



## Measure Information

This document contains the information submitted by measure developers/stewards, but is organized according to NQF's measure evaluation criteria and process. The item numbers refer to those in the submission form but may be in a slightly different order here. In general, the item numbers also reference the related criteria (e.g., item 1b.1 relates to subcriterion 1b).

### Brief Measure Information

**NQF #: 1632**

**Corresponding Measures:**

**De.2. Measure Title:** CARE - Consumer Assessments and Reports of End of Life

**Co.1.1. Measure Steward:** Center for Gerontology and Health Care Research

**De.3. 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.

We are asking NQF approval for a single composite derived from the survey items that is presented as single score that varies from 0 to 100. This score indicates an institution quality of care end of life care in the last week of life.

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.

<p>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.</p> <p>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.</p> <p>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.</p> <p><b>1b.1. Developer Rationale:</b> 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.</p>
<p><b>S.4. Numerator Statement:</b> The numerator of the total of bereaved family member reports of concerns with the quality of care in the last 2-7 days of life at that institutional setting. Respondent reports of concerns with the quality of care, their self-efficacy in basic tasks of caregiving, or unmet needs that indicate an opportunity to improved end of life care provided by either a nursing home, hospital, hospice, or home health agency.</p> <p><b>S.7. Denominator Statement:</b> Non-traumatic deaths and deaths from chronic progressive illnesses based on ICD 9/10 codes are included. A list will be provided as technical appendix to the proposed survey. Note the survey is for only persons that died with the following services or location of care: nursing home, hospital, hospice, or home health agency</p> <p><b>S.10. Denominator Exclusions:</b> We excluded deaths due to accidents, trauma, during surgery, lethal injection, acute overwhelming infections, and from complications of pregnancy. If there are more than 3 items missing, than a composite score will not be calculated.</p>
<p><b>De.1. Measure Type:</b> Outcome</p> <p><b>S.23. Data Source:</b> Other</p> <p><b>S.26. Level of Analysis:</b> Facility, Other, Population : Community, County or City, Population : Regional and State</p>
<p><b>IF Endorsement Maintenance – Original Endorsement Date:</b> Feb 14, 2012 <b>Most Recent Endorsement Date:</b> Feb 14, 2012</p>
<p><b>IF this measure is included in a composite, NQF Composite#/title:</b></p> <p><b>IF this measure is paired/grouped, NQF#/title:</b></p> <p><b>De.4. IF PAIRED/GROUPED, what is the reason this measure must be reported with other measures to appropriately interpret results?</b> 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 administered 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.</p>

<p><b>1. Evidence, Performance Gap, Priority – Importance to Measure and Report</b></p>
<p>Extent to which the specific measure focus is evidence-based, important to making significant gains in healthcare quality, and improving health outcomes for a specific high-priority (high-impact) aspect of healthcare where there is variation in or overall less-than-optimal performance. <b>Measures must be judged to meet all subcriteria to pass this criterion and be evaluated against the remaining criteria.</b></p>
<p><b>1a. Evidence to Support the Measure Focus – See attached Evidence Submission Form</b>  <a href="#">Template_MeasSubm_Evidence_2013-08-20.docx</a></p>
<p><b>1b. Performance Gap</b>          Demonstration of quality problems and opportunity for improvement, i.e., data demonstrating:</p> <ul style="list-style-type: none"> <li>considerable variation, or overall less-than-optimal performance, in the quality of care across providers; and/or</li> <li>disparities in care across population groups.</li> </ul> <p><b>1b.1. Briefly explain the rationale for this measure (e.g., the benefits or improvements in quality envisioned by use of this measure)</b>          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.</p>

**1b.2. Provide performance scores on the measure as specified (current and over time) at the specified level of analysis.** *(This is required for endorsement maintenance. Include mean, std dev, min, max, interquartile range, scores by decile. Describe the data source including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included).* This information also will be used to address the subcriterion on improvement (4b.1) under Usability and Use.

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. If no or limited performance data on the measure as specified is reported in 1b2, then provide a summary of data from the literature that indicates opportunity for improvement or overall less than optimal performance on the specific focus of measurement.**

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. Provide disparities data from the measure as specified (current and over time) by population group, e.g., by race/ethnicity, gender, age, insurance status, socioeconomic status, and/or disability.** *(This is required for endorsement maintenance. Describe the data source including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities include.)* This information also will be used to address the subcriterion on improvement (4b.1) under Usability and Use.

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. If no or limited data on disparities from the measure as specified is reported in 1b4, then provide a summary of data from the literature that addresses disparities in care on the specific focus of measurement. Include citations.**

#### **1c. High Priority** (previously referred to as High Impact)

The measure addresses:

- a specific national health goal/priority identified by DHHS or the National Priorities Partnership convened by NQF; OR
- a demonstrated high-priority (high-impact) aspect of healthcare (e.g., affects large numbers of patients and/or has a substantial impact for a smaller population; leading cause of morbidity/mortality; high resource use (current and/or future); severity of illness; and severity of patient/societal consequences of poor quality).

##### **1c.1. Demonstrated high priority aspect of healthcare**

Affects large numbers, Patient/societal consequences of poor quality

##### **1c.2. If Other:**

**1c.3. Provide epidemiologic or resource use data that demonstrates the measure addresses a high priority aspect of healthcare. List citations in 1c.4.**

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 Set<sup>2</sup>, 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)

**1c.4. Citations for data demonstrating high priority provided 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.

**1c.5. If a PRO-PM (e.g. HRQoL/functional status, symptom/burden, experience with care, health-related behaviors), provide evidence that the target population values the measured PRO and finds it meaningful. (Describe how and from whom their input was obtained.)**

We have conducted extensive focus group testing of the conceptual model that is summarized in a paper by Teno and colleagues in JPSM.

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. Reliability and Validity—Scientific Acceptability of Measure Properties

Extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of care when implemented. **Measures must be judged to meet the subcriteria for both reliability and validity to pass this criterion and be evaluated against the remaining criteria.**

**2a.1. Specifications** The measure is well defined and precisely specified so it can be implemented consistently within and across organizations and allows for comparability. eMeasures should be specified in the Health Quality Measures Format (HQMF) and the Quality Data Model (QDM).

**De.5. Subject/Topic Area** (check all the areas that apply):

Palliative Care and End-of-Life Care

**De.6. Non-Condition Specific** (check all the areas that apply):

**S.1. Measure-specific Web Page** (Provide a URL link to a web page specific for this measure that contains current detailed specifications including code lists, risk model details, and supplemental materials. Do not enter a URL linking to a home page or to

general information.)

**S.2a. If this is an eMeasure**, HQMF specifications must be attached. Attach the zipped output from the eMeasure authoring tool (MAT) - if the MAT was not used, contact staff. (Use the specification fields in this online form for the plain-language description of the specifications)

**This is not an eMeasure Attachment:**

**S.2b. Data Dictionary, Code Table, or Value Sets** (and risk model codes and coefficients when applicable) must be attached. (Excel or csv file in the suggested format preferred - if not, contact staff)

**No data dictionary Attachment:**

**S.3. For endorsement maintenance**, please briefly describe any changes to the measure specifications since last endorsement date and explain the reasons.

No changes made. We report that the National Health and Aging Trends study is using key items from the composite that has allowed us to examine the change in the quality of end of life care between 2000 and 2011/12.

**S.4. Numerator Statement** (Brief, narrative description of the measure focus or what is being measured about the target population, i.e., cases from the target population with the target process, condition, event, or outcome)

IF an OUTCOME MEASURE, state the outcome being measured. Calculation of the risk-adjusted outcome should be described in the calculation algorithm.

The numerator of the total of bereaved family member reports of concerns with the quality of care in the last 2-7 days of life at that institutional setting. 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.

**S.5. Time Period for Data** (What is the time period in which data will be aggregated for the measure, e.g., 12 mo, 3 years, look back to August for flu vaccination? Note if there are different time periods for the numerator and denominator.)

Depending on the size of the health care system, we recommend that a sufficient sample of deaths ( $\geq 100$ ) be done. As noted, the respondent is asked about the quality of care in the last 2-7 days of life that the decedent was that institutional setting.

**S.6. 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, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b)

IF an OUTCOME MEASURE, describe how the observed outcome is identified/counted. Calculation of the risk-adjusted outcome should be described in the calculation algorithm.

Detailed information is provided below.

**S.7. 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

**S.8. Target Population Category** (Check all the populations for which the measure is specified and tested if any):

Elderly

**S.9. Denominator Details** (All information required to identify and calculate the target population/denominator such as definitions, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b)

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](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.

**S.10. 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. If there are more than 3 items missing, than a composite score will not be calculated.

**S.11. Denominator Exclusion Details** (All information required to identify and calculate exclusions from the denominator such as definitions, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b)

See answer to S.9

**S.12. Stratification Details/Variables** (All information required to stratify the measure results including the stratification variables, definitions, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format with at S.2b)

There is no proposed stratification variable

**S.13. Risk Adjustment Type** (Select type. Provide specifications for risk stratification in S.12 and for statistical model in S.14-15)

No risk adjustment or risk stratification

If other:

**S.14. Identify the statistical risk model method and variables** (Name the statistical method - e.g., logistic regression and list all the risk factor variables. Note - risk model development and testing should be addressed with measure testing under Scientific Acceptability)

**S.15. Detailed risk model specifications** (must be in attached data dictionary/code list Excel or csv file. Also indicate if available at measure-specific URL identified in S.1.)

Note: Risk model details (including coefficients, equations, codes with descriptors, definitions), should be provided on a separate worksheet in the suggested format in the Excel or csv file with data dictionary/code lists at S.2b.

**S.15a. Detailed risk model specifications** (if not provided in excel or csv file at S.2b)

**S.16. Type of score:**

Other (specify):

If other: Composite score is a number expressed as percent, ranging from 0 to 100.

**S.17. 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 = Higher score

**S.18. 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
```

**S.19. Calculation Algorithm/Measure Logic Diagram URL or Attachment** (You also may provide a diagram of the Calculation Algorithm/Measure Logic described above at measure-specific Web page URL identified in S.1 OR in attached appendix at A.1)  
No diagram provided

**S.20. Sampling** (If measure is based on a sample, provide instructions for obtaining the sample and guidance on minimum sample size.)

IF a PRO-PM, identify whether (and how) proxy responses are allowed.

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.

**S.21. Survey/Patient-reported data** (If measure is based on a survey, provide instructions for conducting the survey and guidance on minimum response rate.)

IF a PRO-PM, specify calculation of response rates to be reported with performance measure results.

Response rates are calculated by dividing number of surveys returned over the number of surveys mailed.

**S.22. Missing data** (specify how missing data are handled, e.g., imputation, delete case.)

Required for Composites and PRO-PMs.

Composite scores are not calculated if 3 survey items are missing.

**S.23. Data Source** (Check ONLY the sources for which the measure is SPECIFIED AND TESTED).

If other, please describe in S.24.

Other

**S.24. Data Source or Collection Instrument** (Identify the specific data source/data collection instrument e.g. name of database, clinical registry, collection instrument, etc.)

If a PRO-PM, identify the specific PROM(s); and standard methods, modes, and languages of administration.

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.

**S.25. Data Source or Collection Instrument** (available at measure-specific Web page URL identified in S.1 OR in attached appendix at A.1)

Available in attached appendix at A.1

**S.26. Level of Analysis** (Check ONLY the levels of analysis for which the measure is SPECIFIED AND TESTED)

Facility, Other, Population : Community, County or City, Population : Regional and State

**S.27. Care Setting** (Check ONLY the settings for which the measure is SPECIFIED AND TESTED)

Home Care, Inpatient/Hospital, Post-Acute Care

If other:

**S.28. COMPOSITE Performance Measure** - Additional Specifications (Use this section as needed for aggregation and weighting rules, or calculation of individual performance measures if not individually endorsed.)

See specifications above.

**2a. Reliability** – See attached Measure Testing Submission Form

**2b. Validity** – See attached Measure Testing Submission Form

Teno\_Jama\_Mortality\_Followback\_Survey.pdf,NQF\_1632\_Meassubm\_meastesting.docx

### 3. Feasibility

Extent to which the specifications including measure logic, require data that are readily available or could be captured without undue burden and can be implemented for performance measurement.

#### 3a. Byproduct of Care Processes

For clinical measures, the required data elements are routinely generated and used during care delivery (e.g., blood pressure, lab test, diagnosis, medication order).

##### 3a.1. Data Elements Generated as Byproduct of Care Processes.

Other

If other: Survey

#### 3b. Electronic Sources

The required data elements are available in electronic health records or other electronic sources. If the required data are not in electronic health records or existing electronic sources, a credible, near-term path to electronic collection is specified.

**3b.1. To what extent are the specified data elements available electronically in defined fields?** (i.e., data elements that are needed to compute the performance measure score are in defined, computer-readable fields)

No data elements are in defined fields in electronic sources

**3b.2. If ALL the data elements needed to compute the performance measure score 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.

**3b.3. If this is an eMeasure, provide a summary of the feasibility assessment in an attached file or make available at a measure-specific URL.**

**Attachment:**

### 3c. Data Collection Strategy

Demonstration that the data collection strategy (e.g., source, timing, frequency, sampling, patient confidentiality, costs associated with fees/licensing of proprietary measures) can be implemented (e.g., already in operational use, or testing demonstrates that it is ready to put into operational use). For eMeasures, a feasibility assessment addresses the data elements and measure logic and demonstrates the eMeasure can be implemented or feasibility concerns can be adequately addressed.

**3c.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.**

**IF a PRO-PM, consider implications for both individuals providing PROM data (patients, service recipients, respondents) and those whose performance is being measured.**

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).

**3c.2. Describe any fees, licensing, or other requirements to use any aspect of the measure as specified (e.g., value/code set, risk model, programming code, algorithm).**

None

## 4. Usability and Use

Extent to which potential audiences (e.g., consumers, purchasers, providers, policy makers) are using or could use performance results for both accountability and performance improvement to achieve the goal of high-quality, efficient healthcare for individuals or populations.

### 4a. Accountability and Transparency

Performance results are used in at least one accountability application within three years after initial endorsement and are publicly reported within six years after initial endorsement (or the data on performance results are available). If not in use at the time of initial endorsement, then a credible plan for implementation within the specified timeframes is provided.

#### 4.1. Current and Planned Use

*NQF-endorsed measures are expected to be used in at least one accountability application within 3 years and publicly reported within 6 years of initial endorsement in addition to performance improvement.*

Planned	Current Use (for current use provide URL)
Quality Improvement (Internal to the specific organization)	

Not in use

**4a.1. For each CURRENT use, checked above, provide:**

- Name of program and sponsor
- Purpose
- Geographic area and number and percentage of accountable entities and patients included

Not applicable

**4a.2. If not currently publicly reported OR used in at least one other accountability application (e.g., payment program, certification, licensing) what are the reasons?** (e.g., Do policies or actions of the developer/steward or accountable entities restrict access to performance results or impede implementation?)

**4a.3. If not currently publicly reported OR used in at least one other accountability application, provide a credible plan for implementation within the expected timeframes -- any accountability application within 3 years and publicly reported within 6 years of initial endorsement.** (Credible plan includes the specific program, purpose, intended audience, and timeline for implementing the measure within the specified timeframes. A plan for accountability applications addresses mechanisms for data aggregation and reporting.)

**4b. Improvement**

Progress toward achieving the goal of high-quality, efficient healthcare for individuals or populations is demonstrated. If not in use for performance improvement at the time of initial endorsement, then a credible rationale describes how the performance results could be used to further the goal of high-quality, efficient healthcare for individuals or populations.

**4b.1. Progress on Improvement. (Not required for initial endorsement unless available.)**

Performance results on this measure (current and over time) should be provided in 1b.2 and 1b.4. Discuss:

- Progress (trends in performance results, number and percentage of people receiving high-quality healthcare)
- Geographic area and number and percentage of accountable entities and patients included

**4b.2. If no improvement was demonstrated, what are the reasons? If not in use for performance improvement at the time of initial endorsement, provide a credible rationale that describes how the performance results could be used to further the goal of high-quality, efficient healthcare for individuals or populations.**

**4c. Unintended Consequences**

The benefits of the performance measure in facilitating progress toward achieving high-quality, efficient healthcare for individuals or populations outweigh evidence of unintended negative consequences to individuals or populations (if such evidence exists).

**4c.1. Were any unintended negative consequences to individuals or populations identified during testing; OR has evidence of unintended negative consequences to individuals or populations been reported since implementation? If so, identify the negative unintended consequences and describe how benefits outweigh them or actions taken to mitigate them.**

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.

**5. Comparison to Related or 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.

**5. Relation to Other NQF-endorsed Measures**

Are there related measures (conceptually, either same measure focus or target population) or competing measures (conceptually

both the same measure focus and same target population)? If yes, list the NQF # and title of all related and/or competing measures.

NoNo

**5.1a. List of related or competing measures (selected from NQF-endorsed measures)**

**5.1b. If related or competing measures are not NQF endorsed please indicate measure title and steward.**

**5a. Harmonization**

The measure specifications are harmonized with related measures;

**OR**

The differences in specifications are justified

**5a.1. If this measure conceptually addresses EITHER the same measure focus OR the same target population as NQF-endorsed measure(s):**

**Are the measure specifications completely harmonized?**

NoNo

**5a.2. If the measure specifications are not completely harmonized, identify the differences, rationale, and impact on interpretability and data collection burden.**

**5b. Competing Measures**

The measure is superior to competing measures (e.g., is a more valid or efficient way to measure);

**OR**

Multiple measures are justified.

**5b.1. If this measure conceptually addresses 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.

**Appendix**

**A.1 Supplemental materials may be provided in an appendix.** All supplemental materials (such as data collection instrument or methodology reports) should be organized in one file with a table of contents or bookmarks. If material pertains to a specific submission form number, that should be indicated. Requested information should be provided in the submission form and required attachments. There is no guarantee that supplemental materials will be reviewed.

**Attachment:**

**Contact Information**

**Co.1 Measure Steward (Intellectual Property Owner):** Center for Gerontology and Health Care Research

**Co.2 Point of Contact:** Joan, Teno, joan\_teno@brown.edu, 401-863-9627-

**Co.3 Measure Developer if different from Measure Steward:** Center for Gerontology and Health Care Research

**Co.4 Point of Contact:** Joan, Teno, joan\_teno@brown.edu, 401-863-9627-

Additional Information
<b>Ad.1 Workgroup/Expert Panel involved in measure development</b> Provide a list of sponsoring organizations and workgroup/panel members' names and organizations. Describe the members' role in measure development. not applicable
<b>Measure Developer/Steward Updates and Ongoing Maintenance</b> <b>Ad.2</b> Year the measure was first released: 2012 <b>Ad.3</b> Month and Year of most recent revision: 08, 2012 <b>Ad.4</b> What is your frequency for review/update of this measure? Every year as part of the FEHC <b>Ad.5</b> When is the next scheduled review/update for this measure? 08, 2015
<b>Ad.6 Copyright statement:</b> 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. <b>Ad.7 Disclaimers:</b>
<b>Ad.8 Additional Information/Comments:</b>