Dyspnea Treatment that all modalities. The Steering Committee agreed with measure developer's response, as it was consistent with Committee deliberations.

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1638: Hospice and Palliative Care- Dyspnea Treatment (measure specifications) (developer materials and meeting summaries)
*Paired with measure 1639: Hospice and Palliative Care- Dyspnea Assessment

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 are separate reliability and validity data for this measure and measure 1639, which was not submitted, as these are paired measures. There was very good ability for independent raters to identify presence of treatment—kappa of 0.89.
2) Abstracters relied on physicians, nursing notes, MARs.
3) That is correct. The measure developer could not find good, well-validated instruments for consistent measurement of dyspnea. Unlike pain, there is not a broad array of well-accepted severity standards
4) Comparable to other measures in set—given different settings—the consensus for the response time was 24 hours.

1. Importance to Measure and Report: Overall, the criteria for importance were met.
(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-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. Reliability Testing: H-7, M-11, L-2, I-0; 2b. Validity Testing: H-10, M-9, L-1, I-0; 2c. Disparities: H-5, M-6, L-4, I-5)

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

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
(4a. Clinical Data Generated During Care Delivery; 4b. Electronic Sources; 4c.Susceptibility to Inaccuracies/Unintended Consequences Identified; 4d. Data Collection Strategy Can Be Implemented)

1638: Hospice and Palliative Care- Dyspnea Treatment (measure specifications) (developer materials and meeting summaries)
*Paired with measure 1639: Hospice and Palliative Care- Dyspnea Assessment

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.

5. Public & Member Comments:

- A comment was received suggesting that this measure should not, in its denominator, exclude those patients with a shortened length of stay. The measure developer noted that the investigators who have developed and tested this quality measure are in agreement with the concern expressed in this comment, but note that all current data available on the Dyspnea Screening measure was collected using this operational definition. The measure has been submitted as it was tested, but the developers endorse the need to collect data and consider expansion in the future to include short-stay patients. The Committee agreed with the concern presented, but recognizes that the measure was presented as tested. The Committee believed that the measure should be revisited in the future, and that future versions of it should be expanded to capture the patients currently excluded by the denominator.
- A comment was received suggesting that the measure should distinguish specifically between "mild" and "moderate-to-severe" dyspnea to be more useful. The measure developer responded that they chose to include all dyspnea because ratings of severity are not yet well developed for nonverbal patients. The Committee added that there are no standard tools supported by current evidence for assessment of dyspnea, making it difficult to determine a severity cut-off when screening.
- A comment was received recommending that any measurements related to symptom management consider the patient's acceptable level along with their desire to engage in a treatment plan. The measure developer responded that this measure addresses the need to treat dyspnea promptly when present, but does not include in its operational definition any standard for treating to a particular level of dyspnea severity; this does not limit care in any manner. The Steering Committee agreed with this response, as it was consistent with Committee deliberations.
- A comment was received requesting clarification on which dyspnea screening tool was recommended by the measure steward, and that the measure should allow for more treatment strategies. The Steering Committee and the measure developer agreed; the developer noted that no one dyspnea screening instrument has proven to be the optimal approach. As such, the measure operational definition does not require the use of a specific clinical screening instrument for this reason.
- Multiple comments were received suggesting that, because this measure includes both screening and treatment, measures 1638 and 1639 should be combined as a composite. The measure developer responded that screening is included in order to ensure that all patients with dyspnea are identified for treatment; patients with dyspnea should first be identified, and then treated. The Steering Committee agreed with the developer's comments; noting the need for both measures, the Committee recommended them for endorsement as paired measures.

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1630: Hospitalized patients who die an expected death who have dyspnea addressed (measure specifications) (developer materials and meeting summaries)

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

1630: Hospitalized patients who die an expected death who have dyspnea addressed (measure specifications) (developer materials and meeting summaries)
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 timeframe simplifies data abstraction.
1. Importance to Measure and Report: The measure did not pass the importance criterion. *(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-4, M-10, L-5, I-1; 1c. Outcome or Evidence: Evidence Quantity: H-1, M-5, L-12, I-2; Evidence Quality: H-0, M-7, L-11, I-2; Evidence Consistency: H-1, M-5, L-7, I-7)* 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. Reliability Testing; 2b. Validity Testing; 2c. Disparities)* Rationale: • Definition of unexpected death is unclear
3. Usability: No vote taken—measure did not pass importance criterion *(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)* Rationale:
4. Feasibility: No vote taken—measure did not pass importance criterion *(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: • Hard to see how this can be implemented with paper medical records.
Public and Member Comments: • No comments were received on this measure.

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 (measure specifications) (developer materials and meeting summaries)
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.

1626: Patients Admitted to ICU who have care preferences documented (measure specifications) (developer materials and meeting summaries)

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. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-19; M-1; L-0; I-0; 1c. Evidence Quantity:H-11; M-9; L-0; I-0; Evidence Quality H-12; M-8; L-0; I-0; Evidence Consistency: H-15; M-5; L-0; I-0)

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 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. Reliability Testing: H-10; M-9; L-1; I-0; 2b. Validity Testing: H-7; M-12; L-1: I-0; 2c. Disparities: H-9; M-7; L-0; I-4)

Rationale:

- Steering Committee members acknowledged that it is difficult to measure whether there was a failure to attempt to meet patient preferences.
- Concern that chart data may not always be present and that definitions are too broad for implementation.
- Concern that many patients may not be communicative in the first 48 hours in the ICU; as such, this measure may not be usable.
- Concern that this measure is an ICU documentation issue rather than one that captures the intended process.
- However, Steering Committee members noted that there is strong inter-rater reliability with the measure.
- Steering Committee stated that face validity was acceptable.

3. Usability: H-10; M-8; L-1; I-1
(Meaningful, understandable, and useful to the intended audiences for 3a. Public Reporting and 3b. Quality Improvement)

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

Rationale:

- Clinical measures are routinely generated during daily patient care. Data are easily obtainable through EMRs or medical record chart documentation.

5. Public & Member Comments:

1626: Patients Admitted to ICU who have care preferences documented (measure specifications) (developer materials and meeting summaries)

- Multiple comments were received about the "vulnerable adults" denominator in this measure. Commenters raised issue with: singling out a specific population; that it is unworkable – a target of 100% of ICU patients is not only appropriate for every patient; and the need to harmonize this definition with that in measure 1617. The measure developer responded that the different definition was an oversight; they will revise to add "VES-13 score >2" to the definition of the vulnerable adult in #1626. The Steering Committee added that the measure could address a broader population, but that it is a good first step for achieving high standards of care.
- A comment was received suggesting that the measure lacked evidence, a clear link to outcomes, and was burdensome for data collection. The measure developer responded that expert consensus concurs that elicitation of care preferences at the time of ICU admission is vital to the provision of care that matches the wishes of the patient. The increase in use of EHR documentation would further facilitate the abstraction and access of these data in the future. The Steering Committee added that its members were able to utilize their expert judgment or apply additional evidence based on their own knowledge or expertise during the evaluation process, a decision consistent with the NQF measure evaluation criteria and guidance outlined in the Evidence Testing Task Force.
- A comment was received suggesting that the measure should not be recommended for endorsement due to it not meeting the scientific acceptability criterion. The Steering Committee noted that the measure had been rigorously tested, and that the Committee had voted to approve it under the measure evaluation criteria. The Committee thoroughly reviewed the testing data for the measure, and noted that interrater reliability for chart abstraction was high. Additionally, the measure developer provided testing information on the process-outcome link for the measure, demonstrating a positive relationship between quality score and patient function and survival. Further, face validity of the measure was reviewed in the ACOVE, ACOVE3 and ASSIST panels, with experts panels reviewing the relevant literature and using a modified Delphi panel to vote on the validity of the measure.
- A comment was received suggesting that there could be modifications to improve this measure, including revisions to the numerator, and tying this conversation to a quality measure in health care facilities. The measure developer responded that the measure requirement is not designed to reflect optimal care, but rather ensure that a reasonable effort has been made to address the patient's care preferences. The Steering Committee agreed with this response, as it was consistent with Committee deliberations.
- A comment was received questioning the measure, and noting that most patients have their care preferences documented, but they are often ignored. The measure developer responded that it is unlikely that any measure could enforce providers' attention to patient care preferences if that intent is lacking. The expectation of regular documentation of these preferences on ICU admission as indicated in this measure would work in the direction of emphasizing the need to elicit preferences and direct care that is compatible with them. The Steering Committee agreed with this response, as it was consistent with Committee deliberations.
- A comment was received concerning the 48 hour measurement window in the measure, and requesting that it be significantly shortened. The measure developer responded that the goal is to ensure that adequate time is allowed for healthcare providers to address the care preference issue along with other care priorities. Forty-eight hours provides for a reasonable time to pass prior to judging the care to be inadequate. The Steering Committee agreed with this response, as it was consistent with Committee deliberations.
- A comment was received requesting harmonization of the definition of "care preferences" with that of "treatment preferences" used in measure 1641. The Committee believed that it was important to make a clear distinction between care preferences (which are universally desired), and treatment preferences (which not every individual has). As such, the Steering Committee views the measures as being related, but intrinsically different.

1641: Hospice and Palliative Care-Treatment Preferences (measure specifications) (developer materials and meeting summaries)

1641: Hospice and Palliative Care-Treatment Preferences (measure specifications) (developer materials and meeting summaries)

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 with NQF-endorsed measure 0326: *Advance Care Plan (NCQA/PCPI)*, it did encourage the developer to improve it by including the completion of a Physicians Order for Life Sustaining Treatment (POLST) or POLST paradigm forms as ~~a~~ ways to document care preferences in the numerator.

1. Importance to Measure and Report: Overall, the criteria for importance were met.
(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-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. This is important because it captures the patient's preferences.

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:

- 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
(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 electronically.

1641: Hospice and Palliative Care-Treatment Preferences (measure specifications) (developer materials and meeting summaries)
• If electronic data are not available, Steering Committee members noted that substantial data collection effort may be required, as data must be extracted from the patient chart. • Concern that the documentation may not be standardized, making it somewhat challenging to extract reliably.
Public & Member Comments: • Commenters suggested that the numerator be modified to allow various state versions of the Physicians Order for Life Sustaining Treatment (POLST) to count toward the numerator. The measure developer has modified the numerator to capture "POLST paradigm" forms, which the Steering Committee agreed adequately addressed the comment. • Several comments suggested that the patient population captured by the measure be broadened. While both the Steering Committee and the measure developer agreed that other patient populations would benefit from the measure, the measure was only tested in the specified patient population. This has been noted by the Steering Committee as an opportunity for future measure development. • A comment was received requesting harmonization of the definition of "care preferences" with that of "treatment preferences" used in measure 1641. The Committee believed that it was important to make a clear distinction between care preferences (which are universally desired), and treatment preferences (which not every individual has). As such, the Steering Committee views the measures as being related, but intrinsically different. • A comment was received questioning the process outcome link, the evidence base for the measure, and the feasibility of implementing the measure. The Steering Committee noted that measure evaluation criteria was strictly applied when evaluating this measure, and that the measure met all criteria including being reasonably linked to the desired outcome and having a supportive evidence base for the focus of the measure. With respect to feasibility of implementation, the Steering Committee acknowledged that implementation of EHR will decrease the burden of data collection; however, testing provided with the measure demonstrated that the measure is feasible as specified.

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

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

Developer Response:

1) The data provided were sufficient for the Steering Committee members.
2) Further specification of the numerator details was sufficient for Steering Committee members.
3) The Steering Committee noted that its own expert opinion on the importance of the measure to report is sufficient for the measure to pass the NQF importance criteria even though the measure may not meet the guidelines for quantity, quality, and consistency of evidence.

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 noted that though the body of evidence for this measure does not yet exist, the benefits to this measure far outweigh any potential risks associated with it. Consensus from the Steering Committee was that though the evidence does not meet the importance criteria, the measure should pass on importance based on the Committee's collective expertise.

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 the measure developer provided was sufficient by common 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.

Public & Member Comments:

- Several comments were received questioning the process outcome link, the evidence base for the measure, and the feasibility of implementing the measure. The Steering Committee noted that measure evaluation criteria was strictly applied when evaluating this measure, and that the measure met all criteria including being reasonably linked to the desired outcome and having a supportive evidence base for the focus of the measure. With respect to feasibility of implementation, the Steering Committee acknowledged that implementation of EHR will decrease the burden of data collection; however, testing provided with the measure demonstrated that the measure is feasible as specified.
- Several comments indicated that an outcome measure addressing patient spiritual needs may be stronger than the submitted

1647: Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss (measure specifications) (developer materials and meeting summaries)
process measure. The Steering Committee acknowledges that this measure is a first step in assessing a patient's spiritual needs; evidence from the measure developer's testing demonstrates that having this conversation leads to an improved outcome in the patient's reported levels of spiritual distress. • Several comments suggested that the measure should address palliative care patients in addition to hospice patients. Both the Steering Committee and the measure developer agreed with this notion; however, this measure has only been tested in the hospice population and thus can only be evaluated for this population. The Steering Committee has noted this area as a gap area for future measure development.

QUALITY OF CARE AT THE END OF LIFE MEASURES

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

0209: Comfortable Dying (measure specifications) (developer materials and meeting summaries)
Description: Number of patients who report being uncomfortable because of pain at the initial assessment (after admission to hospice services) who report pain was brought to a comfortable level within 48 hours. Numerator Statement: Patients whose pain was brought to a comfortable level (as defined by patient) within 48 hours of initial assessment (after admission to hospice services). Denominator Statement: Patients who replied "yes" when asked if they were uncomfortable because of pain at the initial assessment (after admission to hospice services). Exclusions: Inclusions: Patients are eligible if they: Report they are uncomfortable because of pain at the initial assessment (after admission to hospice services); Are able to communicate and understand the language of the person asking the question; Are able to self-report; and, Are at least 18 years of age or older. Adjustment/Stratification: No risk adjustment or stratification. Level of Analysis: Facility, Population: National Type of Measure: Outcome Data Source: Patient Reported Data/Survey Measure Steward: National Hospice and Palliative Care Organization, 1731 King Street, Suite 100, Alexandria, Virginia 22314
Steering Committee Recommendation for Endorsement: Y-20; N-0; A-0 Rationale: 1) The measure affects 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. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-17; M-3; L-0; I-0; 1c. Evidence: This measure is an outcome measure; as such, evidence criteria were not individually voted on)* Rationale: • Management of pain is a key priority identified by NPP.
2. Scientific Acceptability of Measure Properties: Overall, the criteria for scientific acceptability were met. *(2b. Reliability Testing: H-12; M-8; L-0; I-0; 2c. Validity Testing: H-13; M-7; L-0: I-0; 2d. Exclusions Justified; 2e. Risk Adjustment/Stratification; 2f. Meaningful Differences; 2g. Comparability; 2h. Disparities: H-9; M-8; L-1; I-2)* Rationale: • The measure was presented with strong data on scientific acceptability.

0209: Comfortable Dying (measure specifications) (developer materials and meeting summaries)

- Some information on disparities was presented indicating no difference in the ethnic distribution of patients whose pain was not brought to a comfortable level to those whose pain was relieved.

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

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

Rationale:

- The measure captures whether pain was controlled or not based on the patient's own perception, acknowledging that pain scales are not reliable across patients. It is usable for that purpose currently. However, the measure does not capture pain relief for patients who are in obvious pain yet unable to answer questions related to their pain, or patients who are unconscious.

4. Feasibility: H-14; M-6; 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 elements are easily accessible through patient self-report.

Public & Member Comments:

- Several commenters expressed concern that many patients are able to self-report their pain at the time of admission, but then are unable to self-report pain at the time of follow-up. This could significantly lower the measure score for hospices if a large number of patients are unable to self-report at the time of follow-up. The measure developer appreciated the concern and noted that NHPCO provides a Problem Score as a complement to the basic measure score. The Problem Score is calculated by dividing the number of patients whose pain was NOT brought to a comfortable level within 48 hours after the initial assessment by the number of patients who were uncomfortable on admission. This number is multiplied by 100 to get the hospice's score as a percent. A lower score/percentile = better performance. The Problem Score offsets negative bias introduced by inclusion of patients unable to respond at follow up and provides additional context and insight for setting performance improvement goals. The Steering Committee agreed that this addressed the concern expressed in the comments.
- A comment was received questioning the process outcome link, the evidence base for the measure, and the feasibility of implementing the measure. The Steering Committee noted that measure evaluation criteria was strictly applied when evaluating this measure, and that the measure met all criteria including being reasonably linked to the desired outcome and having a supportive evidence base for the focus of the measure. With respect to feasibility of implementation, the measure developer noted that the actions needed to generate data for the measure (determining patient goals for comfort on initial assessment, putting interventions in place consistent with those goals, and timely assessment of the effectiveness of the interventions - plus documentation of those actions) are all elements inherent in good pain management practice. The Steering Committee agreed with this rationale.

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1625: Hospitalized Patients who Die an Expected Death with an ICD that has been deactivated (measure specifications) (developer materials and meeting summaries)

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

1625: Hospitalized Patients who Die an Expected Death with an ICD that has been deactivated (measure specifications) (developer materials and meeting summaries)

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 affects many patients, and ICD use is becoming much more prevalent. This measure will become more useful as ICD use continues to grow.
- There is emerging literature about ICS use near death.

If Applicable, Conditions/Questions for Developer:

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

(1a. High Impact: H-20; M-0; L-0; I-0; 1b. Performance Gap: H-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 use of ICDs in patients is increasing.

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

(2a. Reliability Testing: H-5; M-9; L-3; I-3; 2b. Validity Testing: H-5; M-7; L-6: I-2; 2c. Disparities: H-7; M-4; L-1; I-8)

Rationale:

- Charts used in reliability testing were for patients who did not have an ICD in place at the time of death. Strong inter-rater reliability of the presence on an ICD was demonstrated.
- Face validity and expert panel review were accepted for scientific acceptability criteria.

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

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

Rationale:

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

4. Feasibility: H-7; M-8; L-5; 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 elements are accessible through paper records.
- The measure developer is working to implement this measure in EHRs, which will make it more feasible to use.

Public & Member Comments:

- Several commenters expressed concern that the number of patients affected by this measure is relatively small. The measure developer acknowledged this concern; however, both the Steering Committee and the measure developer stated that the negative consequences of patients who experience this at the end of life make this an important care measure.
- A comment was received questioning whether a gap in performance of this measure exists. The measure developer noted that in literature cited in the measure submission, of 900 randomly selected hospices, 97% admit patients with ICDs and 58% report that a patient had been shocked in the past year. Additionally, other literature and the developer's own study evidence were cited for ICDs' only being addressed prior to the expected death of the patient in 25-27% of cases. The Steering Committee acknowledged that this was a significant gap in performance of this measure.

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0208: Family Evaluation of Hospice Care (measure specifications) (developer materials and meeting summaries)

Description: Composite Score: Derived from responses to 17 items on the Family Evaluation of Hospice Care (FEHC) survey presented

0208: Family Evaluation of Hospice Care (measure specifications) (developer materials and meeting summaries)

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 1000 hospices offers good evidence of its feasibility and utility.

If Applicable, Conditions/Questions for Developer:

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

Response:

1) The developer provided the Committee with additional information on the numerator specifications and updated evidence. The updates also included the composite score and information on importance. Additional information was provided on reliability and validity, along with added data on disparities that was unintentionally left out of the original submission. The Committee raised no concerns with this information being presented.

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 demonstrating that the measured aspects of care are those valued by patients and for which the patients (or in this case, the bereaved family members surveyed) are the best and only source of information.

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.

0208: Family Evaluation of Hospice Care (measure specifications) (developer materials and meeting summaries)

- 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

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

Rationale:

- This measure is already in extensive use.

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.
- This survey process is not a part of normal hospital or office routine, and it requires additional resources to obtain responses.

Public & Member Comments:

- A comment was received suggesting that while important for institutions to collect this information, it is not a topic for performance measurement. The Steering Committee and the measure developer respectfully disagreed, noting that it is very important to measure and report patient's experience with care at the end of life and that the measure as proposed met the measure evaluation criteria.
- A comment was received questioning the need for measures 0208, 1632, and 1623 as all address similar topic areas. The Committee believed that these measures address related but not competing questions on the quality of life and patient experience with care. Each serve a different patient population or purpose and they determined it was appropriate to recommend the three measures for endorsement.
- A comment was received expressing concern over the time window for administration of the survey impacting measure data. The measure developer noted that in testing, the timing of administration of the survey had no impact on the responses received from the bereaved family. The Steering Committee agreed that this addressed the concern expressed in the comments.

1632: CARE- Consumer Assessments and Reports of End of Life (measure specifications) (developer materials and meeting summaries)

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

1632: CARE- Consumer Assessments and Reports of End of Life (measure specifications) (developer materials and meeting summaries)

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.
- 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 additional detail on the numerator specifications and updated evidence. The Committee raised no concerns with the 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)

1632: CARE- Consumer Assessments and Reports of End of Life (measure specifications) (developer materials and meeting summaries)

Rationale:

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

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.

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 usability of the measure.

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.

Public & Member Comments:

- A comment was received suggesting that while important for institutions to collect this information, it is not a topic for performance measurement. The Steering Committee and the measure developer respectfully disagreed, noting that it is very important to measure and report patient's experience with care at the end of life and that the measure as proposed met the measure evaluation criteria.
- A comment was received questioning the need for measures 0208, 1632, and 1623 as all address similar topic areas. The Committee believed that these measures address related but not competing questions on the quality of life and patient experience with care. Each serve a different patient population or purpose and they determined it was appropriate to recommend the three measures for endorsement.
- A comment was received expressing concern over the feasibility of implementation for this measure. The Committee did consider the feasibility of the measure ("the extent to which the required data are readily available or could be captured without undue burden and can be implemented for performance measurement"), and determined that the measure passed this criteria.

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1623: Bereaved Family Survey (measure specifications) (developer materials and meeting summaries)

Description: The purpose of this measure is to assess families´ perceptions of the quality of care that Veterans received from the VA in the last month of life. The BFS consists of 19 items (17 structured and 2 open-ended). The BFS items were selected from a longer survey that was developed and validated with the support of a VA HSR&D Merit Award and have been approved for use by the Office of Management and Budget.

Seventeen items in the survey have predefined response options and ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support.

1623: Bereaved Family Survey (measure specifications) (developer materials and meeting summaries)

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

1623: Bereaved Family Survey (measure specifications) (developer materials and meeting summaries)

- 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:

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-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. Reliability Testing: H-7; M-10; L-2; I-0; 2b. Validity Testing: H-7; M-11; L-1: I-0; 2c. Disparities: H-8; M-9; L-0; I-2)

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

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 percentage of veterans receive their end-of-life care in VA facilities.
- The Steering Committee believes that the BFS measure results will be meaningful and understandable to the public.

4. Feasibility: H-8; M-11; 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 data are not routinely generated as part of care and would require a follow-back survey.
- As this is a survey, electronic data collection is not possible. This survey process is not a part of normal hospital or office routine, and it requires additional resources to make three attempts to contact next of kin by phone, with a follow-up written survey sent when not reached.

1623: Bereaved Family Survey (measure specifications) (developer materials and meeting summaries)

Public & Member Comments:

- A comment was received suggesting that while important for institutions to collect this information, it is not a topic for performance measurement. The Steering Committee and the measure developer respectfully disagreed, noting that it is very important to measure and report patient's experience with care at the end of life and that the measure as proposed met the measure evaluation criteria.
- A comment was received questioning the need for measures 0208, 1632, and 1623 as all address similar topic areas. The Committee believed that these measures address related but not competing questions on the quality of life and patient experience with care. Each serve a different patient population or purpose and they determined it was appropriate to recommend the three measures for endorsement.
- A comment was received expressing concern over the feasibility of implementation for this measure. The Committee did consider the feasibility of the measure ("the extent to which the required data are readily available or could be captured without undue burden and can be implemented for performance measurement"), and determined that the measure passed this criteria.

APPENDIX A: NQF PALLIATIVE CARE AND END-OF-LIFE CARE MEASURE SPECIFICATIONS

	Measure 0208: Family Evaluation of Hospice Care (National Hospice and Palliative Care Organization)
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	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.
Numerator Details	Composite Score: Responses to the following questions on the FEHC survey: B2 (How much medicine did the patient receive for his/her pain?) B4 (Did you want more information than you got about the medicines used to manage the patient's pain?) B6 (How much help in dealing with his/her breathing did the patient receive while under the care of hospice?) B8 (Did you want more information than you got about what was being done for the patient's trouble with breathing?) B10 (How much help in dealing with these feelings did the patient receive?)(refers to feelings of anxiety and sadness) D3 (How confident did you feel about doing what you needed to do in taking care of the patient?) D4 (How confident were you that you knew as much as you needed to about the medicines being used to manage the patient's pain, shortness of breath, or other symptoms?) D5 (How often did the hospice team keep you or other family members informed about the patient's condition?) D7 (Would you have wanted more information about what to expect while the patient was dying?) D8 (How confident were you that you knew what to expect while the patient was dying?) D9 (How confident were you that you knew what to do at the time of death?) E2 (Did you have as much contact of that kind as you wanted?) (refers to spiritual care) E3 (How much emotional support did the hospice team provide to you prior to the patient's death?) E4 (How much emotional support did the hospice team provide to you after the patient's death?) F1 (How often did someone from the hospice team give confusing or contradictory information about the

	patient's medical treatment?) F2 (While under the care of hospice, was there always one nurse who was identified as being in charge of the patient's overall care?) F3 (Was there any problem with hospice doctors or nurses not knowing enough about the patient's medical history to provide the best possible care?) Global Score: Number of responses of "Excellent" to the overall rating of care quality on the FEHC survey, question G1 (Overall, how would you rate the care the patient received while under the care of hospice?)
Denominator	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.
Denominator Details	Composite Score: 100 (100 is the best possible composite score which indicates 0% incidence of problem scores). Global Score: All responses to overall rating of care question on the FEHC survey (G1) are included. If survey respondent has not entered a response, the question is not included in the denominator.
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.
Exclusion details	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.
Risk Adjustment	No risk adjustment or risk stratification
Stratification	N/A
Numerator Time window	Time period eligible for inclusion is the entire length of service the patient was enrolled in hospice.
Type	Composite
Type of Score	Weighted score/composite/scale
Data Source	Patient Reported Data/Survey
Level	Facility, Population : National
Setting	Hospice

	Measure 0209: Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment (National Hospice and Palliative Care Organization)
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	Patients whose pain was brought to a comfortable level (as defined by patient) within 48 hours of initial assessment (after admission to hospice services).
Numerator Details	Number of patients who replied "yes" when asked if their pain was brought to a comfortable level within 48 hours of initial assessment (after admission to hospice services).
Denominator	Patients who replied "yes" when asked if they were uncomfortable because of pain at the initial assessment (after admission to hospice services).
Denominator Details	Adult patients who are able to self report pain information and 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.
Exclusion details	Exclusion: Patients are excluded if they are: Are less than 18 years of age; Cannot understand language of hospice nurse performing the assessment; Cannot self report pain information; Deny being uncomfortable because of pain
Risk Adjustment	No risk adjustment or risk stratification
Stratification	None
Numerator Time window	Up to 48 hours after initial assessment (after admission to hospice services).
Type	Outcome
Type of Score	Rate/proportion
Data Source	Patient Reported Data/Survey
Level	Facility, Population : National
Setting	Hospice

	Measure 1617: Patients Treated with an Opioid who are Given a Bowel Regimen (RAND Corporation)
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	Patients from the denominator that are given a bowel regimen or there is documentation as to why this was not needed
Numerator Details	Patients from the denominator given a bowel regimen defined as an offer/prescription of a laxative, stool softener, or high fiber supplement/diet OR documentation of why such a bowel regimen is not needed.
Denominator	Vulnerable adults who are given a new prescription for an opioid
Denominator Details	All vulnerable adults >18 years old prescribed an opioid as an inpatient OR as an outpatient in those patients who are not already taking this type of medication "Vulnerable" is defined as any of the following: - >74 years of age - Vulnerable Elder Survey-13 (VES-13) score >2 (Saliba 2001) - Poor prognosis/terminal illness defined as life expectancy of <6 months - Stage IV cancer Saliba D, Elliott M, Rubenstein LZ, et al. The vulnerable elders survey: a tool for identifying vulnerable older people in the community. J Amer Geriatr Soc 2001;48:1691-1699
Exclusions	None
Exclusion details	None
Risk Adjustment	No risk adjustment or risk stratification
Stratification	
Numerator Time window	Within 24 hours of new opioid prescription.
Type	Process
Type of Score	Rate/proportion
Data Source	Electronic Clinical Data : Electronic Health Record, Paper Records, Patient Reported Data/Survey
Level	Clinician : Group/Practice, Clinician : Individual, Facility, Health Plan
Setting	Ambulatory Care : Clinician Office, Hospital/Acute Care Facility

	Measure 1623: Bereaved Family Survey (PROMISE Center)
Description	The purpose of this measure is to assess families´ perceptions of the quality of care that Veterans received from the VA in the last month of life. The BFS consists of 19 items (17 structured and 2 open-ended). The BFS items were selected from a longer survey that was developed and validated with the support of a VA HSR&D Merit Award and have been approved for use by the Office of Management and Budget. Seventeen items in the survey have predefined response options and ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support. Two additional items are open-ended and give family members the opportunity to provide comments regarding the care the patient received. A growing body of research has underscored the degree to which end-of-life care in the United States needs to be improved. The challenges of end-of-life care are particularly significant in the U.S. Department of Veterans Affairs Health Care system because 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 additional items (not used in scoring) are open-ended and give family members the opportunity to provide comments regarding the care the patient received. The BFS has undergone extensive development and has been pilot-tested for all inpatient deaths in Q4FY2008 in seven VISNs (1,2,4,5,8,11, and 22). As of October 1, 2009, Q1FY2010, all inpatient deaths in all VISNs were included in the project.
Numerator	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.
Numerator Details	Included are those patients included in the denominator with completed surveys (at least 12 of 17 structured items completed) that receive an optimal response on the global item question.
Denominator	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.
Denominator Details	The indicator denominator is comprised of the number of Veterans who die in an inpatient VA facility (intensive care, acute care, hospice unit, nursing home care or community living center) for whom a survey is completed. Completed surveys are defined as those with at least 12 of the 17 structured items completed.
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. -
Exclusion details	Name, address, and phone number of patient´s family member or emergency contact are required for determining exclusion. In addition, information regarding the patient´s admission(s) during the last 31 days of life, including length of stay and circumstances of death are also required to determine exclusion.
Risk Adjustment	No risk adjustment or risk stratification
Stratification	Variables necessary to stratify the measure are VISN, facility, quarter, year, outcome. VISN refers to "Veterans Integrated Service Network" and is a geographic area of the country where a facility is located. Facility is the actual VA medical center or affiliated community living center where the Veteran died. Quarter is the 3 month time period in which the patient died. Year is the VA fiscal year (runs from Oct 1 to Sept 30). Outcome refers to whether or not a survey was completed.
Numerator Time window	Does not apply to this measure
Type	Outcome
Type of Score	Rate/proportion
Data Source	Other
Level	Facility, Population : National, Population : Regional
Setting	Hospice, Post Acute/Long Term Care Facility : Nursing Home/Skilled Nursing Facility

	Measure 1625: Hospitalized Patients Who Die an Expected Death with an ICD that Has Been Deactivated (RAND Corporation)
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	Patients from the denominator who have their ICDs deactivated prior to death or have documentation of why this was not done
Numerator Details	Documentation in the medical record that the ICD was deactivated or documentation of a discussion of deactivation of the ICD with the patient or documentation of why ICD deactivation was not done.
Denominator	Patients who died an expected death who have an ICD in place
Denominator Details	Hospitalizations of adult patients of at least 3 days duration that ended in an expected death. Expected death is defined as physician documentation at least 3 days before death that the patient´s illness was terminal or that the patient had a grave prognosis, was receiving comfort care, was receiving hospice care, had a life-threatening disease, or was expected to die.
Exclusions	None
Exclusion details	
Risk Adjustment	No risk adjustment or risk stratification
Stratification	None
Numerator Time window	During hospitalization ending in an expected death
Type	Process
Type of Score	Rate/proportion
Data Source	Paper Records
Level	Facility
Setting	Hospital/Acute Care Facility

	Measure 1626: Patients Admitted to ICU who Have Care Preferences Documented (RAND Corporation)
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	Patients in the denominator who had their care preferences documented within 48 hours of ICU admission or have documentation of why this was not done.
Numerator Details	Patients whose medical record includes documentation of care preferences within 48 hours of admission to ICU. Care preferences may include any of the following: - Code status, preferences for general aggressiveness of care, mechanical ventilation, hemodialysis, transfusion, or permanent feeding tube, OR - Documentation that a care preference discussion was attempted and/or reason why it was not done
Denominator	All vulnerable adults admitted to ICU who survive at least 48 hours after ICU admission.
Denominator Details	All vulnerable adults admitted to ICU who survive at least 48 hours after ICU admission. "Vulnerable" is defined as any of the following: - >74 years of age - Vulnerable Elder Survey-13 (VES-13) score >2 (Saliba 2001) - Poor prognosis/terminal illness defined as life expectancy of <6 months - Stage IV cancer
Exclusions	None
Exclusion details	
Risk Adjustment	No risk adjustment or risk stratification
Stratification	
Numerator Time window	48 hours starting from time of ICU admission
Type	Process
Type of Score	Rate/proportion
Data Source	Electronic Clinical Data : Electronic Health Record, Paper Records
Level	Facility, Health Plan, Integrated Delivery System
Setting	Hospital/Acute Care Facility

	Measure 1628: Patients with Advanced Cancer Screened for Pain at Outpatient Visits (RAND Corporation)
Description	Adult patients with advanced cancer who are screened for pain with a standardized quantitative tool at each outpatient visit
Numerator	Outpatient visits from the denominator in which the patient was screened for pain (and if present, severity noted) with a quantitative standardized tool
Numerator Details	Pain screening with a standardized quantitative tool during the primary care or cancer-related/specialty outpatient visit(s). Screening may be completed using verbal, numeric, visual analog, rating scales designed for use with nonverbal patients, or other standardized tools.
Denominator	Adult patients with advanced cancer who have at least 1 primary care or cancer-related/specialty outpatient visit
Denominator Details	Adult patients with Stage IV cancer who are alive 30 days or more after diagnosis and who have had at least 1 primary care visit or cancer-related/specialty outpatient visit. Cancer-related visit = any oncology (medical, surgical, radiation) visit, chemotherapy infusion
Exclusions	None (other than those patients noted in 2a1.7. who did not survive at least 30 days after cancer diagnosis)
Exclusion details	
Risk Adjustment	No risk adjustment or risk stratification
Stratification	
Numerator Time window	At the time of outpatient visit(s)
Type	Process
Type of Score	Rate/proportion
Data Source	Electronic Clinical Data, Electronic Clinical Data : Registry, Paper Records
Level	Facility, Health Plan, Integrated Delivery System
Setting	Ambulatory Care : Clinician Office

	Measure 1630: Hospitalized Patients Who Die an Expected Death Who Have Dyspnea Addressed (RAND Corporation)
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	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
Numerator Details	Dyspnea treatment = Any of the following: - administration of supplemental oxygen or increase in rate of flow if already on supplemental oxygen, - respiratory therapy - nonpharmacologic intervention targeted at easing dyspnea (e.g., position change, pillow support, etc.) - pharmacologic intervention targeted at easing dyspnea (e.g., opiate, benzodiazipine, etc.) Dyspnea follow up = Any assessment of the patient´s response to treatment or reassessment of untreated dyspnea
Denominator	Hospitalized patients who died an expected death and who had dyspnea in the 7 days prior to death
Denominator Details	Adult hospitalized patients who had dyspnea in the 7 days prior to an expected death during a hospitalization of at least 3 days duration. Expected death is defined as physician documentation at least 3 days before death that the patient´s illness was terminal or that the patient had a grave prognosis, was receiving comfort care, was receiving hospice care, had a life-threatening illness, or was expected to die. Although the original indicator was targeted at vulnerable elders, it was applied to all hospitalized adults in the sample who died an expected death because these patients are also vulnerable and would be expected to benefit from the identified processes of care.
Exclusions	None
Exclusion details	
Risk Adjustment	No risk adjustment or risk stratification
Stratification	
Numerator Time window	Within 24 hours of noting the presence of dyspnea
Type	Process
Type of Score	Rate/proportion
Data Source	Electronic Clinical Data : Electronic Health Record, Paper Records

Level	Facility
Setting	Hospital/Acute Care Facility

	Measure 1632: CARE - Consumer Assessments and Reports of End of Life (Center for Gerontology and Health Care Research)
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. 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	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.
Numerator Details	Detailed information is provided below.
Denominator	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
Denominator Details	1. Denominator for Mortality Follow Back Survey Decedents age 18 and older with chronic progressive illness who receive care from an home health agency, hospice, hospital, or nursing home. Respondents are the person who stated they know best about the decedent and would have or were involved in medical decision making. It is easiest to define the chronic progressive illness by listing what diseases are excluded. Accidents or trauma listed as cause of death - V01---V99, W00—W99, X00-X99, Y00—Y89.9 Acute overwhelming infections A00—A99, B03—B81.8, J00—J06 Death from complications of pregnancy 024.9—099.8 Please note a list of these codes are at http://www.chcr.brown.edu/dying/SAMPLE_FOR_MFB_FOR_WWW_SITE_JAMA_FINAL.PDF The denominators for the domains will be explained separately in the specification of the denominator for each of those domains.
Exclusions	We excluded deaths due to accidents, trauma, during surgery, lethal injection, acute overwhelming infections, and from complications of pregnancy.
Exclusion details	See answer to 2a1.7
Risk Adjustment	No risk adjustment or risk stratification
Stratification	There is no proposed stratification variable
Numerator Time window	Respondent perceptions are reported for the last place of care for the care received up to and inclusive of the last week of life. The decedent must have spent at least 48 hours in that location of care.
Type	Patient Engagement/Experience
Type of Score	Non-weighted score/composite/scale
Data Source	Other
Level	Facility, Population : Community, Population : National, Population : Regional
Setting	Home Health, Hospice, Hospital/Acute Care Facility, Post Acute/Long Term Care Facility : Nursing

	Home/Skilled Nursing Facility

	Measure 1634: Hospice and Palliative Care -- Pain Screening (University of North Carolina-Chapel Hill) *Paired with measure 1637: Hospice and Palliative Care- Pain Assessment
Description	Percentage of hospice or palliative care patients who were screened for pain during the hospice admission evaluation / palliative care initial encounter.
Numerator	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 palliative care.
Numerator Details	Patients who are screened for the presence or absence of pain (and if present, rating of its severity) using a standardized 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	Patients enrolled in hospice for 7 or more days OR patients receiving hospital-based palliative care for 1 or more days.
Denominator Details	The Pain Screening quality measure is intended for patients with serious illness who are enrolled in hospice care OR receive palliative care in an acute hospital setting. Conditions may include, but are not limited to: cancer, heart disease, pulmonary disease, dementia and other progressive neurodegenerative diseases, stroke, HIV/AIDS, and advanced renal or hepatic failure. [NOTE: This quality measure should be paired with the Pain Assessment quality measure to ensure that all patients who report pain are clinically assessed.]
Exclusions	Patients with length of stay < 7 days in hospice, or < 1 day in palliative care.
Exclusion details	Calculation of length of stay; discharge date - date of initial encounter.
Risk Adjustment	No risk adjustment or risk stratification
Stratification	N/A
Numerator Time window	Hospice admission evaluation / initial clinical encounter for palliative care
Type	Process
Type of Score	Rate/proportion
Data Source	Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record
Level	Clinician : Group/Practice, Facility
Setting	Hospice, Hospital/Acute Care Facility

	Measure 1637: Hospice and Palliative Care -- Pain Assessment (University of North Carolina- Chapel Hill) *Paired with measure 1634: Hospice and Palliative Care- Dyspnea Screening
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	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.
Numerator Details	Patients with a comprehensive clinical assessment including at least 5 of the following 7 characteristics of the pain: location, severity, character, duration, frequency, what relieves or worsens the pain, and the effect on function or quality of life.
Denominator	Patients enrolled in hospice OR receiving palliative care who report pain when pain screening is done on the admission evaluation / initial encounter.
Denominator Details	The Pain Assessment quality measure is intended for patients with serious illness who are enrolled in hospice care OR receive specialty palliative care in an acute hospital setting. Conditions may include, but are not limited to: cancer, heart disease, pulmonary disease, dementia and other progressive neurodegenerative diseases, stroke, HIV/AIDS, and advanced renal or hepatic failure. For patients enrolled in hospice, a positive screen is indicated by any pain noted in screening (any response other than none on verbal scale, any number >0 on numerical scale or any observation or self-report of pain), due to the primacy of pain control and comfort care goals in hospice care. For patients receiving specialty palliative care, a positive screen is indicated by moderate or severe pain noted in screening (response of moderate or severe on verbal scale, >4 on a 10-point numerical scale, or any observation or self-report of moderate to severe pain). Only management of moderate or severe pain is targeted for palliative care patients, who have more diverse care goals. Individual clinicians and patients may still decide to assess mild pain, but this subset of patients is not included in the quality measure denominator. [NOTE: This quality measure should be paired with the Pain Screening quality measure to ensure that all patients are screened and therefore given the opportunity to report pain and enter the denominator population for Pain Assessment.]
Exclusions	Patients with length of stay < 1 day in palliative care or < 7 days in hospice, patients who were not screened for pain. Patients who screen negative for pain are excluded from the denominator.
Exclusion details	Calculation of length of stay; discharge date - date of initial encounter
Risk Adjustment	No risk adjustment or risk stratification
Stratification	N/A
Numerator Time window	24 hours
Type	Process
Type of Score	Rate/proportion

Data Source	Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record
Level	Clinician : Group/Practice, Facility
Setting	Hospice, Hospital/Acute Care Facility

	Measure 1638: Hospice and Palliative Care -- Dyspnea Treatment (University of North Carolina- Chapel Hill) *Paired with measure 1639: Hospice and Palliative Care- Dyspnea Screening
Description	Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening.
Numerator	Patients who screened positive for dyspnea who received treatment within 24 hours of screening.
Numerator Details	Treatment is administered if within 24 hours of the positive screen for dyspnea, medical treatment plan, orders or pharmacy records show inhaled medications, steroids, diuretics, or non-medication strategies such as oxygen and energy conservation. Treatment may also include benzodiazepine or opioid if clearly prescribed for dyspnea.
Denominator	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.
Denominator Details	The Dyspnea Treatment quality measure is intended for patients with serious illness who are enrolled in hospice care OR receive specialty palliative care in an acute hospital setting. Conditions may include, but are not limited to: cancer, heart disease, pulmonary disease, dementia and other progressive neurodegenerative diseases , stroke, HIV/AIDS, and advanced renal or hepatic failure. For patients enrolled in hospice or palliative care, a positive screen is indicated by any dyspnea noted as other than none on a verbal screen, any number > 0 on a numeric scale or any observational or self-report of dyspnea. [NOTE: This quality measure should be paired with the Dyspnea Screening quality measure to ensure that all patients are screened and therefore given the opportunity to report dyspnea and enter the denominator population for Dyspnea Treatment.]
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.
Exclusion details	Discharge date – admission date = 1 or hospice patients with discharge date – admission date = 7.
Risk Adjustment	No risk adjustment or risk stratification
Stratification	N/A
Numerator Time window	24 hours
Type	Process
Type of Score	Rate/proportion
Data Source	Electronic Clinical Data
Level	Clinician : Group/Practice, Facility
Setting	Hospice, Hospital/Acute Care Facility

	Measure 1639: Hospice and Palliative Care -- Dyspnea Screening (University of North Carolina- Chapel Hill) *Paired with measure 1638: Hospice and Palliative Care- Dyspnea Treatment
Description	Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation / palliative care initial encounter.
Numerator	Patients who are screened for the presence or absence of dyspnea and its severity during the hospice admission evaluation / initial encounter for palliative care.
Numerator Details	Patients who are screened for the presence or absence of dyspnea during the admission evaluation for hospice / initial encounter for hospital-based palliative care, and asked to rate its severity. Screening may be completed using verbal, numeric, visual analog, or rating scales designed for use with non-verbal patients.
Denominator	Patients enrolled in hospice for 7 or more days OR patients receiving hospital-based palliative care for 1 or more days.
Denominator Details	The Dyspnea Screening quality measure is intended for patients with serious illness who are enrolled in hospice care OR receive specialty palliative care in an acute hospital setting. Conditions may include, but are not limited to: cancer, heart disease, pulmonary disease, dementia and other progressive neurodegenerative diseases, stroke, HIV/AIDS, and advanced renal or hepatic failure. [NOTE: This quality measure should be paired with the Dyspnea Treatment quality measure to ensure that all patients who report dyspnea are clinically considered for treatment.]
Exclusions	Patients with length of stay < 7 days in hospice, or < 1 day in palliative care.
Exclusion details	Calculation of length of stay; discharge date - date of initial encounter.
Risk Adjustment	No risk adjustment or risk stratification
Stratification	N/A
Numerator Time window	Hospice admission evaluation / initial clinical encounter for palliative care
Type	Process
Type of Score	Rate/proportion
Data Source	Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record
Level	Clinician : Group/Practice, Facility
Setting	Hospice, Hospital/Acute Care Facility

	Measure 1641: Hospice and Palliative Care – Treatment Preferences (University of North Carolina-Chapel Hill)
Description	Percentage of patients with chart documentation of preferences for life sustaining treatments.
Numerator	Patients whose medical record includes documentation of life sustaining preferences
Numerator Details	Documentation of life-sustaining treatment preferences should reflect patient self-report; if not available, discussion with surrogate decision-maker and/or review of advance directive documents are acceptable. The numerator condition is based on the process of eliciting and recording preferences, whether the preference statement is for or against the use of life-sustaining treatments. This item is meant to capture evidence of discussion and communication. Therefore, brief statements about an order written about life-sustaining treatment, such as "Full Code" or "DNR/DNI" do not count in the numerator. Documentation using the POLST paradigm with evidence of patient or surrogate involvement, such as co-signature or description of discussion, is adequate evidence and can be counted in this numerator.
Denominator	Seriously ill patients enrolled in hospice OR receiving specialty palliative care in an acute hospital setting.
Denominator Details	The Treatment Preferences quality measure is intended for patients with serious illness who are enrolled in hospice care OR receive specialty palliative care in an acute hospital setting. Conditions may include, but are not limited to: cancer, heart disease, pulmonary disease, dementia and other progressive neurodegenerative diseases, stroke, HIV/AIDS, and advanced renal or hepatic failure.
Exclusions	Patients with length of stay < 1 day in palliative care or < 7 days in hospice
Exclusion details	Calculation of length of stay; discharge date - date of initial encounter.
Risk Adjustment	No risk adjustment or risk stratification
Stratification	N/A
Numerator Time window	N/A
Type	Process
Type of Score	Rate/proportion
Data Source	Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record
Level	Clinician : Group/Practice, Facility
Setting	Hospice, Hospital/Acute Care Facility
	Measure 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, LLC)

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	Number of patient with clinical record documentation of spiritual/religious concerns or documentation that the patient/family did not want to discuss.
Numerator Details	Examples of a discussion may include asking about patient's need for spiritual or religious support, questions about the cause or meaning of illness or death. Other examples include discussion of God or a higher power related to illness, or offer of a spiritual resource including a chaplain. Discussion of spiritual or religious concerns may occur between patient and/or family and clergy or pastoral worker or patient and/or family and member of the interdisciplinary team. Documentation of only patient's religious or spiritual affiliation does not count for inclusion in numerator. Data are collected via chart review. Criteria are: 1) evidence of a discussion about spiritual/religious concerns, or 2) evidence that the patient, and/or family declined to engage in a conversation on this topic. Evidence may be found in the initial screening/assessment, comprehensive assessment, update assessments across the entire period of care, visit notes documented by any member of the team, and/or the spiritual care assessment. Note that these examples and not a complete list.
Denominator	Total number of patient's discharged from hospice care during the designated reporting period.
Denominator Details	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.
Exclusion details	N/A
Risk Adjustment	No risk adjustment or risk stratification
Stratification	N/A – The measure does not require stratification.
Numerator Time window	Cases are eligible for inclusion upon admission to a hospice program. The numerator criteria must be met during the time the patient is enrolled in the hospice program and can be met anytime during that period. The numerator data is collected within 1 to 12 months following discharge from hospice services.
Type	Process
Type of Score	Non-weighted score/composite/scale
Data Source	Electronic Clinical Data, Electronic Clinical Data : Electronic Health Record, Paper Records
Level	Facility
Setting	Hospice

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APPENDIX B: PROJECT STEERING COMMITTEE AND NQF STAFF

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APPENDIX C: 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:

Cross-cutting Issues

- The need for a common denominator to identify palliative care patients across settings would enable measurement of important aspects of care (e.g., pain in cancer patients, pain in hospice patients, pain in the vulnerable elderly) and further promote harmonization.
- The systematic exclusion of patients who have died, who have very serious illness, or are discharged to hospice from many hospital-specific measures limits the applicability of important measures to populations for whom the focus of the measure is appropriate. These exclusions should be examined to determine whether they unintentionally exclude very relevant populations.
- Composite measures of outcomes and process.
- Measures that assess the narrative skills of healthcare providers to ensure that the values and goals of patients are addressed and integrated into their care.

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 that 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 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.
- Measures that assess earlier and more holistic integration of palliative care into patients' treatment regimens.
- Measures addressing patients' functional status.
- Measures capturing overuse of medical interventions at the end of life.

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.

APPENDIX D: NQF PALLIATIVE CARE AND END-OF-LIFE CARE RELATED OR COMPETING MEASURES

	0326: Advance Care Plan	1641: Hospice and Palliative Care – Treatment Preferences
Steward	NCQA/AMA-PCPI	UNC
Description	Percentage of patients aged 65 years and older who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan	Percentage of patients with chart documentation of preferences for life sustaining treatments.
Type	Process	Process
Data Source	Administrative claims data; Other: PQRS Registry	Electronic Clinical Data, Electronic Clinical Data: Electronic Health Record
Level	Clinician: Individual; Clinician: Group Practice	Clinician: Group/Practice, Facility
Setting	Ambulatory Care: Clinician Office, Ambulatory Care: Ambulatory Surgery Center (ASC), Ambulatory Care: Clinic/Urgent Care; Ambulatory Care: Clinician; Home Health; Hospital/Acute Care Facility; Post Acute/Long Term	Hospice, Hospital/Acute Care Facility
Numerator Statement	Patients who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan	Patients whose medical record includes documentation of life sustaining preferences
Numerator Details	Numerator Instructions: If patient's cultural and/or spiritual beliefs preclude a discussion of advance care planning, report 1124F.	Documentation of life-sustaining treatment preferences should reflect patient self-report; if not available, discussion with surrogate decision-maker and/or review of advance directive documents are acceptable. The numerator condition is based on the process of eliciting and recording preferences, whether the preference statement is for or against the use of life-sustaining

	0326: Advance Care Plan	1641: Hospice and Palliative Care – Treatment Preferences
	Definition: Documentation that Patient did not Wish or was not able to Name a Surrogate Decision Maker or Provide an Advance Care Plan – May also include, as appropriate, the following: • That the patient's cultural and/or spiritual beliefs preclude a discussion of advance care planning, as it would be viewed as harmful to the patient's beliefs and thus harmful to the physician-patient relationship. Numerator Quality-Data Coding Options for Reporting Satisfactorily: Advance Care Planning Discussed and Documented CPT II 1123F: Advance Care Planning discussed and documented; advance care plan or surrogate decision maker documented in the medical record OR CPT II 1124F: Advance Care Planning discussed and documented in the medical record; patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan	treatments. This item is meant to capture evidence of discussion and communication. Therefore, brief statements about an order written about life-sustaining treatment, such as "Full Code" or "DNR/DNI" do not count in the numerator.

	0326: Advance Care Plan	1641: Hospice and Palliative Care – Treatment Preferences
	OR Advance Care Planning not Documented, Reason not Specified Append a reporting modifier (8P) to CPT Category II code 1123F to report circumstances when the action described in the numerator is not performed and the reason is not otherwise specified. 1123F *with* 8P: Advance care planning not documented, reason not otherwise specified	
Denominator Statement	All patients aged 65 years and older	Seriously ill patients enrolled in hospice OR receiving specialty palliative care in an acute hospital setting.
Denom Categories	Female; Male Aged 65 years and older	Adult/Elderly Care

	0326: Advance Care Plan	1641: Hospice and Palliative Care – Treatment Preferences
Denominator Details	Denominator Criteria (Eligible Cases): Patients aged ≥ 65 years on date of encounter Patient encounter during the reporting period (CPT): 99201, 99202, 99203, 99204, 99205, 99212, 99213, 99214, 99215, 99218, 99219, 99220, 99221, 99222, 99223, 99231, 99232, 99233, 99234, 99235, 99236, 99291*, 99304, 99305, 99306, 99307, 99308, 99309, 99310, 99324, 99325, 99326, 99327, 99328, 99334, 99335, 99336, 99337, 99341, 99342, 99343, 99344, 99345, 99347, 99348, 99349, 99350, 99387, 99397, 99401, 99402, 99403, 99404 *Clinicians indicating the place of service as the emergency department will not be included in this measure.	The Treatment Preferences quality measure is intended for patients with serious illness who are enrolled in hospice care OR receive specialty palliative care in an acute hospital setting. Conditions may include, but are not limited to: cancer, heart disease, pulmonary disease, dementia and other progressive neurodegenerative diseases, stroke, HIV/AIDS, and advanced renal or hepatic failure.
Exclusions	N/A	Patients with length of stay < 1 day in palliative care or <7 days in hospice
Exclusion Details	N/A	Calculation of length of stay; discharge date – date of initial encounter
Risk Adjustment	No risk adjustment or risk stratification	No risk adjustment or risk stratification
Stratification	No risk stratification	No risk stratification
Type Score	Better score = better quality	Better quality = higher score

	0326: Advance Care Plan	1641: Hospice and Palliative Care – Treatment Preferences
Algorithm	See attached for calculation algorithm.	Chart documentation of life sustaining preferences: a. Step 1 – Identify all patients with serious, life-limiting illness who are enrolled in hospice OR who received specialty palliative care in an acute hospital b. B. Step 2 – Exclude palliative care patients if length of stay is < 1 day. Exclude hospice patients if length of stay is < 7 days c. Step 3 – Identify patients with documented discussion of preference for life sustaining treatments Quality measure = Numerator: Patients with documented discussion in Step 3 / Denominator: Patients in Step 1 – Patients excluded in Step 2

676

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