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 #: 1623 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: Bereaved Family Survey

Co.1 Measure Steward: PROMISE Center | 3800 Woodland Avenue, Building 4100 | Philadelphia | Pennsylvania | 19104

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

Seventeen items in the survey have predefined response options and ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support. Two additional items are open-ended and give family members the opportunity to provide comments regarding the care the patient received.

A growing body of research has underscored the degree to which end-of-life care in the United States needs to be improved. The challenges of end-of-life care are particularly significant in the U.S. Department of Veterans Affairs Health Care system because he VA provides care for an increasingly older population with multiple comorbid conditions. In FY2000, approximately 104,000 enrolled Veterans died in the U.S., and approximately 27,200 Veterans died in VA facilities. At least 30% of the Veterans are over age 65 now, and 46% will be over 65 by 2030. Therefore, it is clear that the number of deaths in VA facilities will increase substantially as the World War II and Korean War Veterans age. These demographic trends mean that, like other healthcare systems, the VA will face substantial challenges of providing care to Veterans near the end-of-life.

The VA has addressed this challenge aggressively in the last 5 year, however the VA has not yet developed and implemented measures of the quality of end-of-life care it provides to Veterans. There are at least 3 reasons why adoption of a quality measurement tool is essential. First, it would make it possible to define and compare the quality of end-of-life care at each VA facility and to identify opportunities for improvement. Second, facilities and VISNs (geographic service divisions within the VA system) would be able to monitor the effectiveness of efforts to improve care locally and nationally, and would enable monitoring of the impact of the Comprehensive End of Life Care Initiative, ensuring that expenditures are producing improvements in care. Third, it will help the VA to recognize those facilities that provide outstanding end-of-life care, so that successful processes and structures of care can be identified and disseminated throughout the VA.

The BFS´s 17 close-ended items ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support, pain management and personal care needs. Two addditional items (not used in scoring) are open-ended and give family members the opportunity to provide comments regarding the care the patient received. The BFS has undergone extensive development and has been pilottested for all inpatient deaths in Q4FY2008 in seven VISNs (1,2,4,5,8,11, and 22). As of October 1, 2009, Q1FY2010, all inpatient deaths in all VISNs were included in the project.

2a1.1 Numerator Statement: The numerator is comprised of completed surveys (at least 12 of 17 structured items completed), where the global item question has an optimal response. The global item question asks "Overall, how would your rate the care that [Veteran] received in the last month of life" and the possible answer choices are: Excellent, Very good, Good, Fair, or Poor. The optimal response is Excellent.

2a1.4 Denominator Statement: The denominator consists of all inpatient deaths for which a survey was completed (at least 12 of 17 structured items completed), excluding: 1) deaths within 24 hours of admission (unless the Veteran had a previous

hospitalization in the last month of life); 2) deaths that occur in the Emergency Department; 3) deaths that occur in the operating room; and 4) deaths due to suicide or accidents. Additional exclusion criteria include: 1) Veterans for whom a family member knowledgeable about their care cannot be identified (determined by the family member's report); or contacted (no current contacts listed or no valid addresses on file); 2) absence of a working telephone available to the family member.

2a1.8 Denominator Exclusions: - Veterans for whom a family member knowledgeable about their care cannot be identified (determined by family member's report)

- Absence of a current address and/or working telephone number for a family member or emergency contact.
- Deaths within in 24 hours of admission without a prior hospitalization of last least 24 hours in the last 31 days of life.
- Deaths that occur in the operating room during an outpatient procedure.
- Deaths due to a suicide or accident
- Surveys in which less than 12 items were answered.

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- 1.1 Measure Type: Outcome 2a1. 25-26 Data Source: Other
- 2a1.33 Level of Analysis: Facility, 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): N/A

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 (<i>check De.5</i>): 5. Similar/related endorsed or submitted measures (<i>check 5.1</i>): Other Criteria:
Staff Reviewer Name(s):
1. IMPACT, OPPORTUITY, 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 C I C I C I C I C I C I C I C I C I
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 (<i>Provide epidemiologic or resource use data</i>): The challenges of end-of-life care are particularly significant for the U.S. Department for Veterans Affairs (VA) health care system

because the VA provides care for an increasingly older population with multiple comorbidities. In FY 2000, approximately 104,000 enrolled Veterans died in the U.S., and approximately 27,200 Veterans died in VA facilities. At least 30% of Veterans are over age 65 now, and 46% will be over 65 by 2030. Therefore, it is clear that the number of deaths in VA facilities will increase substantially as the World War II and Korean War Veterans age. These demographic trends mean that, like other healthcare systems, the VA

will face substantial challenges of providing care to Veterans near the end-of-life.
1a.4 Citations for Evidence of High Impact cited in 1a.3: 1) VetPop 2001. Vol. 2002: Office of the Actuary Assistant Secretary for Policy & Planning Department of Veterans Affairs; 2002. 2) Hallenbeck J., Building or expanding palliative care programs in the Department of Veterans Affairs Healthcare system.
www.va.gov/oaa (accessed Auguust 9, 2008)
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: Possible improvements include improving the care provided to Veterans at end-of-life.
1b.2 Summary of Data Demonstrating Performance Gap (Variation or overall less than optimal performance across providers): [For <u>Maintenance</u> – Descriptive statistics for performance results <u>for this measure</u> - distribution of scores for measured entities by quartile/decile, mean, median, SD, min, max, etc.]
The VA has not yet developed and implemented extensive national measures of hte quality of end-of-life care it provides to Veterans. There are at least 3 reasons why this is essential. First, a system-wide quality measurement strategy would make it possible to define and compare the quality of end-of-life care at each facility and to identify opportunities for improvement. Second, facilities and VISNs would be able to monitor the effectiveness of efforts to improve care locally and nationally. Third, a system-wide measurement strategy will help the VA to recognize facilities that provide outstanding end-of-life care, so that successful processes and structures of care can be identified and disseminated throughout the VA.
1b.3 Citations for Data on Performance Gap: [For <u>Maintenance</u> – 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 Edes, T., Shreve, S., Casarett, D. Increasing access and quality in Department of Veterans Affairs care at the end-of-life: A lesson in change. Journal of the American Geriatrics Society. 2007;55:1645-49.
1b.4 Summary of Data on Disparities by Population Group: [For <u>Maintenance</u> –Descriptive statistics for performance results for this measure by population group]
Preliminary analysis on pilot data has shown that there appears to be large racial disparities in families' perceptions of the quality of end-of-life care that Veterans receive. Despite widespread progress in enhancing access to the palliative care services, these services do not appear to have been effective in reducing racial disparities in care. In addition, Veterans without family or family involvement in care appear to receive more aggressive treatment near the end of life, and are less likely to receive interventions, such as palliative care consults, that are consistent with high-quality end of life care.
In bivariate analysis, patients who received a consultation
had significantly higher FATE scores than those who did not (64 vs 54; rank sum test Po.001). In a multivariable model
that included consultation and the propensity score, ethnicity
(white vs nonwhite) (b50.053; P5.01) and older
age (b50.02; P5.001) were independently associated with
higher FATE scores, so these variables were included in this
and all subsequent models. Patients receiving a consultation had higher FATE scores after adjusting for the propensity
score, age, and ethnicity (65, 95% CI562–66 vs 54, 95%
CI551–56) (Table 2). This effect was significant for patients
who died in the institution served by the palliative
consultation team (n5311; adjusted mean 65, 95%
CI562–68 vs 56, 95% CI551–61; Po.001) and for those who died in other settings (n5213; adjusted mean
61, 95% CI557–65 vs 51, 95% CI547–54; Po.001).
Patients who received a palliative consultation had significantly
higher scores for five of the six domains: information
and communication (Po.001), access to home care
services (P5.007), emotional and spiritual support

			NQF #1623 Be	ereaved Family Survey		
around the higher sco family afte (P5.07) (T of palliativ facility ser mean 67 v	e time of dones for been the paties fable 2). Some consultance by the last 55; P5.0	eath (Po.001) (nefits and servent had died was cores for this detions for patient e consultation to 1047) but not for	5.001), and care (Table 2). A trend toward ices provided to the is not significant omain showed a benefit its who died in the eam (b50.10; adjusted those who died in other 3 vs 45; P5.75).			
reported ii included] Casarett [quality implement of the content	Casarett DJ, Pickard AP, Bailey FA, et al. Important aspects of end-of-life care for veterans: Implications for measurement and quality improvement. Journal of Pain & Symptom Management. 2008;35:115-125. 3. Casarett DJ, Pickard AP, Bailey FA, et al. A nationwide VA palliative care quality measure: the family assessment of treatment at the end of life. Journal of Palliative Medicine. 2008;11:68-75. 4. Casarett DJ, Pickard AP, Bailey FA, et al. Do palliative care consultations improve patient outcomes? Journal of the American Geriatric Society. 2008;56:593-99. 5. Alici Y, Lu H, Smith D, et al. Incidence and severity of PTSD-related symptoms among veterans near the end of life. Under review, Journal of Palliative Medicine.					
	asure foc	us a health ou	health outcome OR meets tcome? Yes☐ No☐ Quality: H☐ M☐ L☐	the criteria for quantity, quality, consistency of the body of evidence.) If not a health outcome, rate the body of evidence. Consistency: H M L I		
Quantity	Quality	Consistency	Does the measure pass	-		
M-H	M-H	M-H	Yes			
L	M-H	M		rch unlikely to change conclusion that benefits to patients outweigh		
М-Н	L	M-H	Yes IF potential benefit	s to patients clearly outweigh potential harms; otherwise No		
L-M-H	L-M-H	L	No 🗌			
Health ou	tcome – ra	tionale support	s relationship to at least	Does the measure pass subcriterion1c?		

one healthcare structure, process, intervention, or service

Yes IF rationale supports relationship

1c.1 Structure-Process-Outcome Relationship (Briefly state the measure focus, e.g., health outcome, intermediate clinical

intermediate clinical outcome-health outcome): Does not apply to this measure

- 1c.2-3 Type of Evidence (Check all that apply): Other Cohort study
- 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):

outcome, process, structure; then identify the appropriate links, e.g., structure-process-health outcome; process- health outcome;

Because the BFS was designed to assess the impact of quality improvement activities that often target a single aspect of care, the discriminant validity of selected items was examined. In this analysis, logistic regression models were used to focus on items for which data could easily be extracted from the medical record about processes of care that should be associated with an item's score. Associations were found between processes of care and BFS items. For instance, families for whom at least one chaplain visit was documented were more likely to report that they received spiritual support.

1c.5 Quantity of Studies in the Body of Evidence (Total number of studies, not articles): 1

Finlay E, Shreve S, Casarett D. Nationwide veterans affairs quality measure for cancer: the Family Assessment of Treatment at End-of-life. Journal of Clinical Oncology. 2008;26:3838-44.

2. Casarett DJ, Pickard AP, Bailey FA, et al. Important aspects of

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):

Study flaws - the study is conducted in a VA population, whose demographic characteristics are atypical of the larger U.S. population. Additionally, the study relies on families´ perceptions of care rather than on direct assessments of perceptions. However, retrospective surveys of family members have several advantages over patient assessments. For instance retrospective surveys can assess the

care of patients whose prognosis is uncertain and who therefore might not be prospectively identified as "terminally ill." They also make it possible to examine the care of patients who are unable to respond to surveys or questionnaires,

which is important because cognitive impairment is

present in at least 50% of inpatients in the last weeks of

present in at least 50% of inpatients in the last weeks of

life.27 Retrospective surveys can also provide insights into

the care that was delivered at the time of death, when prospective

data collection from patients or families may be

unacceptably intrusive. These surveys offer the only way to

assess the care that is provided to the family after a patient's death.

- 1c.7 Consistency of Results across Studies (Summarize the consistency of the magnitude and direction of the effect): n/a
- 1c.8 **Net Benefit** (*Provide* estimates of effect for benefit/outcome; identify harms addressed and estimates of effect; and net benefit over harms):

n/a

- 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:
- 1c.11 System Used for Grading the Body of Evidence: Other
- 1c.12 If other, identify and describe the grading scale with definitions: n/a
- 1c.13 Grade Assigned to the Body of Evidence:
- 1c.14 Summary of Controversy/Contradictory Evidence:
- 1c.15 Citations for Evidence other than Guidelines (Guidelines addressed below):

Casarett D, Shreve S, Luhrs C, Lorenz K, Smith D, De Sousa M, Richardson, D. "Measuring families' perceptions of care across a health care system: Preliminary experience with the Family Assessment of Treatment at End-of-Life Short Form (FATE-S)" Journal of Pain and Symptom Management 2010 (In Press)

1c.16 Quote verbatim, the specific quideline recommendation (Including quideline # and/or page #):

Guideline 7.1 Signs and symptoms of impending death are recognized and communicated in developmentally appropriate language for children and patients with cognitive disabilities with respect to family preferences. Care appropriate for this phase of illness is provided to patient and family.

1c.17 Clinical Practice Guideline Citation: National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. 2nd ed. Pittsburgh (PA): National Consensus Project for Quality Palliative Care; 2009. 80p.
1c.18 National Guideline Clearinghouse or other URL: http://www.guideline.gov/content.aspx?id=14423&search=palliative
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: n/a
1c.23 Grade Assigned to the Recommendation:
1c.24 Rationale for Using this Guideline Over Others: This guideline is most aligned with the VA's nationwide Comprehensive End of Life Care Initiative, which will dramatically increase Veterans' access to high quality en-of life care. This initiative includes funding for the development of palliative care programs and inpatient units, as well as a range of innovative training and outreach programs. The BFS assess the Initiative's impact on the care that facilities provide to Veterans and their families.
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: High 1c.26 Quality: High 1c.27 Consistency: Low
Was the threshold criterion, <i>Importance to Measure and Report</i> , 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
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> .
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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? Yes
Extent to which the measure, <u>as specified</u> , produces consistent (reliable) and credible (valid) results about the quality of care when implemented. (evaluation criteria) 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? Yes S.2 If yes, provide web page URL: www.cherp.research.va.gov/PROMISE.asp

The numerator is comprised of completed surveys (at least 12 of 17 structured items completed), where the global item question has an optimal response. The global item question asks "Overall, how would your rate the care that [Veteran] received in the last month of life" and the possible answer choices are: Excellent, Very good, Good, Fair, or Poor. The optimal response is Excellent.

population, e.g., cases from the target population with the target process, condition, event, or outcome):

- 2a1.2 Numerator Time Window (The time period in which the target process, condition, event, or outcome is eligible for inclusion): Does not apply to this measure
- 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: Included are those patients included in the denominator with completed surveys (at least 12 of 17 structured items completed) that receive an optimal response on the global item quesstion.
- 2a1.4 **Denominator Statement** (Brief, narrative description of the target population being measured):

The denominator consists of all inpatient deaths for which a survey was completed (at least 12 of 17 structured items completed), excluding: 1) deaths within 24 hours of admission (unless the Veteran had a previous hospitalization in the last month of life); 2) deaths that occur in the Emergency Department; 3) deaths that occur in the operating room; and 4) deaths due to suicide or accidents. Additional exclusion criteria include: 1) Veterans for whom a family member knowledgeable about their care cannot be identified (determined by the family member's report); or contacted (no current contacts listed or no valid addresses on file); 2) absence of a working telephone available to the family member.

- 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*): Oct 1, 2009 (Q1FY2010) TBD
- 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):

The indicator denominator is comprised of the number of Veterans who die in an inpatient VA facility (intensive care, acute care, hospice unit, nusing home care or community living center) for whom a survey is completed. Completed surveys are defined as those with at least 12 of the 17 structured items completed.

- 2a1.8 **Denominator Exclusions** (Brief narrative description of exclusions from the target population):
- Veterans for whom a family member knowledgeable about their care cannot be identified (determined by family member's report)
- Absence of a current address and/or working telephone number for a family member or emergency contact.
- Deaths within in 24 hours of admission without a prior hospitalization of last least 24 hours in the last 31 days of life.
- Deaths that occur in the operating room during an outpatient procedure.
- Deaths due to a suicide or accident
- Surveys in which less than 12 items were answered.
- 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):

Name, address, and phone number of patient's family member or emergency contact are required for determining exclusion. In addition, information regarding the patient's admission(s) during the last 31 days of life, including length of stay and circumstances of death are also required to determine exclusion.

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):

Variables necessary to stratify the measure are VISN, facility, quarter, year, outcome. VISN refers to "Veterans Integrated Service Network" and is a geographic area of the country where a facility is located. Facility is the actual VA medical center or affiliated community living center where the Veteran died. Quarter is the 3 month time period in which the patient died. Year is the VA fiscal year (runs from Oct 1 to Sept 30). Outcome refers to whether or not a survey was completed.

- 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.): N/A

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: Rate/proportion

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 = higher 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 17 structured items of the Bereaved Family Survey are scored as either "1" (optimal response) or "0" (all other answer choices). A score of "1" indicates that the family member perceived that the care they and/or the Veteran received was the best possible care (Always or Excellent). For instance, that Veteran's health care provider always communicated in a way that was understandable, or that the Veteran's pain was always controlled to a level that was comfortable in a way that was comfortable for him/her. As score of "0" reflects all other possible responses (Usually, Sometimes, or Never). Items are coded as missing if respondents cannot answer and as not applicable if they were not relevant to the patient (e.g. for the "pain" item, if a patient did not experience pain in the last month of life). Thus, the score for each item can be expressed as a fraction corresponding to the number of families who reported that the Veteran received optimal care (numerator), divided by the number of valid, non-missing responses for that item (denominator). Similarly, the score for the 17-item survey is calculated based on the global question item (Overall, how would you rate the care received in the last month of life? - Excellent, Very Good, Good, Fair, Poor). The global item is scored as the # of optimal responses/# of valid, non missing responses for all completed surveys (12 of 17 structured items answered). This scoring system produces a facility- or VISN-level score that reflects the proportion of Veterans who received the best possible care overall (BFS score) and in specific areas corresponding to BFS items (e.g. pain management, communication, personal care, etc).

2a1.21 – 23 Calculation Algorithm/Measure Logic Diagram URL or attachment: URL http://www.cherp.research.va.gov/PROMISE/PROMISE_Analysis_and_Scoring.asp

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):

All inpatient deaths identified through the VA Electronic Medical Records and provided at the VISN-level. Inpatient deaths are screened for inclusion/exclusion criteria (items 2a.9). Approximately 4 weeks after death, an introductory letter is sent to all the identified Next of Kin (NOK) of all eligible Veterans with a toll-free opt-out line. Approximately 6-10 weeks after death, three attempts are made by telephone to the identified NOK to complete the survey by telephone. After three failed attempts, a follow-up mail survey is sent to the identified NOK to complete and return.

NOKs are identified in the following order:

- 1) Official listing of Next of Kin (NOK)
- 2) Primary decision-maker as documented in a Social Work or other clinical note
- 3) Primary decision-maker as documented in an Advance Directive note (this would take precedence over #2 if the Advance Directive note is more recent)
- 4) Designated Durable Power of Attorney for Health Care

The survey may be administered during the initial contact telephone call, or at a later time, depending on the family member's preference and availability. Previous experience has shown that some family members will prefer to do the interview immediately, whereas others may prefer a different time or may simply want more time to collect their thoughts.

The survey should be administered in a single telephone call (introduction, consent, survey questions, and conclusion). Interviews are best done in a quiet place, with a minimum of background noise and freedom from interruptions. Wherever possible, doors should be closed and pagers or cell phones should be set to vibrate mode to avoid unnecessary distractions.

The following guidelines should be used when conducting the interviews:

Speak slowly and carefully. This is particularly important when the family member is an older adult, or when the family

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- Be prepared to stop and respond to requests for clarification of questions.
- Do not "write your own questions." When a family member is confused by a question, do not give your explanation of what the question means. While this is a very natural reaction, it means that you may influence the family's responses in subtle but important ways. You can repeat the question and gently ask that the family member answer to the best of his or her ability.
- Be prepared for families to exhibit signs of distress (eg, sadness, tearfulness) and even anger. This is a normal part of the interviewing process for many people, who still usually find the interview to be valuable.

Additional demographic data is collected using the VA's Electronic Record System.

A minimum sample size of 30 respondents is suggested to make comparisons between groups (facilities, VISNs).

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.): For 2a1.25 - Family reported data/survey.

For 2a1.26 - Bereaved Family Survey

2a1.27-29 Data Source/data Collection Instrument Reference Web Page URL or Attachment: URL http://www.cherp.research.va.gov/PROMISE/The_PROMISE_Survey.asp

2a1.30-32 Data Dictionary/Code Table Web Page URL or Attachment: URL http://www.cherp.research.va.gov/PROMISE/The PROMISE Survey.asp

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

2a1.34-35 Care Setting (Check all the settings for which the measure is specified and tested): Hospice, Post Acute/Long Term Care Facility: Nursing Home/Skilled Nursing Facility 122841

- 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):

Pilot testing was performed on 1,122 family members from inpatient deaths in 5 VISNS and 32 facilities.

2a2.2 Analytic Method (Describe method of reliability testing & rationale):

The BFS's domain structure was evaluated using measures of homogeneity (e.g., Cronbach) and exploratory factor analysis.

2a2.3 Testing Results (*Reliability statistics, assessment of adequacy in the context of norms for the test conducted*): The BFS gives a continuous score (possible range 0-100), reflecting the average of 17 dichotomous items, which is approximately normally distributed (mean 57, median 60, standard deviation 25; actual range 0-100). Only 5% of surveys had a score >90, indicating no ceiling effect. Cronbach's alpha for the survey was 0.81, indicating good homogeneity that is sufficient for betweengroup comparisons (e.g. comparisons among facilities).

2b. VALIDITY. Validity	r, Testing, including all Threats to Validity:	$H \square M \square L \square I \square$

- 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:
- 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):

Of 5513 patients who died in one of 51 participating VA facilities between July 2008 and March 2009, 274 were selected at random for exclusion to manage interviewer workload. An additional 684 were determined to be ineligible. (two patients committed suicide, 565 had missing or inaccurate contact information, and 94 died within 24 hours of admission. Two respondents did not speak

English or Spanish and 21 respondents had health conditions that made the interview impossible). Of the remaining patients (n=4555), 2359 family members completed a telephone survey (52% of those who were eligible) and 468 completed a mail survey.

2b2.2 Analytic Method (Describe method of validity testing and rationale; if face validity, describe systematic assessment):

Validity was examined in three ways. First, using a linear regression model, clustered by facility (e.g. 51 clusters) and weighted to account for nonresponse bias, to examine the association between the BFS score (based onall items except the global item) and the single-item global item. This five-point global rating has been widely used in other instruments and provides a test of criterion validity. The BFS score was strongly associated with the global rating. Significant associations were also present in logistic regression models between the global rating and each of the BFS item. next, different scores were looked at across facilities. The BFS score showed considerable variation among facilities. Bivariate regression was used to evaluate the discriminant validity of hte BFS by comparing scores among groups for which the quality of pallitive care would be expected to differ.

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):

The BFS score was strongly associated with the global rating ($\beta = 0.17$, 95% confidence interval [CI] = 0.16–0.17; P < 0.001). Significant associations were also present in logistic regression models between the global rating and each of the FATE-S items (P < 0.001 for all).

The BFS score showed considerable variation among facilities (unweighted range: 32–88; interquartile range: 58–67). The overall and interquartile ranges (unweighted) among long-term care facilities (32–88; 62–73, respectively) were slightly larger than those among acute care hospitals (46–77; 57–66).

Bivariate regression showed discriminant validity for the BFS. Patients who were seen by a palliative care consult service in the last month of life had significantly better BFS scores compared with those who did not (mean: 64 vs. 60; β = 0.04; 95% CI = 0.01, 0.06; P = 0.005). Similarly, patients who died in a hospice unit had higher scores compared with those who died in other settings (66 vs. 61; β = 0.06; 95% CI = 0.02, 0.09; P = 0.001), and those who died in an acute care ward had lower scores compared with those who died in other settings (58 vs. 65; β = -0.06; 95% CI: -0.09, -0.03; P < 0.001). Patients who died with a DNR order had higher scores than other patients (64 vs. 54; β = 0.10; 95% CI: 0.06, 0.14; P < 0.001). Patients also had better scores when a discussion about the patient's goals with a family member was documented (64 vs. 55; β = 0.10; 95% CI: 0.06, 0.13; P < 0.001).

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):

 n/a
- 2b3.2 Analytic Method (Describe type of analysis and rationale for examining exclusions, including exclusion related to patient preference):

n/a

- 2b3.3 **Results** (*Provide statistical results for analysis of exclusions, e.g., frequency, variability, sensitivity analyses*):
- **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):

 n/a
- 2b4.2 **Analytic Method** (Describe methods and rationale for development and testing of risk model or risk stratification including selection of factors/variables):

 n/a
- 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. <u>Risk stratification</u>: Provide quantitative assessment of relationship of risk factors to the outcome and differences in outcomes among the strata):

- 2b4.4 If outcome or resource use measure is not risk adjusted, provide rationale and analyses to justify lack of adjustment: n/a
- **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):
- Of 5513 patients who died in one of 51 participating VA facilities between July 2008 and March 2009, 274 were selected at random for exclusion to manage interviewer workload. An additional 684 were determined to be ineligible. (Two patients committed suicide, 565 had missing or inaccurate contact information, and 94 died within 24 hours of admission. Two respondents did not speak English or Spanish, and 21 respondents had health conditions that made the interview impossible.) Of the remaining patients (n = 4555), 2359 family members completed a telephone survey (52% of those who were eligible) and 468 completed a mail survey.
- 2b5.2 **Analytic Method** (Describe methods and rationale to identify statistically significant and practically/meaningfully differences in performance):
- BFS scores were calculated for all facilities. BFS scores are calculated as the number of optimal responses divided by the number of valid, non-missing responses. This scoring system produces a facility-level score that reflects the proportion of veterans who received the best possible care overall (BFS score) and in specific areas corresponding to BFS items (e.g. pain management, communication, personal care).
- 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):
- The BFS score showed considerable variation among facilities (unweighted range: 32–88; interquartile range: 58–67). The overall and interquartile ranges (unweighted) among long-term care facilities (32–88; 62–73, respectively) were slightly larger than those among acute care hospitals (46–77; 57–66).
- **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):

 n/a
- 2b6.2 **Analytic Method** (Describe methods and rationale for testing comparability of scores produced by the different data sources specified in the measure):

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):

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

n/a

n/a

2.1-2.3 Supplemental Testing Methodology Information:

Steering Committee: Overall, was the criterion, Scientific Acceptability of Measure Properties, met?

NGI #1023 beleaved Failing Sulvey
(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)
3.1 Current Use (Check all that apply; for any that are checked, provide the specific program information in the following questions): Public Reporting; Quality Improvement (Internal to the specific organization)
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.] n/a
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: The BFS is currently an optional Performance Measure as part of the VA's nationwide Comprehensive End of Life Care Initiative. This measure is most aligned with the VA's nationwide Comprehensive End-of-Life Care Initiative, which will dramatically increase Veterans' access to high quality end-of-life care. This initiative includes funding for the development of palliative care programs and inpatient units, as well as a range of innovative training and outreach programs. The BFS assess the Initiative's impact on the care that facilities provide to Veterans and their families.
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 data from the Bereaved Family Survey are also used to evaluate the added value of the Comprehensive End-of-Life Care Initiative (CELC). A majority of the funding by the CELC was to support the creation of inpatient units at every facility and to develop an active Hospice and Palliative care team to improve end-of-life care. In quarterly reports provided separately to VISNs and facilities, the data collected are stratified not only by VISN and facility, but also by venue of death (Acute care, community living centers (VA nursing homes) and inpatient hospice unites. Research supports that notion that patients dying with hospice and palliative care have higher levels of family satisfaction. Therefore the Bereaved Family Survey results are stratified by venue of death to identify if this indeed the case in facilities with established inpatient hospice units. These VISN and facility reports also provide scores for the remaining 16 structured items of the Bereaved Family Survey so that facilities can target specific processes of care that can result in increased overall satisfaction with care at the end-of-life. Those items are also scores as the proportion of optimal responses/all responses.
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 BFS is currently an optional Performance Measure as part of the VA's nationwide Comprehensive End of Life Care Initiative and the reporting can be found at: http://klfmenu.med.va.gov/products.asp?PgmArea=13

Data from the measure and reports are shared on a quarterly basis with the Office of Quality and Performance, VISNs (Veterans Integrated Service Network and Facilities).
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 data provided on a quarterly basis to the Office of Quality and Perfomance includes the global item question stratified by VISN and facility. The measure is evaluated on the VISN score (the proportion of optimal responses/all responses) although facility scores are also provided. Facility scores are provided for VISNs to identify which of their facilities are high or low performers. Using data from FY2010, an internal benchmark was set at 46% (20th percentile). VISNs performing below that benchmark are considering to be failing.
Overall, to what extent was the criterion, <i>Usability</i> , met? H M L I C I C 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: Coded by someone other than person obtaining original information (e.g., DRG, ICD-9 codes on claims); Abstracted from a record by someone other than person obtaining original information (e.g., chart abstraction for quality measure or registry)
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): Some 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:
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: The survey identifies areas for improvement in care within facilities in the VA. However, some facilities have a very small number of deaths and so caution should be taken when interpreting results since 'n's may be too small to identify significant findings.
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): Three key lessons have emerged from pilot testing in 32 facilities. First, procedures have been developed to permit an efficient and accurate identification of deaths. These include a system of checks to ensure that veterans are deceased, and that they are eligible. Second, we have refined contact procedures to maximize interviewer efficiency, thereby decreasing costs. Third, we have developed operating procedures for addressing unresolved issues that are identified during interviews. This allows interviewers to make rapid referrals to the appropriate VA resources to provide assistance to bereaved family members (e.g. for assistant with burial or funeral benefits).
Overall, to what extent was the criterion, <i>Feasibility</i> , met? H M L I C

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 <u>NQF-endorsed measure(s)</u>: 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*):

NQF 0208 Family Evaluation of Hospice Care

NQF 0308 LBP: Evaluation of Patient Experience

Although the Bereaved Family Survey is in many ways similar to the Family Evaluation of Hospice Care, it provides information on a specific population (Veterans) and measures the quality of care provided a single health care system. Unlike the FEHC, the BFS provides a coherent measurement strategy that allows comparisons across systems of care and sites of death in a single health care system. This measure is assesses the quality of care of the largest unified health care system in the United States and cares for more than 5 million patients annually. Because it is a unified health system, the VA is uniquely situated to make use of hte quality data that can be easily disseminated quickly. The BFS also measures satisfaction of care that are unique to a Veteran population (i.e, survivor and funeral benefits, PTSD). The popoulation of Veterans and families that the VA serves is unique in several key respects: 1) Veterans and their families may face different challenges at the end of life than non-Veterans do. The costs of hospitalization are less likely to be relevant to non-VA populations.

CONTACT INFORMATION

- Co.1 Measure Steward (Intellectual Property Owner): PROMISE Center | 3800 Woodland Avenue, Building 4100 | Philadelphia | Pennsylvania | 19104
- Co.2 Point of Contact: Hien | Lu, BA | hien.lu@va.gov | 215-823-5800-7932
- Co.3 Measure Developer if different from Measure Steward: PROMISE Center | 3800 Woodland Avenue, Building 4100 | Philadelphia | Pennsylvania, 19104
- Co.4 Point of Contact: Hien | Lu, BA | hien.lu@va.gov | 215-823-5800-7932
- Co. 5 Submitter: Hien | Lu, BA | hien.lu@va.gov | 215-823-5800-7932 | PROMISE Center
- Co.6 Additional organizations that sponsored/participated in measure development:
- Co.7 Public Contact: Hien | Lu, BA | hien.lu@va.gov | 215-823-5800-7932 | PROMISE Center

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.

An Expert panel review was used to refine item content and wording. The expert panel included: Therese Bernardo Cortez, RN MSN NP; Kimberly Kelley, LCSW; Carol Luhrs, MD; Paul Swerdlow, JD; Kathleen Bixby, BSN; Carla Anderson, MSN, RN; and Karyn Berlin, MSW

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:

Measure Developer/Steward Updates and Ongoing Maintenance

Ad.3 Year the measure was first released: 2008

Ad.4 Month and Year of most recent revision:

Ad.5 What is your frequency for review/update of this measure? 3 years

Ad.6 When is the next scheduled review/update for this measure? 12/2012

Ad.7 Copyright statement/disclaimers: This material is based upon work supported (or supported in part) by the Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development, HSR&D. Use or publication of any materials used in the Bereaved Family Survey is

Ad.8 Additional Information/Comments:

Date of Submission (MM/DD/YY): May 03, 2011