NATIONAL QUALITY FORUM

Measure Submission and Evaluation Worksheet 5.0

This form contains the information submitted by measure developers/stewards, organized according to NQF's measure evaluation criteria and process. The evaluation criteria, evaluation guidance documents, and a blank online submission form are available on the submitting standards web page.

NQF #: 1632 **NQF Project:** Palliative Care and End-of-Life Care
(for Endorsement Maintenance Review) **Original Endorsement Date:** **Most Recent Endorsement Date:**

BRIEF MEASURE INFORMATION
De.1 **Measure Title:** CARE - Consumer Assessments and Reports of End of Life
Co.1.1 **Measure Steward:** Center for Gerontology and Health Care Research
De.2 **Brief Description of Measure:** 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.

2a1.1 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.

2a1.4 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

2a1.8 Denominator Exclusions: We excluded deaths due to accidents, trauma, during surgery, lethal injection, acute overwhelming infections, and from complications of pregnancy.

1.1 Measure Type: Patient Engagement/Experience
2a1. 25-26 Data Source: Other
2a1.33 Level of Analysis: Facility, Population : Community, Population : National, Population : Regional

1.2-1.4 Is this measure paired with another measure? No

De.3 If included in a composite, please identify the composite measure (*title and NQF number if endorsed*):
There is not a paired or included in other composite measure. However, it should be noted that this is the parent measure of the Family Evaluation of Hospice Care (FEHC) - NQF measure 0208. The FEHC focused on the care provided by a hospice provider. This CARE survey examines bereaved family members perceptions of care provided at the last place of care -- either a nursing home, hospital, home health agency, or hospice. This telephone aministered survey is the almost identical to the FEHC with the exception of a new question in the FEHC, telephone administration, and changes that were made to questions to take the FEHC to self-administration.

STAFF NOTES (*issues or questions regarding any criteria*)

Comments on Conditions for Consideration:

Is the measure untested?   Yes☐ No☐   If untested, **explain how it meets criteria for consideration for time-limited endorsement:**

1a. Specific national health goal/priority identified by DHHS or NPP addressed by the measure (*check De.5*):
5. Similar/related endorsed or submitted measures (*check 5.1*):
Other Criteria:

Staff Reviewer Name(s):

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1. IMPACT, OPPORTUNITY, EVIDENCE - IMPORTANCE TO MEASURE AND REPORT

Importance to Measure and Report is a threshold criterion that must be met in order to recommend a measure for endorsement. All three subcriteria must be met to pass this criterion. See guidance on evidence.
Measures must be judged to be important to measure and report in order to be evaluated against the remaining criteria. (evaluation criteria)

1a. High Impact: H☐ M☐ L☐ I☐
(*The measure directly addresses a specific national health goal/priority identified by DHHS or NPP, or some other high impact aspect of healthcare.*)

De.4 Subject/Topic Areas (*Check all the areas that apply*):
De.5 Cross Cutting Areas (*Check all the areas that apply*)**:** Palliative Care and End of Life Care

1a.1 Demonstrated High Impact Aspect of Healthcare: Affects large numbers, Patient/societal consequences of poor quality

1a.2 If "Other," please describe:

1a.3 **Summary of Evidence of High Impact** *(Provide epidemiologic or resource use data)*:
Each year 2.4 million Americans die. Too often, this dying experience is marred by untreated pain or other symptoms, lack of shared decision making, and families who report the lacked adequate emotions support. In 2004, Teno and colleagues used the CARE instrument to examine families' perspective on end of life care at the last place of care. (1) Results of this study provide evidence of the important unmet needs and concerns with the quality of care of the dying:
1.   Bereaved family member reported that about one in four persons with pain or dyspnea did not receive adequate treatment.
2.   A similar rate reported concerns that physician communication about prognosis and treatment decision making.
3.   More than one third of respondents who did not have hospice services at home stated they did not have enough emotional support.
4.   Nearly 30% had a concern with not enough information was provided regarding what to expect while the patient was dying.
5.   About one in five stated dying person was not always treated with respect.
6.   Fifteen percent noted a concern with coordination.

The viewpoints of family members are confirmed by rates of pain and other symptoms noted on the Minimum Data Set2, and recent studies published within the last 2 years. (3,4) We have previously summarized guidelines and position statement in JPSM article. (5) Each of the proposed domains were supported by the majority of the guidelines summarized in 2001 and they are supported by the NQF preferred practices in palliative medicine.(6)

1a.4 **Citations for Evidence of High Impact cited in 1a.3:** 1. 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.
2.   Teno JM, Weitzen S, Wetle T, Mor V. Persistent pain in nursing home residents. JAMA. 2001 Apr 25 2001;285(16):2081.
3.   Puntillo KA, Arai S, Cohen NH, et al. Symptoms experienced by intensive care unit patients at high risk of dying. Critical care medicine. Nov 2010;38(11):2155-2160.
4.   Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. N Engl J Med. Oct 15 2009;361(16):1529-1538.
5.   Teno JM, Clarridge B, Casey V, Fowler J. Toolkit of Instruments to Measure End of Life Care: Bereaved Family Member Interview - Psychometric properties. J Pain Symptom Manage. In Press, 2001 2001.
6.   (NQF) NQF. National Framework and Preferred Practices for Palliative and Hospice Care.

1b. Opportunity for Improvement: H☐ M☐ L☐ I☐
(There is a demonstrated performance gap - variability or overall less than optimal performance)

1b.1 **Briefly explain the benefits (improvements in quality) envisioned by use of this measure:**
The proposed benefit of this survey is to ensure that the quality of care for persons at the close of life reflect the needs of the dying persons and their family.

1b.2 **Summary of Data Demonstrating Performance Gap** *(Variation or overall less than optimal performance across providers)*:
[*For Maintenance – Descriptive statistics for performance results for this measure - distribution of scores for measured entities by quartile/decile, mean, median, SD, min, max, etc.*]
The 2004 JAMA study noted significant opportunities to improve with evidence of less than optimal performance across setting of care. (1) A subsequent research article reported that bereaved family members of persons who died with regions that varied with the intensity of care reported different level of concerns with the quality of care and unmet needs as measured by the CARE survey (2) and that African Americans reported more concerns and unmet needs compared to respondents of white decedents.(3) The CARE survey was adopted to a self administered survey for the National Hospice and Palliative Care Organization. This is an NQF endorsed survey, called the Family Evaluation of Hospice Care Survey. The FEHC is currently used by over 1200 hospice programs with striking variation reported among hospice programs(4) and persistent differences among black and white patients.(5)

1b.3 **Citations for Data on Performance Gap:** [*For Maintenance – Description of the data or sample for measure results reported in 1b.2 including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included*]
1.   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.
2.   Teno JM, Fisher ES, Mor V, Roy J, Clarridge B, Wennberg JE. Dying in HSA with higher ICU utilization: is more better? J

Am Geriatr Soc. April 2003 2003;51(S4):S39-40.
3.   Welch LC, Teno JM, Mor V. End-of-life care in black and white: race matters for medical care of dying patients and their families. J Am Geriatr Soc. 2005 Jul 2005;53(7):1145-1153.
4.   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.
5.   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.

1b.4 Summary of Data on Disparities by Population Group: [*For Maintenance –Descriptive statistics for performance results for this measure by population group*]
A 2005 JAGS publication reported significant disparities in black vs. white decedents.(3) Blacks reported more concerns with physician communication (OR 1.9), more concern with emotional support for the family (OR 2.6), more unmet needs in not providing enough information on what to expect while dying (OR 2.5). Analysis of the FEHC data repository found differences among unmet needs for pain and other symptoms (e.g., OR 1.5 for pain), concerns for emotional support provided to the family (OR 1.4), and concerns with coordination of care (OR 1.3).(5)

1b.5 Citations for Data on Disparities Cited in 1b.4: [*For Maintenance – Description of the data or sample for measure results reported in 1b.4 including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included*]
See reference 3 and 5 above

1c. Evidence (*Measure focus is a health outcome OR meets the criteria for quantity, quality, consistency of the body of evidence.*) **Is the measure focus a health outcome?   Yes☐ No☐   If not a health outcome**, rate the body of evidence.

Quantity: H☐ M☐ L☐ I☐   Quality: H☐ M☐ L☐ I☐   Consistency: H☐ M☐ L☐ I☐

Quantity	Quality	Consistency	Does the measure pass subcriterion1c?
M-H	M-H	M-H	Yes☐
L	M-H	M	Yes☐ IF additional research unlikely to change conclusion that benefits to patients outweigh harms: otherwise **No**☐
M-H	L	M-H	Yes☐ IF potential benefits to patients clearly outweigh potential harms: otherwise **No**☐
L-M-H	L-M-H	L	No ☐

Health outcome – rationale supports relationship to at least one healthcare structure, process, intervention, or service	Does the measure pass subcriterion1c? Yes☐ IF rationale supports relationship

1c.1 Structure-Process-Outcome Relationship (*Briefly state the measure focus, e.g., health outcome, intermediate clinical outcome, process, structure; then identify the appropriate links, e.g., structure-process-health outcome; process- health outcome; intermediate clinical outcome-health outcome*):
Patient experience
As we have previously stated, the focus of the measure is based on conceptual model of patient focused, family centered medical care. This model was developed based on expert advice, a structured review of guidelines, and focus groups with bereaved family members.(1)11 We have provided a Table modified from Teno and Connors JAMA publication in 2009. (2) 12 In table provided as an appendix, we provide the conceptual model, relationship to NQF preferred practices, the proposed relationship between structure, process, and examples of survey questions from CARE/FEHC.

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, Connor SR. Referring a patient and family to high-quality palliative care at the close of life: "We met a new personality... with this level of compassion and empathy". JAMA. Feb 11 2009;301(6):651-659.

1c.2-3 **Type of Evidence** *(Check all that apply)*:
Systematic review of body of evidence (other than within guideline development)

1c.4 **Directness of Evidence to the Specified Measure** *(State the central topic, population, and outcomes addressed in the body of evidence and identify any differences from the measure focus and measure target population)*:
The CARE survey is based on expert opinion, focus groups, and structured literature review of guidelines about what domains define high quality care at the end of life. In addition, we have provided a cross walk of the NQF preferred practices with the proposed domains and items of the CARE survey.
In our initial review of guidelines, we identified 30 publications that identified important domains of end of life care. This review is summarized in Table 1(1) 11 of an article by Teno and colleagues defining the conceptual model. Additionally, focus groups with bereaved family members were used to narrow these domains to those that were supported by these consumers.
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.

1c.5 **Quantity of Studies in the Body of Evidence** *(Total number of studies, not articles)*: As noted above, we reviewed guidelines and conducted focus groups. They were not studies.

1c.6 **Quality of Body of Evidence (***Summarize the certainty or confidence in the estimates of benefits and harms to patients across studies in the body of evidence resulting from study factors. Please address: a) study design/flaws; b) directness/indirectness of the evidence to this measure (e.g., interventions, comparisons, outcomes assessed, population included in the evidence); and c) imprecision/wide confidence intervals due to few patients or events)*: not applicable

1c.7 **Consistency of Results across Studies** *(Summarize the consistency of the magnitude and direction of the effect):* not applicable

1c.8 **Net Benefit** *(Provide estimates of effect for benefit/outcome; identify harms addressed and estimates of effect; and net benefit - benefit over harms)*:
not applicable

1c.9 **Grading of Strength/Quality of the Body of Evidence**. Has the body of evidence been graded? No

1c.10 **If body of evidence graded, identify the entity that graded the evidence including balance of representation and any disclosures regarding bias:** Not applicable

1c.11 **System Used for Grading the Body of Evidence:** Other

1c.12 **If other, identify and describe the grading scale with definitions:** Not applicable

1c.13 **Grade Assigned to the Body of Evidence:** not applicable

1c.14 **Summary of Controversy/Contradictory Evidence:** not applicable

1c.15 **Citations for Evidence other than Guidelines***(Guidelines addressed below)*:
not applicable

1c.16 **Quote verbatim, the specific guideline recommendation** *(Including guideline # and/or page #)*:
not applicable

1c.17 **Clinical Practice Guideline Citation:** not applicable

1c.18 **National Guideline Clearinghouse or other URL:** not applicable

1c.19 Grading of Strength of Guideline Recommendation. Has the recommendation been graded? No

1c.20 If guideline recommendation graded, identify the entity that graded the evidence including balance of representation and any disclosures regarding bias:

1c.21 System Used for Grading the Strength of Guideline Recommendation: Other

1c.22 If other, identify and describe the grading scale with definitions: not applicable

1c.23 Grade Assigned to the Recommendation: not applicable

1c.24 Rationale for Using this Guideline Over Others: not appliacable

Based on the NQF descriptions for rating the evidence, what was the <u>developer's assessment</u> of the quantity, quality, and consistency of the body of evidence?
1c.25 Quantity: Moderate   1c.26 Quality: Moderate 1c.27 Consistency: Moderate

Was the threshold criterion, *Importance to Measure and Report*, met?
(*1a & 1b must be rated moderate or high and 1c yes*)   Yes☐ No☐
Provide rationale based on specific subcriteria:

For a new measure if the Committee votes NO, then STOP.
For a measure undergoing endorsement maintenance, if the Committee votes NO because of 1b. (no opportunity for improvement), it may be considered for continued endorsement and all criteria need to be evaluated.

2. RELIABILITY & VALIDITY - SCIENTIFIC ACCEPTABILITY OF MEASURE PROPERTIES

Extent to which the measure, <u>as specified</u>, produces consistent (reliable) and credible (valid) results about the quality of care when implemented. (<u>evaluation criteria</u>)
Measure testing must demonstrate adequate reliability and validity in order to be recommended for endorsement. Testing may be conducted for data elements and/or the computed measure score. Testing information and results should be entered in the appropriate field. Supplemental materials may be referenced or attached in item 2.1. See <u>guidance on measure testing</u>.

S.1 Measure Web Page *(In the future, NQF will require measure stewards to provide a URL link to a web page where current detailed specifications can be obtained)*. Do you have a web page where current detailed specifications for <u>this</u> measure can be obtained? No

S.2 If yes, provide web page URL:

2a. RELIABILITY. Precise Specifications and Reliability Testing: H☐ M☐ L☐ I☐

2a1. Precise Measure Specifications. (*The measure specifications precise and unambiguous.*)

2a1.1 Numerator Statement *(Brief, narrative description of the measure focus or what is being measured about the target population, e.g., cases from the target population with the target process, condition, event, or outcome)*:
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.

2a1.2 Numerator Time Window *(The time period in which the target process, condition, event, or outcome is eligible for inclusion)*:
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.

2a1.3 Numerator Details *(All information required to identify and calculate the cases from the target population with the target process, condition, event, or outcome such as definitions, codes with descriptors, and/or specific data collection items/responses)*:
Detailed information is provided below.

2a1.4 Denominator Statement *(Brief, narrative description of the target population being measured)*:
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

2a1.5 Target Population Category *(Check all the populations for which the measure is specified and tested if any)*: Adult/Elderly Care

2a1.6 Denominator Time Window *(The time period in which cases are eligible for inclusion)*:
The last days spent in hospice, hospital, home health agency, or nursing home up to 7 days. Respondents only report on the last place that decedent spent at least 48 hours.

2a1.7 Denominator Details (*All information required to identify and calculate the target population/denominator such as definitions, codes with descriptors, and/or specific data collection items/responses)*:
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.

2a1.8 Denominator Exclusions *(Brief narrative description of exclusions from the target population)*:
We excluded deaths due to accidents, trauma, during surgery, lethal injection, acute overwhelming infections, and from complications of pregnancy.

2a1.9 Denominator Exclusion Details *(All information required to identify and calculate exclusions from the denominator such as definitions, codes with descriptors, and/or specific data collection items/responses)*:
See answer to 2a1.7

2a1.10 Stratification Details/Variables *(All information required to stratify the measure results including the stratification variables, codes with descriptors, definitions, and/or specific data collection items/responses)*:
There is no proposed stratification variable

2a1.11 Risk Adjustment Type *(Select type. Provide specifications for risk stratification in 2a1.10 and for statistical model in 2a1.13)*: No risk adjustment or risk stratification   **2a1.12** If "Other," please describe:

2a1.13 Statistical Risk Model and Variables *(Name the statistical method - e.g., logistic regression and list all the risk factor variables. Note - risk model development should be addressed in 2b4.)*:

2a1.14-16 Detailed Risk Model Available at Web page URL (or attachment). Include coefficients, equations, codes with descriptors, definitions, and/or specific data collection items/responses. Attach documents only if they are not available on a webpage and keep attached file to 5 MB or less. NQF strongly prefers you make documents available at a Web page URL. Please supply login/password if needed:

2a1.17-18. **Type of Score:** Non-weighted score/composite/scale

2a1.19 **Interpretation of Score** *(Classifies interpretation of score according to whether better quality is associated with a higher score, a lower score, a score falling within a defined interval, or a passing score)*: Better quality = Lower score

2a1.20 **Calculation Algorithm/Measure Logic***(Describe the calculation of the measure score as an ordered sequence of steps including identifying the target population; exclusions; cases meeting the target process, condition, event, or outcome; aggregating data; risk adjustment; etc.)*:
The CARE instrument is composed of 6 domains based on the conceptual model of patient focused, family centered medical care. A home care agency, hospice, hospital, or nursing home provides high quality of care when they:

1.   Provided the desired physical comfort and emotional support;
2.   Promote shared decision making – that medical decisions are based on the goals and values of the dying patient ;
3.   Treat the dying patient with respect;
4.   Attend to the need of the caregiver for information and skills in providing care for the patient measured by 2 composite scores;
5.   Attend to the needs of caregivers for emotional and spiritual support prior to and after the death of the patient;
6.   Coordination of care across settings of care and health care providers.

A 0-100 composite score
The survey is attached as an appendix. In the table below, we list questions that correspond to the actual proposed domain listed above.

Domain Questionnaire Items
Provided desired physical comfort and emotional support   D3 (pain), D5b (dyspnea), D6b (patient's emotions) - each scored as single item, an unmet need.
Promote Shared Decision Making
C4 and C4a – as single item, scored as concern if they state they wanted to speak with a physician and did not.
For those who spoke with a physician, C5, C6, C7, C8 as problem score that counts the number of concerns with the quality of that communication.
Treat the dying patient with respect D7 – treated with respect
Attend to the needs of caregiver for information and skills in providing care for the patient
Composite score = D4 and D4a, D12 and D12a, D13 and D13a, scored as 3 item problem score indicating that they wanted (some/more) information.
        Score = D12b, D13b, and D4b
Attend to the needs of the caregiver for emotional and spiritual support E.1., 1a, 1b, 1c, E2, E3, E3a, E3b, scored as 3 items score indicating an unmet need and/or opportunity to improve.
Coordination   D11 - scores as single item

Please note that we are proposing either a single item or composite score for each domains and overall 0-100 score that is made up all the domains except promote shared decision making. The reason that we dropped that domain is based on the number of persons that state they did not speak with a physician (even when they were in a hospital).

We will describe the approach to them sequentially.

Provide desired physical comfort and emotional support

This is based on 3 questions that get scored as an unmet need. In this case of pain, the unmet need is defined as stating they did not receive enough, too much, or the patient was in pain without the receipt of any medications. A similar strategy was followed for dyspnea and emotions except the wording of the question focuses on help rather than medications.   Each items is reported as dichotomous item.

Promote shared decision-making

You can't ask about shared decision making with a physician unless a conversation occurred with a physician at the place of care. Thus, we divided this domain into two type of reports. For those persons who did not talk with a physician, a rate of how many persons wanted to speak with a physician. The second composite score is a count of opportunities to improve the quality of that conversation based on 3 survey items. An indication that the respondent had a problem understanding the physician, that the physician did not listen to what they had to say about medical treatment, or that they receive "too little" or "too much" information about the patient' medical condition was counted as an opportunity to improve. The composite score varies between 0 and 3 with 3 indicating more concerns with the quality of conversation with the physician.

Treat the dying patient with respect

A single item asks how often was the patient treated with respect. For the purpose of quality improvement, we report out the rate of response that indicates the patient was NOT always treated with respect.

Attend to the needs of the caregiver for information and skills

Three items ask about information needs of the family. The response that they wanted more information is treated as a unmet need. The composite score varies between 0 and 3.
A second scale was created by three questions (12b, 13b, and 14b) that asks about the respondent's confidence in certain tasks that caregivers are involved at the end of life. These items are reversed coded (very confident =3) to create a scale between 1 and 9.

Attend to the needs of the caregiver for emotional and spiritual support

Three items ask about the provision of emotional and spiritual support to the respondent. In the first question, the response that they did not receive the "right amount" support about the patients' death was counted an unmet need. For the question about whether someone talked to the respondent about your spiritual beliefs or how you might feel after the patient's death, the response that they did not have that conversation and wanted that information or the conversation was not done in a sensitive manner are counted as opportunity to improve. The composite score varies between 0 and 3 with the score of 3 indicating more concerns with the quality of care.

Coordination – information continuity

A single item ask whether there was problem with the doctor or nurse not knowing enough about the patient's medical history. The response yes was counted as an opportunity to improve the quality of care.

0-   to 100 score is based on 14 out of the 17 items. We created this score based on factor analysis with imputation that if a decedent did not experience a symptom that score was treat as a "met" need.
The calculation of this score is as follows based on the following STATA Code.
gen overall_step1a = ((imp_unmet_pain_scale *.2632) + (imp_unmet_sob_scale *.2045) + (imp_unmet_anx_scale *.3691)+ (n_e2 *.5775) + (n_e3 *.4674) + (n_e1 *.4605) + (med_info_scale *.6275) + (die_info_scale*.6618) + (time_of_death_info_scale * .6591) + (not_respect_scale * .4558)+ (imp_nd16 * 0.5001) + (imp_nd4b*.5865)+ (imp_nd12b*.5773)+ (imp_nd13b*.5517))
gen overall_0_100a = 14.36 * overall_step1a
gen overall_100_scorea = 100-overall_0_100a

2a1.21-23 **Calculation Algorithm/Measure Logic Diagram URL or attachment:**

2a1.24 **Sampling (Survey) Methodology.** If measure is based on a sample (or survey), provide instructions for obtaining the

sample, conducting the survey and guidance on minimum sample size (response rate):
The CARE survey is part of an initial project entitled, the Toolkit of Instruments to Measure End of Life Care. We have prepared resource guide that has separate chapter on conducting the survey (http://www.chcr.brown.edu/pcoc/resourceguide.htm). We recommend between 20 and 30 interviews for the purpose of quality improvement. Based on experience with the widespread use of the Family Evaluation of Hospice Care Survey, we tell programs to aim for response rate of 40% or higher. While the initial administration of the survey was based mortality followback approach based on death certificates, we envision that in the future that a health plan or accountable care organization may want to use this survey to monitor quality of care of the dying for a population of patients. We suggest that a nursing home, hospice, hospital, home health agency, or health plan contact the persons listed as health care proxy, informant, or next of kin. Once you have contacted that person, we have a series of questions that verifies that this is the right person to interview. If not, one obtains contact information for another respondent.

2a1.25 Data Source (*Check all the sources for which the measure is specified and tested*). If other, please describe:
 Other

2a1.26 Data Source/Data Collection Instrument (*Identify the specific data source/data collection instrument, e.g. name of database, clinical registry, collection instrument, etc.*): CARE survey - which is retrospective post death survey of the person who knew best and was or would have been involved in decision making is sent as appendix.

2a1.27-29 Data Source/data Collection Instrument Reference Web Page URL or Attachment: URL
http://www.chcr.brown.edu/pcoc/resourceguide.htm

2a1.30-32 Data Dictionary/Code Table Web Page URL or Attachment:

2a1.33 Level of Analysis (*Check the levels of analysis for which the measure is specified and tested*):   Facility, Population : Community, Population : National, Population : Regional

2a1.34-35 Care Setting (*Check all the settings for which the measure is specified and tested*): Home Health, Hospice, Hospital/Acute Care Facility, Post Acute/Long Term Care Facility : Nursing Home/Skilled Nursing Facility

2a2. Reliability Testing. (*Reliability testing was conducted with appropriate method, scope, and adequate demonstration of reliability.*)

2a2.1 Data/Sample (*Description of the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included*):
The initial work on reliability and validity of the CARE Instrument (as well as the Family Evaluation of hospice care) survey was completed on a sample of 156 bereaved family members who died receiving care from hospice, nursing home, and hospital. This was published in JPSM in 2001. (1) In this first test, we examined short-term test-retest (4 to 8 weeks after the original interview) and internal consistency was examined with Crohnbach´s alpha among the entire sample of 156 interviews for each of the proposed composite scores. This analysis was updated for the 2004 publication of the mortality followback survey published in JAMA (2) with the result published in an online appendix on a Brown University web site (http://www.chcr.brown.edu/dying/MEASURES_JAMA_PAPER_LAST_PLACE_OF_CARE.PDF).

(1) 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.
(2) 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.

2a2.2 Analytic Method (*Describe method of reliability testing & rationale*):
1. Short term reliability over 4-8 weeks was done among 29 family members with all the key items of the survey. The reliability was examined among a Kappa statistic or an intraclass correlation. This was published in 2001 JPSM article. (1)
(1) 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.

2. The internal consistency of all proposed composite scores was examined with Crohnbach´s alpha with items dropped. This has been done for the initial validation study and national mortality follow back survey in 2004 (2). This was published in the 2001 JPSM article (1) and online with the 2004 JAMA publication.(2)
(1) 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.
(2) 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.

2a2.3 **Testing Results** *(Reliability statistics, assessment of adequacy in the context of norms for the test conducted)*:
Based on reliability testing of the survey given 4-8 weeks apart, we decided to drop 4 items which have a Kappa under 0.4. Two items that we retained have skewed marginals with a high percent agreement of 79% and 82%. The remaining items all had a Kappa or ICC above 0.49 and higher.

Examination of internal consistency was done with the Crohnbach´s alpha. We relied on a national mortality followback survey published in JAMA in 2004 to report the internal consistency of NQF evaluation. As we have previously stated, there are 3 composite scores. For the composite score examining physician communication, the Crohnbach´s Alpha was 0.67 while the other two composite scores exceed 0.70.

Based on reliability testing of the survey given 4-8 weeks apart, we decided to drop 4 items which have a Kappa under 0.4. Two items that we retained have skewed marginals with a high percent agreement of 79% and 82% which is a known problem with the Kappa Statistic. The remaining items all had a Kappa or ICC above 0.49 and higher.

Examination of internal consistency was done with the Crohnbach´s alpha. We relied on a national mortality followback survey published in JAMA in 2004 to report the internal consistency for this NQF evaluation. As we have previously stated, there are 3 composite scores. For the composite score examining physician communication, the Crohnbach´s Alpha was 0.67 while the other two composite scores exceed 0.70.

Based on factor analysis, we created a composite score of 14 out of the 17 proposed items. We dropped the 3 items that examined physician communication based on the large number of persons who did not have contact with the physician. The 14 items 0-100 composite score had a Crohnbach´s alpha -0.80

2b. VALIDITY. Validity, Testing, including all Threats to Validity:   H☐ M☐ L☐ I☐

2b1.1 **Describe** **how the measure specifications** *(measure focus, target population, and exclusions)* **are consistent with the evidence cited in support of the measure focus** *(criterion 1c)* **and identify any differences from the evidence:**
Our proposed measure is of the patient and family experience in the last week of life. According of World Health Organization, the goal of palliative care considers the dying patient and family the unit of care with recent evidence finding that quality of care effects those who survive in terms of post traumatic stress disorders and prolonged grief. As we have noted, we used focus groups and structured literature review to find those items that reflect the values and preferences of dying patients and their families. Our main exclusion criteria allow us to focus on persons who had a minimum of length of stay at the last place of care. Thus, our exclusions do not result in any difference than the existing evidence.

2b2. Validity Testing. (*Validity testing was conducted with appropriate method, scope, and adequate demonstration of validity.*)

2b2.1 **Data/Sample** *(Description of the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included)*:
We conducted validity testing on the sample of 156 respondents (1) and 1380 respondents (2) who died in a nursing home, hospital, home health agency, or hospice at home. We will report the latter. Respondents were next of kin listed the death certificates sampled from 22 states which account for more than 70% of all deaths in the USA. The cooperation rate for the survey was 65%. Characteristics of this national data is reported in Table 1 of the 2004 JAMA publication. In brief, the average age of the decedent was 74.8, 86.8% white, and 53.4% were women. The respondent were women (71%), usually a spouse (30.1%) or child (40.5%) of the decedent. Nearly 3/4th of these respondent had contact with the decedent for the entire last week of life.

(1) 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.
(2) 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.

2b2.2 Analytic Method *(Describe method of validity testing and rationale; if face validity, describe systematic assessment)*:
Both construct and discriminant validity was examined for the proposed six domains and the overall composite score that uses 14 out of the 17 items. As w mentioned, 3 items that examined physician communication was dropped based on the large number of bereaved family members reported that the they di not have contact with the physician.
Both criterion and discriminant validity was examined for the proposed six domains and the overall composite score that uses 14 out of the 17 items. As we mentioned, 3 items that examined physician communication was dropped based on the large number of bereaved family members reported that they did not have contact with the physician.

For criterion validity, we examine the correlation with of each individual item or composite score with overall rating of the quality of care using the response task of Excellent to Poor. Discriminant validity examined whether the six domains and the 14 item 0-100 score differentiate bereaved family members perceptions of quality of care between those who died at home with hospice and other settings of care.

2b2.3 Testing Results *(Statistical results, assessment of adequacy in the context of norms for the test conducted; if face validity, describe results of systematic assessment)*:
Criterion validity was examined with Spearman correlation. They are listed below.

Unmet need for pain	.21	
Unmet need for SOB		.17
Unmet need for emotions	.32	
Physician communication		.33
Surrogate emotional support	.43	
Informing surrogate what to expect	.46	
Self efficacy	.51	
Information continuity		.40

For the composite core of 14 items that creates a score between 0 and 100, we found correlation of 0.58.

We hypothesize there would be a moderate correlation. With the exception of unmet need for dyspnea and Pain, all items were in the moderate correlation range.

Discriminate validity examined whether the proposed measured differentiates care in a NH, hospital, home health agency, and hospice at home. Please see Table 3 of the 2004 JAMA article for difference between the 4 groups of health care providers. The mean self-efficacy scores and 0-100 score are provided below.

	Self Efficacy (3-9)	0-100
Home health	7.4	77.1
Hospice at home	7.8	83.2
Hospital	7.4	74.1
Nursing home	7.0	71.2

POTENTIAL THREATS TO VALIDITY. (*All potential threats to validity were appropriately tested with adequate results.*)

2b3. Measure Exclusions. (*Exclusions were supported by the clinical evidence in 1c or appropriately tested with results demonstrating the need to specify them.*)

2b3.1 Data/Sample for analysis of exclusions *(Description of the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included)*:
We excluded those persons at a setting of care less than 48 hours to allow sufficient time at that location to evaluate the quality of care.

2b3.2 Analytic Method (*Describe type of analysis and rationale for examining exclusions, including exclusion related to patient preference)*:
None – the 2 days rule was based on expert opinion and Dr. Teno experience with the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments.

2b3.3 Results *(Provide statistical results for analysis of exclusions, e.g., frequency, variability, sensitivity analyses):*
Not applicable

2b4. Risk Adjustment Strategy. (*For outcome measures, adjustment for differences in case mix (severity) across measured entities was appropriately tested with adequate results.*)

2b4.1 Data/Sample *(Description of the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included)*:
Not applicable

2b4.2 Analytic Method (*Describe methods and rationale for development and testing of risk model or risk stratification including selection of factors/variables)*:
Not applicable

2b4.3 Testing Results (*Statistical risk model: Provide quantitative assessment of relative contribution of model risk factors; risk model performance metrics including cross-validation discrimination and calibration statistics, calibration curve and risk decile plot, and assessment of adequacy in the context of norms for risk models. Risk stratification: Provide quantitative assessment of relationship of risk factors to the outcome and differences in outcomes among the strata)*:
Not applicable

2b4.4 If outcome or resource use measure is not risk adjusted, provide rationale and analyses to justify lack of adjustment: The proposed measure is based on bereaved family member perceptions. The socio-demographic characteristic that is strongly associated with proposed measure is race. Blacks consistently have more unmet needs and concerns with the quality of care. Is this difference in perceptions reflect a plausible mechanism or reflect actual treatments that dying patient and family received? We believe that risk adjustment should not obscure disparities in care. Other characteristics (such as diagnosis, etc.) were not associated with the proposed measure.

2b5. Identification of Meaningful Differences in Performance. (*The performance measure scores were appropriately analyzed and discriminated meaningful differences in quality.*)

2b5.1 Data/Sample *(Describe the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included)*:
The data sample for the proposed initial meaningful difference in performance is the sample for the 2004 mortality followback survey, which was national sample of death certificates.

2b5.2 Analytic Method *(Describe methods and rationale to identify statistically significant and practically/meaningfully differences in performance)*:
This is one area where more work is needed. We are able to provide meaningful difference between the places of care. However, more work is needed to provide meaningful evidence of difference between performance of the selected entities. The FEHC with the widespread use - we are able to set benchmarks based on 2 years of data. With the FEHC, we provide feedback to providers based on the their percentile group into the following categories

The top 10%
The next 40%
The next 40%
The bottom 10%

 For the initial use CARE survey, we propose to use 2004 JAMA publication to set bench marks for the 0-100 as follows:
The cut off for the top 10% is perfect score of 100 while the bottom 10% is a score 37.9% and lower. The median score is 83.3 and median of 75.2.

2b5.3 Results *(Provide measure performance results/scores, e.g., distribution by quartile, mean, median, SD, etc.; identification of statistically significant and meaningfully differences in performance)*:

Overall the results of nation wide mortality followback survey provides ample evidence that all places of care can improve the quality of care. As we noted above, we propose to use the 2004 JAMA publication to set bench marks for the 0-100 as follows: The cut off for the top 10% is perfect score of 100 while the bottom 10% is a score 37.9% and lower. The median score is 83.3 and median of 75.2. We report in the JAMA 2004 article difference in performance by place of care. For the 0-100 composite score, we have the following differences:

Place of care	Mean	SD
Home Health	77.1	17
Hospice	83.1	20
Hospital	74.8	26
Nursing home	71.3	25

2b6. Comparability of Multiple Data Sources/Methods. (*If specified for more than one data source, the various approaches result in comparable scores.*)

2b6.1 Data/Sample *(Describe the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included)*:
not applicable

2b6.2 Analytic Method *(Describe methods and rationale for testing comparability of scores produced by the different data sources specified in the measure)*:
not applicable

2b6.3 Testing Results *(Provide statistical results, e.g., correlation statistics, comparison of rankings; assessment of adequacy in the context of norms for the test conducted)*:
not applicable

2c. Disparities in Care: H☐ M☐ L☐ I ☐ NA☐ (*If applicable, the measure specifications allow identification of disparities.*)

2c.1 If measure is stratified for disparities, provide stratified results *(Scores by stratified categories/cohorts)*: not applicable

2c.2 If disparities have been reported/identified (e.g., in 1b), but measure is not specified to detect disparities, please explain:
not applicable

2.1-2.3 Supplemental Testing Methodology Information:
Attachment
Teno Jama Mortality Followback Survey.pdf

Steering Committee: Overall, was the criterion, *Scientific Acceptability of Measure Properties*, met?
(*Reliability and Validity must be rated moderate or high*) Yes☐ No☐
Provide rationale based on specific subcriteria:

If the Committee votes No, STOP

3. USABILITY

Extent to which intended audiences (e.g., consumers, purchasers, providers, policy makers) can understand the results of the measure and are likely to find them useful for decision making. (**evaluation criteria**)

C.1 Intended Purpose/ Use *(Check all the purposes and/or uses for which the measure is intended)*:   Public Reporting, Quality Improvement (Internal to the specific organization), Quality Improvement with Benchmarking (external benchmarking to multiple organizations)

3.1 Current Use *(Check all that apply; for any that are checked, provide the specific program information in the following*

questions): Not in use

3a. Usefulness for Public Reporting: H☐ M☐ L☐ I☐
(*The measure is meaningful, understandable and useful for public reporting.*)

3a.1. **Use in Public Reporting - disclosure of performance results to the public at large** *(If used in a public reporting program, provide name of program(s), locations, Web page URL(s)).* If not publicly reported in a national or community program, state the reason AND plans to achieve public reporting, potential reporting programs or commitments, and timeline, e.g., within 3 years of endorsement: [*For Maintenance – If not publicly reported, describe progress made toward achieving disclosure of performance results to the public at large and expected date for public reporting; provide rationale why continued endorsement should be considered.*]
The CARE survey is not currently used in public reporting. Parts of the FEHC is used in public reporting in Florida and project by the American Hospice Foundation.

3a.2. **Provide a rationale for why the measure performance results are meaningful, understandable, and useful for public reporting.** If usefulness was demonstrated (e.g., focus group, cognitive testing), describe the data, method, and results: No data is available for the CARE survey.
The American Hospice Foundation and Dr. Shoshana Sofaer have conducted focus groups regarding the development of the hospice report card. Based on brief email exchange with Dr. Sofaer, she stated they had conducted extensive multi-round cognitive testing on the report – in regards to the labels, navigation, and the drill downs regarding the data collection and composite items.

3.2 **Use for other Accountability Functions (payment, certification, accreditation).** If used in a public accountability program, provide name of program(s), locations, Web page URL(s): The CARE survey has not been used in this capacity.

3b. **Usefulness for Quality Improvement: H☐ M☐ L☐ I☐**
(*The measure is meaningful, understandable and useful for quality improvement.*)

3b.1. **Use in QI.** If used in quality improvement program, provide name of program(s), locations, Web page URL(s):
[*For Maintenance – If not used for QI, indicate the reasons and describe progress toward using performance results for improvement*].
The CARE survey has not been used for QI, but the FEHC has been widely used by the NHPCO for QI. In planning the current revision of the FEHC, we held focus groups with 31 hospice quality managers. The majority stated the importance of the FEHC to their QI efforts. For example, one respondent stated "we use FEHC throughout our organization. It's the framework for our operation, our staffing, our quality program, it, it's the foundation -of what we do."

3b.2. **Provide rationale for why the measure performance results are meaningful, understandable, and useful for quality improvement.** If usefulness was demonstrated *(e.g., QI initiative),* describe the data, method and results:
The development of the survey emphasize face validity with involvement of experts and bedside clinicians who reviewed and commented on the survey. The evidence to support the CARE survey comes indirectly from the FEHC -- feedback from 31 quality managers who participated in focus groups about the FEHC provided evidence for the interpretability and understanding of the FEHC.

Overall, to what extent was the criterion, *Usability*, met? H☐ M☐ L☐ I☐
Provide rationale based on specific subcriteria:

4. FEASIBILITY

Extent to which the required data are readily available, retrievable without undue burden, and can be implemented for performance measurement. (**evaluation criteria**)

4a. **Data Generated as a Byproduct of Care Processes: H☐ M☐ L☐ I☐**

4a.1-2 **How are the data elements needed to compute measure scores generated?** *(Check all that apply).*
Data used in the measure are:
Other
Survey

4b. Electronic Sources: H☐ M☐ L☐ I☐

4b.1 Are the data elements needed for the measure as specified available electronically *(Elements that are needed to compute measure scores are in defined, computer-readable fields)*: No data elements are in electronic sources

4b.2 If ALL data elements are not from electronic sources, specify a credible, near-term path to electronic capture, OR provide a rationale for using other than electronic sources: This question is not applicable to survey.

4c. Susceptibility to Inaccuracies, Errors, or Unintended Consequences: H☐ M☐ L☐ I☐

4c.1 Identify susceptibility to inaccuracies, errors, or unintended consequences of the measurement identified during testing and/or operational use and strategies to prevent, minimize, or detect. If audited, provide results:
Based on the previous use of the survey, only 10 out of the 1586 persons interviewed had a very negative reaction to the interview. We have not observe unintended consequences. The entity administering the telephone survey must follow standard methods for the conduct of survey.

4d. Data Collection Strategy/Implementation: H☐ M☐ L☐ I☐

A.2 Please check if either of the following apply *(regarding proprietary measures)*:
4d.1 Describe what you have learned/modified as a result of testing and/or operational use of the measure regarding data collection, availability of data, missing data, timing and frequency of data collection, sampling, patient confidentiality, time and cost of data collection, other feasibility/implementation issues *(e.g., fees for use of proprietary measures)*:
The CARE survey has not had widespread use like the FEHC. The CARE survey has been used in two new research studies. They are listed below:

1.   Evaluation of the NH palliative care intervention to prevent terminal hospitalizations. Manuscript currently under review.
2.   Examination of the bereaved family member perceptions for NH residents with dementia that died with and without hospice services, in press JAGS.
There are no fees for the use of the survey.
As noted previously, there is online guide for the use of the survey as part of the Toolkit of Instrument to Measure End of Life Care that addresses issues of data collection, sampling, and confidentiality.
Based on our work in the development of the survey, The CARE survey and other issues were covered in national study of dying in the US. We found the following things that may be helpful to understand the burden of the measure.
1.   Only 10 out of the 1586 persons interviewed had a very negative reaction to the interview.
2.   For the smaller initial study of 156 respondents, we found the survey took on average 28.5 minutes (median 25.8 minutes, range 14-70 minutes) . Since that study, we have eliminated several questions (including those dropped and those questions added for the purpose of validity testing).

Overall, to what extent was the criterion, *Feasibility*, met? H☐ M☐ L☐ I☐
Provide rationale based on specific subcriteria:

OVERALL SUITABILITY FOR ENDORSEMENT

Does the measure meet all the NQF criteria for endorsement? Yes☐ No☐
Rationale:

If the Committee votes No, STOP.
If the Committee votes Yes, the final recommendation is contingent on comparison to related and competing measures.

---

5. COMPARISON TO RELATED AND COMPETING MEASURES

If a measure meets the above criteria and there are endorsed or new related measures (either the same measure focus or the same target population) or competing measures (both the same measure focus and the same target population), the measures are compared to address harmonization and/or selection of the best measure before a final recommendation is made.

5.1 If there are related measures *(either same measure focus or target population)* or competing measures *(both the same measure focus and same target population)*, list the NQF # and title of all related and/or competing measures:

5a. Harmonization
5a.1 If this measure has EITHER the same measure focus OR the same target population as [NQF-endorsed measure(s)]: Are the measure specifications completely harmonized?   **5a.2** If the measure specifications are not completely harmonized, identify the differences, rationale, and impact on interpretability and data collection burden:

5b. Competing Measure(s)
5b.1 If this measure has both the same measure focus and the same target population as NQF-endorsed measure(s): Describe why this measure is superior to competing measures *(e.g., a more valid or efficient way to measure quality);* OR provide a rationale for the additive value of endorsing an additional measure. *(Provide analyses when possible)*:   As stated previously, the CARE survey predates the FEHC survey. The FEHC survey has undergone modifications that make it the superior (self- administered, question wording better suited to the hospice environment, and widespread use and acceptance by the hospice industry) and preferred instrument for measurement of the quality of hospice care. Our goal in submission of the CARE survey is to be responsive to an unmet need as identified as part of the NPCRC Key Palliative Measures Bundle. The CARE survey can measure bereaved persons' perceptions of the quality of care across settings of care. Thus, CARE would be practical for use with innovative healthcare financing models, such as Accountable Care Organizations, or for managed care organizations and provider networks as a consistent and equivalent tool to examine the quality of end-of-life care for their enrollees across multiple care settings.

CONTACT INFORMATION

Co.1 **Measure Steward (Intellectual Property Owner):** Center for Gerontology and Health Care Research, 121 South Main Street, Providence, Rhode Island, 02912

Co.2 **Point of Contact:** Joan, Teno, MD, MS, joan_teno@brown.edu, 401-863-9627-

Co.3 **Measure Developer if different from Measure Steward:** Center for Gerontology and Health Care Research, 121 South Main Street, Providence, Rhode Island, 02912

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Co.5 **Submitter:** Joan, Teno, MD, MS, joan_teno@brown.edu, 401-863-9627-, Center for Gerontology and Health Care Research

Co.6 **Additional organizations that sponsored/participated in measure development:**
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Susan Egman-Levitan

FEHC Team at NHPCO
Dr. Carol Spence
Dr. David Casarett – in his role as consultant and subcontract to the revision grant.
Dr. Steve Connor (formerly at NHPCO, worked on the implementation of the FEHC)

Co.7 **Public Contact:** Joan, Teno, MD, MS, joan_teno@brown.edu, 401-863-9627-, Center for Gerontology and Health Care Research

ADDITIONAL INFORMATION

Workgroup/Expert Panel involved in measure development

Ad.1 Provide a list of sponsoring organizations and workgroup/panel members' names and organizations. Describe the members' role in measure development.

not applicable

Ad.2 If adapted, provide title of original measure, NQF # if endorsed, and measure steward. Briefly describe the reasons for adapting the original measure and any work with the original measure steward: not applicable

Measure Developer/Steward Updates and Ongoing Maintenance

Ad.3 Year the measure was first released:

Ad.4 Month and Year of most recent revision:

Ad.5 What is your frequency for review/update of this measure? Every year as art of the FEHC

Ad.6 When is the next scheduled review/update for this measure? 08, 2012

Ad.7 Copyright statement: The copyright holder is Brown University which make the instrument available for use free of charge with the provision it is not modified or sold.

Ad.8 Disclaimers:

Ad.9 Additional Information/Comments: Please note additional information has emailed because of difficulty of uploading files

Date of Submission (*MM/DD/YY*): 06/12/2011