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# Memo

**November 17, 2020**

**To**: Consensus Standards Approval Committee (CSAC)

**From**: Geriatrics and Palliative Care Project Team

**Re**: Geriatrics and Palliative Care Fall 2019 Track 2 Measures[a]

## COVID-19 Updates

Considering the recent COVID-19 global pandemic, many organizations needed to focus their attention on the public health crisis. In order to provide greater flexibility for stakeholders and continue the important work in quality measurement, the National Quality Forum (NQF) extended commenting periods and adjusted measure endorsement timelines for the fall 2019 cycle.

Commenting periods for all measures evaluated in the fall 2019 cycle were extended from 30 days to 60 days. Based on the comments received during this 60-day extended commenting period, measures entered one of two tracks:

> **Track 1: Measures that Remained in Fall 2019 Cycle**
> **Measures that did not receive public comments or only received comments in support of the Standing Committees' recommendations** moved forward to the CSAC for review and discussion during its meeting on July 28-29, 2020.
>
> - **Exceptions**
>   Exceptions were granted to measures if non-supportive comments received during the extended post-comment period were similar to those received during the pre-evaluation meeting period and have already been adjudicated by the respective Standing Committees during the measure evaluation fall 2019 meetings.
>
> **Track 2: Measures Deferred to Spring 2020 Cycle**
> **Fall 2019 measures that required further action or discussion from a Standing Committee were deferred to the spring 2020 cycle.** This includes measures where consensus was not reached or those that require a response to public comments received. Measures undergoing maintenance review retained endorsement during that time. Track 2 measures will be reviewed by the CSAC in November.

During the CSAC meeting on November 17-18, 2020, the CSAC will review fall 2019 measures assigned to Track 2. Evaluation summaries for measures in Track 2 have been described in this memo and related Geriatrics and Palliative Care draft report. A list of measures assigned to Track 1 can be found in the

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[a] This memo is funded by the Centers for Medicare and Medicaid Services under contract HHSM-500-2017-00060I Task Order HHSM-500-T0001.

Executive Summary section of the Geriatrics and Palliative Care draft report for tracking purposes and can also be found in a separate report.

## CSAC Action Required

The CSAC will review recommendations from the Geriatrics and Palliative Care project at its November 17-18, 2020 meeting and vote on whether to uphold the recommendations from the Committee.

This memo includes a summary of the project, measure recommendations, and responses to the public and member comments and the results from the NQF member expression of support. The following documents accompany this memo:

1. **Geriatrics and Palliative Care Fall 2019 Track 2 Draft Report**. The draft report includes measure evaluation details on all measures that followed Track 2. The complete draft report and supplemental materials are available on the project webpage. Measures that followed Track 1 were reviewed during the CSAC's meeting in July.
2. **Comment Table**. This table lists one received during the post-meeting comment period.

## Background

Since 2006, when it first developed a measurement framework for palliative and end-of-life care, and endorsed 38 evidence-based preferred practices for high quality palliative care programs, NQF has endorsed more than 30 measures in this topic area, many of which currently are used in federal quality improvement and public reporting programs. In 2017, NQF expanded the scope of the Standing Committee charged with the oversight of NQF's portfolio of palliative and end-of-life care measures by adding measures specifically relevant to the geriatric population. This renamed "Geriatrics and Palliative Care Standing Committee" has the requisite expertise to evaluate and assume oversight of measures that focus on key issues specific to older adults.

## Draft Report

The Geriatrics and Palliative Care Fall 2019 Track 2 draft report presents the results of the evaluation of one measure considered under the Consensus Development Process (CDP). This measure is recommended for endorsement.

The measures were evaluated against the 2019 version of the measure evaluation criteria.

| | Maintenance | New | Total |
|---|---|---|---|
| Measures under consideration | 1 | 0 | 1 |
| Measures recommended for endorsement | 1 | 0 | 1 |

## CSAC Action Required

Pursuant to the CDP, the CSAC is asked to consider endorsement of one candidate consensus measures.

### Measures Recommended for Endorsement

- NQF 2651 CAHPS® Hospice Survey (experience with care) (Centers for Medicare and Medicaid Services)

Overall Suitability for Endorsement: Yes-18; No-0

## Comments and Their Disposition

NQF received one comment from one member organization pertaining to the draft report and to the measures under consideration.

A table of comments submitted during the comment period, with the NQF responses to each comment, is posted to the Geriatrics and Palliative Care project webpage.

### Comments Received and Committee Response

#### 2651: CAHPS® Hospice Survey (experience with care)

The commenter encouraged the measure developer to improve the specificity in the questionnaire with respect to person-centered care. The commenter suggested that communication may be too limiting a term to capture the dialogue that occurs between the healthcare team and the patient/proxy with respect to what matters most in hospice care. The commenter suggested that this recommendation can be done by using language that prioritizes the patient/caregiver, while minimizing the focus on academic person-centered care. The commenter provided a possible methodology to address this concern in the CAHPS Hospice Survey by: 1) identifying and empathizing what matters most, specific to the patient/primary caregiver; 2) distilling the priorities and care preferences into actionable healthcare activities; 3) communicating healthcare activities in a meaningful way; and 4) as illness progresses and changes in functional/cognitive/emotional status occur, priorities are reassessed, responded to, and clearly communicated. The commenter also noted that the measures should address the complexity of person-centered care for older adults with multiple chronic conditions and emphasized the need to develop appropriate patient reported outcome measures.

> **Measure Steward/Developer Response:** CMS thanks the American Geriatrics Society (AGS) for their thoughtful comments on the CAHPS Hospice Survey measures. In response to stakeholder feedback, CMS is currently drafting and preparing to field-test a revised version of the CAHPS Hospice Survey. CMS will be sure to consider AGS's suggestions when developing the revised content. Specifically, we will explore with a technical expert panel, and in patient interviews, survey items that assess the degree to which the team was able to communicate about what mattered most to the patient, and how care was tailored to meet patient preferences.
>
> As a reminder, the CAHPS Hospice Survey is administered to the informal caregiver of the hospice patient 2 to 3 months following the patient's death. This approach allows for assessment of care for all hospice decedents, including those who may not have been able to respond to a survey themselves during the course of hospice care due to the acuity of their illness or the speed of their decline.
>
> **Standing Committee Response:** The Committee supported and accepted the developer's response to the comment submitted by AGS.

## Member Expression of Support

Throughout the 16-week continuous public commenting period, NQF members had the opportunity to express their support ('support' or 'do not support') for each measure submitted for endorsement consideration to inform the Committee's recommendations. No NQF members provided their expression of support.

## Appendix A: CSAC Checklist

The table below lists the key considerations to inform the CSAC's review of the measures submitted for endorsement consideration.

| Key Consideration | Yes/No | Notes |
|---|---|---|
| Were there any process concerns raised during the CDP project? If so, briefly explain. | No | |
| Did the Standing Committee receive requests for reconsideration? If so, briefly explain. | No | |
| Did the Standing Committee overturn any of the Scientific Methods Panel's ratings of Scientific Acceptability? If so, state the measure and why the measure was overturned. | No | |
| If a recommended measure is a related and/or competing measure, was a rationale provided for the Standing Committee's recommendation? If not, briefly explain. | Yes | The committee stated that 1623 and 2651 are different measures with different populations. The Committee felt the differences between the VA and other health systems justified different measures. Committee members did identify areas, such as questions around supports, where the content of the questions could be more aligned, stating there is strong evidence around best-practices in these areas. |
| Were any measurement gap areas addressed? If so, identify the areas. | No | |
| Are there additional concerns that require CSAC discussion? If so, briefly explain. | No | |

# Appendix D: Details of Measure Evaluation

## 2651 CAHPS® Hospice Survey (experience with care)

Submission

**Description**: The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death.

The publicly reported measures described here include the following six multi-item measures.

- Hospice Team Communication
- Getting Timely Care
- Treating Family Member with Respect
- Getting Emotional and Religious Support
- Getting Help for Symptoms
- Getting Hospice Training

In addition, there are two global rating items that are publicly-reported measures.

- Rating of the hospice care
- Willingness to recommend the hospice

Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS surveys.

List of CAHPS Hospice Survey Measures

Multi-Item Measures

Hospice Team Communication (Composed of 6 items)

+ While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?

+ While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?

+ How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

+ While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?

+ While your family member was in hospice care, how often did the hospice team listen carefully to you?

+ While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

Getting Timely Care (Composed of 2 items)

+ While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?

+ How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

Treating Family Member with Respect (Composed of 2 items)

+ While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

+ While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

Providing Emotional Support (Composed of 3 items)

+ While your family member was in hospice care, how much emotional support did you get from the hospice team?

+ In the weeks after your family member died, how much emotional support did you get from the hospice team?

+ Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

Getting Help for Symptoms (Composed of 4 items)

+ Did your family member get as much help with pain as he or she needed?

+ How often did your family member get the help he or she needed for trouble breathing?

+ How often did your family member get the help he or she needed for trouble with constipation?

+ How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?

Getting Hospice Care Training (Composed of 5 items)

+ Did the hospice team give you enough training about what side effects to watch for from pain medicine?

+ Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?

+ Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?

+ Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

+ Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with your or your family member?

Global Rating Measures:

In addition to the multi-item measures, there are two “global” ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice.

+ Rating of Hospice Care: Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member’s hospice care?

+ Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family?

The CAHPS Hospice Survey is part of the CAHPS family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/ . CMS initiated national implementation of the CAHPS Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a “dry run” for at least one month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care)

A list of the CAHPS Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A

**Numerator Statement**: CMS calculates CAHPS Hospice Survey measure scores using top-, middle- and bottom-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below.

**Denominator Statement**: CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection.

The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility.

**Exclusions**: The eight measures included here are calculated only for hospices that have at least 30 completed surveys over eight quarters of data collection.

The exclusions noted in here are those who are ineligible to participate in the survey. The one exception is caregivers who report on the survey that they "never" oversaw or took part in the decedent's care; these respondents are instructed to complete the "About You" and "About Your Family Member" sections of the survey only.

Cases are excluded from the survey target population if:

- The hospice patient is still alive
- The decedent's age at death was less than 18
- The decedent died within 48 hours of his/her last admission to hospice care
- The decedent had no caregiver of record
- The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address
- The decedent had no caregiver other than a nonfamilial legal guardian
- The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted)
- The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased
- The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care

**Adjustment/Stratification**: Statistical risk model
**Level of Analysis:** Facility
**Setting of Care:** Other
**Type of Measure**: Outcome: PRO-PM
**Data Source**: Instrument-Based Data
**Measure Steward**: Centers for Medicare and Medicaid Services

**STANDING COMMITTEE MEETING 2/20/2020 and 2/25/2020**

**1. Importance to Measure and Report: The measure meets the Importance criteria**

(1a. Evidence; 1b. Performance Gap)

1a. Evidence: **No vote**; 1b. Performance Gap: **H-8**; **M-10**; **L-0**; **I-0**

Rationale:

- During the prior review in 2016, as evidence for this measure, the developer provided a table linking multiple processes or structures of care to the outcomes captured in the 8 measures that are derived from the Hospice CAHPS survey. The developer also summarized results from focus groups and individual interviews with family members of hospice decedents who reviewed the Survey and supported its contents. The Committee agreed there was no change in evidence from the previous NQF evaluation. The Committee agreed there is no need for repeat vote on Evidence.
- The developer provided performance data from 2,933 hospice agencies that had at least 30 respondents in the third quarter of 2016 to the second quarter in 2018. Mean measures scores ranged from 75.1 (Standard Deviation (SD) =6.0) for "Getting help for symptoms" to 90.5 (SD=3.9) for "Treating family member with respect".
- The developer presented 2015-2016 CAHPS Hospice Survey data (including CAHPS Hospice Survey measure scores by age, gender, race, ethnicity, education, and caregiver respondent language), noting potential racial and ethnic disparities in the experience of care measures.
- The Committee agreed that variation in agency scores for each measure indicates a performance gap exists. Members also noted that the disparities data were particularly compelling, given the direction of the identified disparities varies across the measures.

**2. Scientific Acceptability of Measure Properties: The measure meets the Scientific Acceptability criteria**

(2a. Reliability - precise specifications, testing; 2b. Validity - testing, threats to validity)

2a. Reliability: **Yes-18; No-0**; 2b. Validity: **Yes-18; No-0**

## 2651 CAHPS® Hospice Survey (experience with care)

Rationale:

- This measure was reviewed by SMP subgroup members who found the eight PRO-PMs included under 2651 to be reliable and valid.
- The SMP's ratings for Reliability: H-2, M-4, L-0, I-0
- The SMP's ratings for Validity: H-0, M-6, L-0, I-0
- The Committee and the developer had a robust discussion around exclusions, examining ways to include as many types of patients and perspectives as possible. The current survey is completed by informal caregivers. The Committee noted that the survey captures the caregiver's perspective on the quality of care received by the patient. Patients may have a different perspective than caregivers and patients without informal caregivers are currently not represented in the survey results.
- Both the Committee and the developer agreed that surveying patients during their final days could be viewed as intrusive and could add to the patient's suffering. There was agreement that capturing the patient's perspective could be useful for care improvement, but no agreement on how to best obtain this information.
- The Committee also noted that caregivers for pediatric hospice patients are excluded from the survey. It was noted that caregivers for pediatric patients are usually the patient's parents and that there may be fundamental differences between parents and informal caregivers as populations to be surveyed.
- The Committee felt this was a major gap in measurement for hospice care. The developer stated they would want to start over and re-examine the survey from the beginning for the pediatric caregiver population to ensure it was appropriate, valid, and reliable. They felt a separate survey would be needed as opposed to stratified results from this survey.
- The Committee was satisfied with the reliability and validity of this measure and unanimously accepted the SMP's rating of moderate for both criteria.

**3. Feasibility: H-2; M-15; L-0; I-0**

*(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c. Susceptibility to inaccuracies/ unintended consequences identified; 3d. Data collection strategy can be implemented)*

Rationale:

- Data for these 8 PRO-PMs are collected via a survey that can be administered via mail, telephone, or mixed. Currently the responses of these surveys are not entered by the caregiver directly into an electronic system. The Hospice CAHPS survey is a survey that is fielded to the caregiver following the death of the hospice patient, and thus the data elements are not routinely generated and used during care delivery. The response rate for the survey is low, although it is comparable to other CAHPS surveys.
- The Committee had questions about number of questions on the survey, the methods of completion, and how providers could communicate about the survey, all targeted towards survey feasibility and increasing survey completion rates. The developer noted that they are working on reducing the number of questions on the survey. The Committee wondered if an option to complete the survey electronically would increase responses. The developer responded that they are working on testing electronic response across all CAHPS surveys.
- Some Committee members noted that rural areas may not have the same access to broadband Internet as other areas and that could be a barrier to online survey completion.
- The Committee had internal discussion about whether online surveys would be a barrier to completion in the older population targeted by the survey. Some felt this group would be less open to technology and some noted high smart phone usage by this population.
- Some Committee members mentioned there is a belief in the provider community that hospices are not allowed to tell caregivers that they might receive a survey, making survey arrival a (sometimes unwelcome) surprise. The developer clarified that providers could tell caregivers they may receive a survey, but they must inform all caregivers and not just a subset. Providers are not allowed to make any statements about how a caregiver would rate them on the survey.
- The Committee was satisfied the measure met the feasibility criterion.

**4. Use and Usability**

## 2651 CAHPS® Hospice Survey (experience with care)

*(4a. Use; 4a1. Accountability and transparency; 4a2. Feedback on the measure by those being measured and others; 4b. Usability; 4b1. Improvement; 4b2. The benefits to patients outweigh evidence of unintended negative consequences to patients)*

4a. Use: **Pass-18; No Pass-0** 4b. Usability*:* **H-6; M-12; L-0; I-0**

Rationale:

- The Committee noted the measure is in use in the Hospice Quality Reporting Program and that the results are available on Hospice Compare. Committee members shared that their organizations carefully reviewed results on this measure and actively worked to improve care to improve measure performance.
- Committee members also reported using the results on Hospice Compare to find hospice care both for patients and family members. They stated that they found the results of this measure personally useful.
- Overall, the Committee had a positive discussion around the use and usability criteria and was satisfied the measure met both criteria.

**5. Related and Competing Measures**

- This measure is related to NQF 1623: Bereaved Family Survey.
  - The result of the Bereaved Family Survey measure is a single score that indicates the family's perceptions of the quality of care that veterans received from the VA during the last month of life; aspects of care included in the measure are communication, emotional and spiritual support, pain management, and personal care needs.
- The Committee engaged in a brief discussion of 1623 and 2651 as related measures. The Committee felt there was a clear difference between the two measures and stated they are different measures with different populations. The Committee felt the differences between the VA and other health systems justified different measures. Committee members did identify areas, such as questions around supports, where the content of the questions could be more aligned, stating there is strong evidence around best-practices in these areas.

**6. Standing Committee Recommendation for Endorsement**: **Y-18**; **N-0**

**7. Public and Member Comment**

- NQF received one comment that addressed the following:
  - The commenter recommended improving specificity in the questionnaire with respect to person-centered care.
  - The commenter also suggested using a different term than communication to capture the dialogue around what matters most in hospice care and to capture whether the team was able to compassionately act on behalf of patients.
  - The commenter noted that the measures should address the complexity of person-centered care for older adults with multiple chronic conditions and emphasized the need to develop appropriate patient reported outcome measures.
- The developer replied to the comment saying that they are drafting and field testing a revised version of the CAHPS Hospice Survey. The developer also mentioned that the team will consider AGS's comment about communication by working with a technical expert panel, conducting inpatient interviews, and developing survey items that assess the degree to which the team was able to communicate about what matters most to the patient. The Committee supported and accepted the developer's response to the comment submitted.

**8. Consensus Standards Approval Committee (CSAC) Vote: Y-X; N-X**

**9. Appeals**

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# Geriatrics and Palliative Care Fall 2019 Review Cycle

## CSAC Review and Endorsement

*November 17, 2020*

*Funded by the Centers for Medicare and Medicaid Services under contract HHSM-500-2017-00060I Task Order HHSM-500-T0001.*

# Standing Committee Recommendations

- One measure reviewed for Fall 2019 Track 2
  - One measure reviewed by the Scientific Methods Panel
- One measure recommended for endorsement
  - **NQF 2651** CAHPS® Hospice Survey (experience with care) (Maintenance Measure)

# Public and Member Comment and Member Expressions of Support

- 1 comment received on NQF 2651
  - Comment included recommendations relating to measure specifications
- No NQF member of expressions of support or non-support received

# Questions?

- Project team:
  - Katie Goodwin, MS, Director
  - Erin Buchanan, MPH, Manager
  - Ngozi Ihenacho, MPH, Analyst
  - Mike DiVecchia, MBA, PMP, Project Manager

- Project webpage: https://www.qualityforum.org/Geriatrics_and_Palliative_Care.aspx

- Project email address: Palliative@qualityforum.org

# THANK YOU.

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# Geriatrics and Palliative Care, Fall 2019 Cycle Track 2: CDP Report

## DRAFT REPORT FOR CSAC REVIEW
## NOVEMBER 17, 2020

This report is funded by the Centers for Medicare and Medicaid Services under contract HHSM-500-2017-00060I Task Order HHSM-500-T0001

http://www.qualityforum.org

# Contents

## Executive Summary

Improving the quality of palliative and end-of-life care, and geriatric care more generally, is becoming increasingly important due to factors that have intensified the need for individualized, person-centered care. Some of these factors include the aging U.S. population; the projected increases in the number of Americans with chronic illnesses, disabilities, and functional limitations; and increases in ethnic and cultural diversity.

Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and alleviating suffering throughout the continuum of a person's illness by addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.[1] Palliative care is holistic, thus requiring an interdisciplinary, team-based approach to care. With its focus on improving quality of life, palliative care is distinct from care intended to cure an illness or condition, although it can be delivered concurrently with curative therapies, and can begin at any point in the disease progression. It can be provided in any setting, including outpatient care settings and at home.

To date, the National Quality Forum (NQF) has endorsed more than 30 measures that address geriatric care, palliative care, and end-of-life care. These measures address physical, spiritual, and legal aspects of care, as well as the care of patients nearing the end of life.

During its fall 2019 evaluation cycle, NQF’s Geriatrics and Palliative Care Standing Committee evaluated two measures undergoing maintenance review against NQF’s standard evaluation criteria and recommended both measures for continued endorsement. The two recommended measures are:

- **NQF 1623** Bereaved Family Survey
- **NQF 2651** CAHPS® Hospice Survey (experience with care)

Due to circumstances around the COVID-19 global pandemic, commenting periods for all measures evaluated in the Fall 2019 cycle were extended from 30 days to 60 days. Based on the comments received during this 60-day extended commenting period, measures entered one of two tracks:

Track 1: measures reviewed in fall 2019 Cycle:

- **NQF 1623** Bereaved Family Survey

Track 2: measures deferred to spring 2020 Cycle:

- **NQF 2651** CAHPS® Hospice Survey (experience with care)

This report contains details of the evaluation of measures assigned to *Track 2* and moved to the spring 2020 cycle. Detailed summaries of the Committee’s discussion and ratings of the criteria for each measure are in Appendix A. The detailed evaluation summary of measures assigned to *Track 1* and remained in the fall 2019 cycle were included in a separate report.

## Introduction

Improving the quality of both palliative and end-of-life care, and geriatric care more generally, is becoming increasingly important due to factors that have intensified the need for individualized, person-centered care. Some of these factors include the aging U.S. population; the projected increases in the number of Americans with chronic illnesses, disabilities, and functional limitations; and increases in ethnic and cultural diversity.[2] In 2018, the 65-and-older population numbered 50.9 million individuals (15.6 percent of the U.S. population), and this figure is expected to increase to 94.7 million by 2060.[3] As many as 35 percent of older Americans have some type of disability (e.g., vision, hearing, ambulation, cognition), while 46 percent of those 75 and older report limitations in physical functioning.[4] Additionally, data indicate that 46 percent of the noninstitutionalized U.S. population aged 65 or older have two or three chronic conditions, and 15 percent have four or more.[5]

Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and alleviating suffering throughout the continuum of a person's illness by addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.[6] Palliative care is holistic, thus requiring an interdisciplinary, team-based approach to care. With its focus on improving quality of life, palliative care is distinct from care intended to cure an illness or condition, although it can be delivered concurrently with curative therapies, and can begin at any point in the disease progression. It can be provided in any setting, including outpatient care settings and at home.

Although palliative care is still provided primarily by specially trained teams of professionals in hospitals and through hospice, there is increased focus on provision of palliative care in the community,[7] often by clinicians who are not palliative care specialists. The provision of palliative care has been shown to increase patient and family satisfaction with care,[8] reduce emergency department visits, hospital admissions, and hospital readmissions,[9] and decrease costs to the healthcare system.[10,11] However, access to hospital-based specialty palliative care continues to vary by hospital size and location, and even when programs are available, not all patients who could benefit actually receive those services.[12]

Palliative care is appropriate for those who are expected to recover, as well as for those who have chronic, progressive, and/or terminal illness. For those with a terminal illness, high quality end-of-life care is comprehensive care that addresses medical, emotional, spiritual, and social needs during the last stages of illness.[13] Much end-of-life care is palliative, when life-prolonging interventions are no longer appropriate, effective, or desired.[14] Thus, for patients nearing the end of life, there often will be a greater emphasis on palliative care over curative treatment. In many instances, this care is provided in the form of hospice.

Hospice is a service delivery system that relies on an interdisciplinary approach that emphasizes symptom management for patients near the end of life. While hospice care is covered through Medicaid and most private insurance plans, approximately 85 percent of hospice enrollees receive coverage through the Medicare hospice benefit.[15] Almost 1.5 million Medicare beneficiaries and their families received hospice care in 2017.[16] For these individuals, the average length of stay was 76.1 days; however, the median length of stay was only 24 days, meaning that many enrolled in hospice too late to fully realize the benefits of the program.[17] Beginning in 2014, Medicare-certified hospices were required to report performance on quality measures as part of the Hospice Quality Reporting Program (HQRP); those not reporting face a reduction in payments from Medicare. Performance rates for these measures are publicly reported on the Centers for Medicare and Medicaid Services (CMS) Hospice Compare website.[18]

Since 2006, when it first developed a measurement framework for palliative and end-of-life care, and endorsed 38 evidence-based preferred practices for high quality palliative care programs,[19] NQF has endorsed more than 30 measures in this topic area, many of which currently are used in federal quality improvement and public reporting programs.

In 2017, NQF expanded the scope of the Standing Committee charged with the oversight of the palliative and end-of-life care measures portfolio by adding measures specifically relevant to older adults (i.e., the geriatric population). Several previously seated and new members of this renamed “Geriatrics and Palliative Care Standing Committee” are geriatric healthcare professionals. Thus, the Committee has the requisite expertise to assume oversight of measures that focus on key issues specific to older adults, such as multimorbidity and frailty. At present, measures specifically relevant to the geriatric population remain aspirational. Thus, for the time being, the geriatrics measures evaluated by this Committee include setting-specific measures that primarily affect older individuals. Examples of such measures include those that assess care provided by home health agencies or other home-based care providers.

## NQF Portfolio of Performance Measures for Geriatrics and Palliative Care Conditions

The Geriatrics and Palliative Care Standing Committee (Appendix C) oversees NQF’s portfolio of Geriatrics and Palliative Care measures (Appendix B). This portfolio contains 36 measures: 18 process measures, 17 outcome measures, and one composite measure (see table below).

**Table 1. NQF Geriatrics and Palliative Care Portfolio of Measures**

| | Process | Outcome | Composite |
|---|---|---|---|
| Palliative/End-of-Life Care | | | |
| Physical Aspects of Care | 9 | 0 | 0 |
| Psychological and Psychiatric Aspects of Care | 0 | 0 | 0 |
| Social Aspects of Care | 0 | 0 | 0 |
| Spiritual, Religious, and Existential Aspects of Care | 1 | 0 | 0 |
| Cultural Aspects of Care | 0 | 0 | 0 |
| Care of the Patient Nearing the End of Life | 3 | 12 | 1 |
| Ethical and Legal Aspects of Care | 3 | 0 | 0 |
| Geriatrics | 2 | 5 | 0 |
| Total | 18 | 17 | 1 |

Some of the measures in the Geriatrics and Palliative Care portfolio will be evaluated by other NQF standing committees. These include a cultural communication measure (Patient Experience and Function Committee) and pain measures for cancer patients (Cancer Committee).

## Geriatrics and Palliative Care Measure Evaluation

On February 20 and 25, 2020, the Geriatrics and Palliative Care Standing Committee evaluated two measures undergoing maintenance review against NQF's standard measure evaluation criteria.

**Table 2. Geriatrics and Palliative Care Measure Evaluation Summary, Fall 2019 Track 2**

| | Maintenance | New | Total |
|---|---|---|---|
| Measures under consideration | 1 | 0 | 1 |
| Measures recommended for endorsement | 1 | 0 | 1 |

### Comments Received Prior to Committee Evaluation

NQF solicits comments on endorsed measures on an ongoing basis through the Quality Positioning System (QPS). In addition, NQF solicits comments for a continuous 16-week period during each evaluation cycle via an online tool located on the project webpage. For this evaluation cycle, the commenting period opened on December 11, 2019. NQF did not receive any comments on the measures as of January 31, 2020.

### Comments Received After Committee Evaluation

Considering the recent COVID-19 global pandemic, many organizations needed to focus their attention on the public health crisis. To provide greater flexibility for stakeholders and continue the important work in quality measurement, NQF extended commenting periods and adjusted measure endorsement timelines for the fall 2019 cycle.

Commenting periods for all measures evaluated in the fall 2019 cycle were extended from 30 days to 60 days. Based on the comments received during this 60-day extended commenting period, measures entered one of two tracks:

**Track 1: Measures Continuing in Fall 2019 Cycle**
**Measures that did not receive public comments or only received comments in support of the Standing Committees' recommendations** will move forward to the Consensus Standards Approval Committee (CSAC) for review and discussion during its meeting on July 28-29, 2020.

- **Exceptions**
  Exceptions were granted to measures if non-supportive comments received during the extended post-comment period were similar to those received during the pre-evaluation meeting period and have already been adjudicated by the respective Standing Committees during the measure evaluation fall 2019 meetings.

> **Track 2: Measures Deferred to Spring 2020 Cycle**
> **Fall 2019 measures requiring further action or discussion from a Standing Committee were deferred to the spring 2020 cycle.** This includes measures where consensus was not reached or those that require a response to public comments received. Measures undergoing maintenance review will retain endorsement during that time.

During the fall 2019 CSAC meeting on November 17-18, 2020, the CSAC will review all measures assigned to Track 2. A list of measures assigned to Track 1 can be found in the Executive Summary section of this report for tracking purposes, but these measures were reviewed during the fall 2019 CSAC review period.

The extended public commenting period with NQF member support closed on May 28, 2020. Following the Committee's evaluation of the measures under consideration, NQF received one comment from one organization pertaining to the draft report and to the measure under consideration. The comment for the measure under consideration was discussed at the July 9, 2020 post-comment meeting and have been summarized in Appendix A.

## Summary of Measure Evaluation: Fall 2019 Measures, Track 2

### 2651 CAHPS® Hospice Survey (experience with care) (Centers for Medicare and Medicaid Services): Recommended

**Description**: The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death; **Measure Type**: Outcome: PRO-PM; **Level of Analysis**: Facility; **Setting of Care**: Other; **Data Source**: Instrument-Based Data

In 2017, nearly 1.5 million Medicare beneficiaries received hospice services, with nearly $18 billion spent on Medicare hospice expenditures. Variation has been reported across hospices regarding processes of care associated with care quality. Evidence of variation in hospice care processes points to the need for performance measures that can be systematically implemented to monitor hospice performance and make fair comparisons across hospices. The CAHPS® Hospice Survey was created to ensure that an assessment of the patient- and family-centeredness of care would be included to monitor hospice performance, promote quality improvement, and inform consumer decision making in the selection of a hospice via public reporting of results.

The Committee agreed there was no change in evidence from previous endorsement and agreed to accept the previous decision and vote from the measure's previous review cycle, which was that the measure passes the evidence criterion. The Committee felt that there is a clear performance gap that warrants a national performance measure. The Committee and the developer had a robust discussion around exclusions, examining ways to include as many types of patients and perspectives as possible. The Committee noted that caregivers for pediatric hospice patients are excluded from the survey and felt this was a major gap in measurement for hospice care. The developer stated they would want to re-examine the survey from the beginning for the pediatric caregiver population to ensure it was appropriate, valid, and reliable. They felt a separate survey would be needed as opposed to stratified results from this survey. The Committee was satisfied with the reliability and validity of this measure and unanimously accepted the SMP rating of moderate for both criteria.

The Committee had questions about number of questions on the survey, the methods of completion, and how providers could communicate about the survey; all targeted towards survey feasibility and increasing survey completion rates. The developer noted that they are working on reducing the number of questions on the survey. The Committee wondered if an option to complete the survey electronically would increase responses and the developer responded that they are working on testing electronic response across all CAHPS surveys. The Committee agreed that the measure met the feasibility criterion. The Committee had a brief and positive discussion around the use and usability criteria. They noted the measure is in use in the Hospice Quality Reporting Program and that the results are available on Hospice Compare. Committee members shared that their organizations carefully reviewed results on this measure and actively worked to improve care to improve measure performance. Committee members also reported using the results on Hospice Compare to find hospice care both for patients and family members. They stated that they found the results of this measure personally useful.

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# Appendix A: Details of Measure Evaluation

**Rating Scale: H**=High; **M**=Moderate; **L**=Low; **I**=Insufficient; **NA**=Not Applicable

## Recommended Measure

### 2651 CAHPS® Hospice Survey (experience with care)

Submission | Specifications

**Description**: The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death.

The publicly reported measures described here include the following six multi-item measures.

- Hospice Team Communication
- Getting Timely Care
- Treating Family Member with Respect
- Getting Emotional and Religious Support
- Getting Help for Symptoms
- Getting Hospice Training

In addition, there are two global rating items that are publicly-reported measures.

- Rating of the hospice care
- Willingness to recommend the hospice

Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS surveys.

List of CAHPS Hospice Survey Measures

Multi-Item Measures

Hospice Team Communication (Composed of 6 items)

+ While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?

+ While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?

+ How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

+ While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?

+ While your family member was in hospice care, how often did the hospice team listen carefully to you?

+ While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

Getting Timely Care (Composed of 2 items)

+ While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?

+ How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

Treating Family Member with Respect (Composed of 2 items)

+ While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

+ While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

Providing Emotional Support (Composed of 3 items)

## 2651 CAHPS® Hospice Survey (experience with care)

+ While your family member was in hospice care, how much emotional support did you get from the hospice team?

+ In the weeks after your family member died, how much emotional support did you get from the hospice team?

+ Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

Getting Help for Symptoms (Composed of 4 items)

+ Did your family member get as much help with pain as he or she needed?

+ How often did your family member get the help he or she needed for trouble breathing?

+ How often did your family member get the help he or she needed for trouble with constipation?

+ How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?

Getting Hospice Care Training (Composed of 5 items)

+ Did the hospice team give you enough training about what side effects to watch for from pain medicine?

+ Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?

+ Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?

+ Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

+ Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with your or your family member?

Global Rating Measures:

In addition to the multi-item measures, there are two “global” ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice.

+ Rating of Hospice Care: Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member’s hospice care?

+ Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family?

The CAHPS Hospice Survey is part of the CAHPS family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/ . CMS initiated national implementation of the CAHPS Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a “dry run” for at least one month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care)

A list of the CAHPS Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A

**Numerator Statement**: CMS calculates CAHPS Hospice Survey measure scores using top-, middle- and bottom-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below.

**Denominator Statement**: CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection.

## 2651 CAHPS® Hospice Survey (experience with care)

The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility.

**Exclusions**: The eight measures included here are calculated only for hospices that have at least 30 completed surveys over eight quarters of data collection.

The exclusions noted in here are those who are ineligible to participate in the survey. The one exception is caregivers who report on the survey that they "never" oversaw or took part in the decedent's care; these respondents are instructed to complete the "About You" and "About Your Family Member" sections of the survey only.

Cases are excluded from the survey target population if:

- The hospice patient is still alive
- The decedent's age at death was less than 18
- The decedent died within 48 hours of his/her last admission to hospice care
- The decedent had no caregiver of record
- The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address
- The decedent had no caregiver other than a nonfamilial legal guardian
- The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted)
- The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased
- The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care

**Adjustment/Stratification**: Statistical risk model

**Level of Analysis:** Facility

**Setting of Care:** Other

**Type of Measure**: Outcome: PRO-PM

**Data Source**: Instrument-Based Data

**Measure Steward**: Centers for Medicare and Medicaid Services

**STANDING COMMITTEE MEETING 2/20/2020 and 2/25/2020**

**1. Importance to Measure and Report: <u>The measure meets the Importance criteria</u>**

(1a. Evidence; 1b. Performance Gap)

1a. Evidence: **No vote**; 1b. Performance Gap: **H-8**; **M-10**; **L-0**; **I-0**

<u>Rationale</u>:

- During the prior review in 2016, as evidence for this measure, the developer provided a table linking multiple processes or structures of care to the outcomes captured in the 8 measures that are derived from the Hospice CAHPS survey. The developer also summarized results from focus groups and individual interviews with family members of hospice decedents who reviewed the Survey and supported its contents. The Committee agreed there was no change in evidence from the previous NQF evaluation. The Committee agreed there is no need for repeat vote on Evidence.
- The developer provided performance data from 2,933 hospice agencies that had at least 30 respondents in the third quarter of 2016 to the second quarter in 2018. Mean measures scores ranged from 75.1 (Standard Deviation (SD) =6.0) for "Getting help for symptoms" to 90.5 (SD=3.9) for "Treating family member with respect".
- The developer presented 2015-2016 CAHPS Hospice Survey data (including CAHPS Hospice Survey measure scores by age, gender, race, ethnicity, education, and caregiver respondent language), noting potential racial and ethnic disparities in the experience of care measures.

## 2651 CAHPS® Hospice Survey (experience with care)

- The Committee agreed that variation in agency scores for each measure indicates a performance gap exists. Members also noted that the disparities data were particularly compelling, given the direction of the identified disparities varies across the measures.

**2. Scientific Acceptability of Measure Properties:** **<u>The measure meets the Scientific Acceptability criteria</u>**

(2a. Reliability precise specifications, testing; 2b. Validity testing, threats to validity)

2a. Reliability: **Yes-18; No-0**; 2b. Validity: **Yes-18; No-0**

Rationale:

- This measure was reviewed by SMP subgroup members who found the eight PRO-PMs included under 2651 to be reliable and valid.
- The SMP's ratings for Reliability: H-2, M-4, L-0, I-0
- The SMP's ratings for Validity: H-0, M-6, L-0, I-0
- The Committee and the developer had a robust discussion around exclusions, examining ways to include as many types of patients and perspectives as possible. The current survey is completed by informal caregivers. The Committee noted that the survey captures the caregiver's perspective on the quality of care received by the patient. Patients may have a different perspective than caregivers and patients without informal caregivers are currently not represented in the survey results.
- Both the Committee and the developer agreed that surveying patients during their final days could be viewed as intrusive and could add to the patient's suffering. There was agreement that capturing the patient's perspective could be useful for care improvement, but no agreement on how to best obtain this information.
- The Committee also noted that caregivers for pediatric hospice patients are excluded from the survey. It was noted that caregivers for pediatric patients are usually the patient's parents and that there may be fundamental differences between parents and informal caregivers as populations to be surveyed.
- The Committee felt this was a major gap in measurement for hospice care. The developer stated they would want to start over and re-examine the survey from the beginning for the pediatric caregiver population to ensure it was appropriate, valid, and reliable. They felt a separate survey would be needed as opposed to stratified results from this survey.
- The Committee was satisfied with the reliability and validity of this measure and unanimously accepted the SMP's rating of moderate for both criteria.

**3. Feasibility: H-2; M-15; L-0; I-0**

*(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c. Susceptibility to inaccuracies/ unintended consequences identified; 3d. Data collection strategy can be implemented)*

Rationale:

- Data for these 8 PRO-PMs are collected via a survey that can be administered via mail, telephone, or mixed. Currently the responses of these surveys are not entered by the caregiver directly into an electronic system. The Hospice CAHPS survey is a survey that is fielded to the caregiver following the death of the hospice patient, and thus the data elements are not routinely generated and used during care delivery. The response rate for the survey is low, although it is comparable to other CAHPS surveys.
- The Committee had questions about number of questions on the survey, the methods of completion, and how providers could communicate about the survey, all targeted towards survey feasibility and increasing survey completion rates. The developer noted that they are working on reducing the number of questions on the survey. The Committee wondered if an option to complete the survey electronically would increase responses. The developer responded that they are working on testing electronic response across all CAHPS surveys.
- Some Committee members noted that rural areas may not have the same access to broadband Internet as other areas and that could be a barrier to online survey completion.
- The Committee had internal discussion about whether online surveys would be a barrier to completion in the older population targeted by the survey. Some felt this group would be less open to technology and some noted high smart phone usage by this population.
- Some Committee members mentioned there is a belief in the provider community that hospices are not allowed to tell caregivers that they might receive a survey, making survey arrival a (sometimes

**2651 CAHPS® Hospice Survey (experience with care)**

unwelcome) surprise. The developer clarified that providers could tell caregivers they may receive a survey, but they must inform all caregivers and not just a subset. Providers are not allowed to make any statements about how a caregiver would rate them on the survey.

- The Committee was satisfied the measure met the feasibility criterion.

**4. Use and Usability**

*(4a. Use; 4a1. Accountability and transparency; 4a2. Feedback on the measure by those being measured and others; 4b. Usability; 4b1. Improvement; 4b2. The benefits to patients outweigh evidence of unintended negative consequences to patients)*

4a. Use: **Pass-18; No Pass-0** 4b. Usability*:* **H-6; M-12; L-0; I-0**

Rationale:

- The Committee noted the measure is in use in the Hospice Quality Reporting Program and that the results are available on Hospice Compare. Committee members shared that their organizations carefully reviewed results on this measure and actively worked to improve care to improve measure performance.
- Committee members also reported using the results on Hospice Compare to find hospice care both for patients and family members. They stated that they found the results of this measure personally useful.
- Overall, the Committee had a positive discussion around the use and usability criteria and was satisfied the measure met both criteria.

**5. Related and Competing Measures**

- This measure is related to NQF 1623: Bereaved Family Survey.
    - The result of the Bereaved Family Survey measure is a single score that indicates the family's perceptions of the quality of care that veterans received from the VA during the last month of life; aspects of care included in the measure are communication, emotional and spiritual support, pain management, and personal care needs.
- The Committee engaged in a brief discussion of 1623 and 2651 as related measures. The Committee felt there was a clear difference between the two measures and stated they are different measures with different populations. The Committee felt the differences between the VA and other health systems justified different measures. Committee members did identify areas, such as questions around supports, where the content of the questions could be more aligned, stating there is strong evidence around best-practices in these areas.

**6. Standing Committee Recommendation for Endorsement**: **Y-18**; **N-0**

**7. Public and Member Comment**

- NQF received one comment that addressed the following:
    - The commenter recommended improving specificity in the questionnaire with respect to person-centered care.
    - The commenter also suggested using a different term than communication to capture the dialogue around what matters most in hospice care and to capture whether the team was able to compassionately act on behalf of patients.
    - The commenter noted that the measures should address the complexity of person-centered care for older adults with multiple chronic conditions and emphasized the need to develop appropriate patient reported outcome measures.
- The developer replied to the comment saying that they are drafting and field testing a revised version of the CAHPS Hospice Survey. The developer also mentioned that the team will consider AGS's comment about communication by working with a technical expert panel, conducting inpatient interviews, and developing survey items that assess the degree to which the team was able to communicate about what matters most to the patient. The Committee supported and accepted the developer's response to the comment submitted.

**8. Consensus Standards Approval Committee (CSAC) Vote: Y-X; N-X**

**9. Appeals**

## Appendix B: Geriatrics and Palliative Care Portfolio—Use in Federal Programs[a]

| NQF # | Title | Federal Programs: Finalized or Implemented as of January 13, 2020 |
|---|---|---|
| 0167 | Improvement in Ambulation and Locomotion | Home Health Value Based Purchasing (Implemented) |
| 0174 | Improvement in Bathing | Home Health Value Based Purchasing (Implemented) |
| 0175 | Improvement in Bed Transferring | Home Health Value Based Purchasing (Implemented) |
| 0176 | Improvement in Management of Oral Medications | Home Health Value Based Purchasing (Implemented)<br>Home Health Quality Reporting (Implemented) |
| 0177 | Improvement in pain interfering with activity | Home Health Value Based Purchasing (Implemented)<br>Home Health Quality Reporting (Implemented) |
| 0209 | Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment | None |
| 0383 | Oncology: Plan of Care for Pain – Medical Oncology and Radiation Oncology (paired with 0384) | Hospital Care (Implemented)<br>Prospective Payment System-Exempt Cancer Hospital Quality Reporting (Implemented)<br>Merit-Based Incentive Payment System (MIPS) Program (Finalized) |
| 0384 | Oncology: Medical and Radiation - Pain Intensity Quantified (paired with 0383) | Merit-Based Incentive Payment System (MIPS) Program (Implemented)<br>Medicaid Promoting Interoperability Program (Proposed) |
| 0420 | Pain Assessment and Follow-Up | None |
| 1617 | Patients Treated with an Opioid who are Given a Bowel Regimen | Hospice Quality Reporting (Implemented) |
| 1628 | Patients with Advanced Cancer Screened for Pain at Outpatient Visits | Prospective Payment System-Exempt Cancer Hospital Quality Reporting (Considered) |
| 1634 | Hospice and Palliative Care — Pain Screening | Hospice Quality Reporting (Implemented) |
| 1637 | Hospice and Palliative Care — Pain Assessment | Hospice Quality Reporting (Implemented) |
| 1638 | Hospice and Palliative Care — Dyspnea Treatment | Hospice Quality Reporting (Implemented) |
| 1639 | Hospice and Palliative Care — Dyspnea Screening | Hospice Quality Reporting (Implemented) |

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[a] Per CMS Measures Inventory Tool as of 03/10/2020

| NQF # | Title | Federal Programs: Finalized or Implemented as of January 13, 2020 |
|---|---|---|
| 1647 | Beliefs and Values - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss | Hospice Quality Reporting (Implemented) |
| 0326 | Advance Care Plan | Home Health Value Based Purchasing (Implemented)<br>Merit-Base Incentive Payment System (MIPS) Program (Finalized)<br>Ambulatory Surgical Center Quality Reporting (Considered)<br>Hospital Outpatient Quality Reporting (Considered) |
| 1626 | Patients Admitted to ICU who Have Care Preferences Documented | None |
| 1641 | Hospice and Palliative Care – Treatment Preferences | Prospective Payment System-Except Cancer Hospital Quality Reporting (Considered)<br>Hospice Quality Reporting (Implemented) |
| 0210 | Proportion receiving chemotherapy in the last 14 days of life | Merit-Base Incentive Payment System (MIPS) Program (Finalized)<br>Hospital Compare (Finalized)<br>Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Finalized) |
| 0213 | Proportion admitted to the ICU in the last 30 days of life | Merit-Base Incentive Payment System (MIPS) Program (Finalized)<br>Hospital Compare (Finalized)<br>Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Finalized) |
| 0215 | Proportion not admitted to hospice | Merit-Base Incentive Payment System (MIPS) Program (Finalized)<br>Hospital Compare (Finalized)<br>Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Finalized) |
| 0216 | Proportion admitted to hospice for less than 3 days | Merit-Base Incentive Payment System (MIPS) Program (Finalized)<br>Hospital Compare (Finalized)<br>Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Finalized) |
| 1623 | Bereaved Family Survey | None |

| NQF # | Title | Federal Programs: Finalized or Implemented as of January 13, 2020 |
|---|---|---|
| 1625 | Hospitalized Patients Who Die an Expected Death with an ICD that Has Been Deactivated | None |
| 2651 | CAHPS Hospice Survey (Experience with Care): 8 PRO-PMs: (Hospice Team Communication; Getting Timely Care; Getting Emotional and Religious Support; Getting Hospice Training; Rating of the Hospice Care; Willingness to Recommend the Hospice; Treating Family Member with Respect; Getting Help for Symptoms) | Hospice Quality Reporting (Implemented) |
| 3235 | Hospice and Palliative Care Composite Process Measure—Comprehensive Assessment at Admission | Hospice Quality Reporting (Implemented) |

# Appendix C: Geriatrics and Palliative Care Standing Committee and NQF Staff

## STANDING COMMITTEE

**R. Sean Morrison, MD (Co-Chair)**
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Analyst

# Appendix D: Measure Specifications

| | **2651 CAHPS® Hospice Survey (experience with care)** |
|---|---|
| Steward | Centers for Medicare and Medicaid Services |
| Description | The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death.<br>The publicly reported measures described here include the following six multi-item measures.<br>• Hospice Team Communication<br>• Getting Timely Care<br>• Treating Family Member with Respect<br>• Getting Emotional and Religious Support<br>• Getting Help for Symptoms<br>• Getting Hospice Training<br>In addition, there are two global rating items that are publicly-reported measures.<br>• Rating of the hospice care<br>• Willingness to recommend the hospice<br>Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS surveys.<br>List of CAHPS Hospice Survey Measures<br>Multi-Item Measures<br>Hospice Team Communication (Composed of 6 items)<br>+ While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?<br>+ While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?<br>+ How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?<br>+ While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?<br>+ While your family member was in hospice care, how often did the hospice team listen carefully to you?<br>+ While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?<br>Getting Timely Care (Composed of 2 items)<br>+ While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?<br>+ How often did you get the help you needed from the hospice team during evenings, weekends, or holidays? |

| | **2651 CAHPS® Hospice Survey (experience with care)** |
|---|---|
| | Treating Family Member with Respect (Composed of 2 items)<br>+ While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?<br>+ While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?<br>Providing Emotional Support (Composed of 3 items)<br>+ While your family member was in hospice care, how much emotional support did you get from the hospice team?<br>+ In the weeks after your family member died, how much emotional support did you get from the hospice team?<br>+ Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?<br>Getting Help for Symptoms (Composed of 4 items)<br>+ Did your family member get as much help with pain as he or she needed?<br>+ How often did your family member get the help he or she needed for trouble breathing?<br>+ How often did your family member get the help he or she needed for trouble with constipation?<br>+ How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?<br>Getting Hospice Care Training (Composed of 5 items)<br>+ Did the hospice team give you enough training about what side effects to watch for from pain medicine?<br>+ Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?<br>+ Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?<br>+ Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?<br>+ Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with your or your family member?<br>Global Rating Measures:<br>In addition to the multi-item measures, there are two “global” ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice.<br>+ Rating of Hospice Care: Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member’s hospice care?<br>+ Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family?<br>The CAHPS Hospice Survey is part of the CAHPS family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/ . CMS initiated national implementation of the CAHPS Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a “dry run” for at least one |

| | **2651 CAHPS® Hospice Survey (experience with care)** |
|---|---|
| | month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care)<br>A list of the CAHPS Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A |
| Type | Outcome: PRO-PM |
| Data Source | Instrument-Based Data CAHPS Hospice Survey; please see S.16 for information regarding modes of data collection. The survey instrument is available in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish and Korean. |
| Level | Facility |
| Setting | Other |
| Numerator Statement | CMS calculates CAHPS Hospice Survey measure scores using top-, middle- and bottom- box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below. |
| Numerator Details | For each survey item, the top and bottom box numerators are the number of respondents who selected the most and least positive response category(ies), respectively, as follows:<br>For items using a “Never/Sometimes/Usually/Always” response scale, the top box numerator is the number of respondents who answer “Always” and the bottom box numerator is the number of respondents who answer “Never” or “Sometimes.” The one exception to this guidance is for the Q10 “While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member’s condition or care?” For this item, the top box numerator is the number of respondents who answer “Never” and the bottom box numerator is the number of respondents who answer “Always” or “Usually.”<br>For items using a “Yes, definitely/Yes, somewhat/No” response scale, the top box numerator is the number of respondents who answer “Yes, definitely” and the bottom box numerator is the number of respondents who answer “No.”<br>For items using a “Too Little/Right Amount/Too Much” response scale, the top box numerator is the number of respondents who answer “Right Amount” and the bottom box numerator is the number of respondents who answer “Too little” or “Too much.” (There is no middle box for items using this response scale.)<br>The top box numerator for the Rating of Hospice item is the number of respondents who answer 9 or 10 for the item (on a scale of 0 to 10, where 10 is the “Best Hospice Care Possible”); the bottom box numerator is the number of respondents who answer 0 to 6.<br>The top box numerator for the Willingness to Recommend item is the number of respondents who answer “Definitely Yes” (on a scale of “Definitely No/Probably No/Probably Yes/Definitely Yes”); the bottom box numerator is the number of respondents who answer “Probably No” or “Definitely No.”<br>Calculation of hospice-level multi-item measures<br>0. Score each item using top- box method, possible values of 0 or 100<br>1. Calculate mode- adjusted scores for each item for each respondent |

| | **2651 CAHPS® Hospice Survey (experience with care)** |
|---|---|
| | 2. Calculate case-mix adjusted scores for each item for each hospice<br>3. Take the unweighted means of the mode- and case-mix-adjusted hospice-level items to form multi-item measures<br>Here is an example of calculations for the measure “Getting Timely Care.”<br>0. Score each item using top box method, possible values of 0 or 100<br>Both items in “Getting Care Quickly” have four response options: Never, Sometimes, Usually, Always. Recode each item as 100 for “Always” and 0 for “Never”, “Sometimes”, or “Usually”.<br>Item #1. While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?<br>Item #2. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?<br>1. Calculate mode-adjusted scores for each item for each respondent<br>2. Calculate case-mix adjusted scores for each item for each hospice<br>Each item is case mix adjusted separately; this step produces case-mix adjusted item-level scores for each hospice.<br>3. Take the unweighted means of the case-mix adjusted hospice-level items to form multi-item measures.<br>If the case-mix adjusted scores for a hospice are 95 for item #1 and 90 for item #2, then the hospice-level ‘Getting Timely Care’ would be calculated as (Item1 + Item2) / 2 = (95 + 90) / 2 = 92.5. |
| Denominator Statement | CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection.<br>The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility. |
| Denominator Details | For each item in a multi-item measure, as well as for the ratings measures, the top box denominator is the number of respondents per hospice who answered the item. For each multi-item measure score, the denominator is the number of respondents who answer at least one item within the multi-item measure. Multi-item measure scores are the average proportion of respondents that gave responses in the most positive category across the items in the multi-item measure (as discussed in S.6).<br>Survey population: Primary caregivers of patients who died while receiving care from a given hospice in a given month.<br>Denominator for Multi-Item Measures: The number of respondents who answer at least one item within the multi-item measure.<br>Denominator for Rating Measures: The number of respondents who answered the item. |
| Exclusions | The eight measures included here are calculated only for hospices that have at least 30 completed surveys over eight quarters of data collection. |

| | **2651 CAHPS® Hospice Survey (experience with care)** |
|---|---|
| | The exclusions noted in here are those who are ineligible to participate in the survey. The one exception is caregivers who report on the survey that they “never” oversaw or took part in the decedent’s care; these respondents are instructed to complete the “About You” and “About Your Family Member” sections of the survey only.<br>Cases are excluded from the survey target population if:<br>• The hospice patient is still alive<br>• The decedent’s age at death was less than 18<br>• The decedent died within 48 hours of his/her last admission to hospice care<br>• The decedent had no caregiver of record<br>• The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address<br>• The decedent had no caregiver other than a nonfamilial legal guardian<br>• The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted)<br>• The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased<br>• The caregiver reports on the survey that he or she “never” oversaw or took part in decedent’s hospice care |
| Exclusion details | Please see S.10.The CAHPS Hospice Survey Quality Assurance Guidelines (available at: http://www.hospicecahpssurvey.org/en/quality-assurance-guidelines/) contain detailed information regarding how to code decedent/caregiver cases, and how to code appropriately and inappropriately skipped items, as well as items with multiple responses. |
| Risk Adjustment | Statistical risk model |
| Stratification | CAHPS Hospice Survey measure scores are used for reporting at the hospice-level (i.e., not stratified by region or other characteristics). |
| Type Score | Rate/proportion better quality = higher score |
| Algorithm | Top Box Score Calculation:<br>1) Identify target respondent population (i.e., primary caregivers of hospice patients who died while receiving hospice care from a given hospice in a given month)<br>2) Identify any exclusions from the respondent population (as described above in S.10)<br>3) Score each item using top box method, possible values of 0 or 100<br>4) Calculate mode adjusted top box scores for each item.<br>5) Calculate case-mix adjusted top box scores for each item for each hospice; case-mix adjustment is a linear regression based approach that adjusts for all variables listed in S.14. Specifically, a regression model predicting item scores is fit using the case-mix adjustor variables and fixed effects for hospices. Adjusted hospice means are then calculated (e.g., using LSMEANS in SAS).<br>6) Top-box scores are averaged across the items within each multi-item measure, weighting each item equally. If data are missing for a respondent for an item(s) within a multi-item measure, the respondent’s answers to other items within the measure are still used in the calculation of multi-item measure scores. (Please see S.22 below for more details). 132021\| 141592\| 108097 |
| Copyright / Disclaimer | This questionnaire is not copyrighted. However, CAHPS is a copyright of the Agency for Healthcare Research and Quality (AHRQ) |

# Appendix E: Related and Competing Measures

## Comparison of NQF 1623 and NQF 2651

1623: Bereaved Family Survey
2651: CAHPS® Hospice Survey (experience with care)

### *Steward*

**1623: Bereaved Family Survey**

Department of Veterans Affairs / Hospice and Palliative Care

**2651: CAHPS® Hospice Survey (experience with care)**

Centers for Medicare and Medicaid Services

### *Description*

**1623: Bereaved Family Survey**

This measure calculates the proportion of Veteran decedent's family members who rate overall satisfaction with the Veteran decedent's end-of-life care in an inpatient setting as "Excellent" versus "Very good", "good", "fair", or "poor".

**2651: CAHPS® Hospice Survey (experience with care)**

The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent’s death.

The publicly reported measures described here include the following six multi-item measures.

- Hospice Team Communication
- Getting Timely Care
- Treating Family Member with Respect
- Getting Emotional and Religious Support
- Getting Help for Symptoms
- Getting Hospice Training

In addition, there are two global rating items that are publicly-reported measures.

- Rating of the hospice care
- Willingness to recommend the hospice

Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS surveys.

List of CAHPS Hospice Survey Measures

Multi-Item Measures

Hospice Team Communication (Composed of 6 items)

+ While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?

+ While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?

+ How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

+ While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?

+ While your family member was in hospice care, how often did the hospice team listen carefully to you?

+ While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

Getting Timely Care (Composed of 2 items)

+ While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?

+ How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

Treating Family Member with Respect (Composed of 2 items)

+ While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

+ While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

Providing Emotional Support (Composed of 3 items)

+ While your family member was in hospice care, how much emotional support did you get from the hospice team?

+ In the weeks after your family member died, how much emotional support did you get from the hospice team?

+ Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

Getting Help for Symptoms (Composed of 4 items)

+ Did your family member get as much help with pain as he or she needed?

+ How often did your family member get the help he or she needed for trouble breathing?

+ How often did your family member get the help he or she needed for trouble with constipation?

+ How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?

Getting Hospice Care Training (Composed of 5 items)

+ Did the hospice team give you enough training about what side effects to watch for from pain medicine?

+ Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?

+ Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?

+ Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

+ Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with your or your family member?

Global Rating Measures:

In addition to the multi-item measures, there are two "global" ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice.

+ Rating of Hospice Care: Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?

+ Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family?

The CAHPS Hospice Survey is part of the CAHPS family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/ . CMS initiated national implementation of the CAHPS Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a "dry run" for at least one month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care)

A list of the CAHPS Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A

## *Type*

### 1623: Bereaved Family Survey

Outcome: PRO-PM

### 2651: CAHPS® Hospice Survey (experience with care)

Outcome: PRO-PM

## *Data Source*

### 1623: Bereaved Family Survey

Instrument-Based Data For 2a1.25 - Family reported data/survey.

For 2a1.26 - Bereaved Family Survey

Available in attached appendix at A.1    No data dictionary

### 2651: CAHPS® Hospice Survey (experience with care)

Instrument-Based Data CAHPS Hospice Survey; please see S.16 for information regarding modes of data collection. The survey instrument is available in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish and Korean.

Available at measure-specific web page URL identified in S.1    No data dictionary

*Level*

**1623: Bereaved Family Survey**

Facility, Other

**2651: CAHPS® Hospice Survey (experience with care)**

Facility

*Setting*

**1623: Bereaved Family Survey**

Inpatient/Hospital, Post-Acute Care

**2651: CAHPS® Hospice Survey (experience with care)**

Other

*Numerator Statement*

**1623: Bereaved Family Survey**

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.

**2651: CAHPS® Hospice Survey (experience with care)**

CMS calculates CAHPS Hospice Survey measure scores using top-, middle- and bottom- box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below.

*Numerator Details*

**1623: Bereaved Family Survey**

Included are those patients included in the denominator with completed surveys (at least 12 of 17 structured items completed) that receive an optimal response on the global item question.

**2651: CAHPS® Hospice Survey (experience with care)**

For each survey item, the top and bottom box numerators are the number of respondents who selected the most and least positive response category(ies), respectively, as follows:

For items using a “Never/Sometimes/Usually/Always” response scale, the top box numerator is the number of respondents who answer “Always” and the bottom box numerator is the number of respondents who answer “Never” or “Sometimes.” The one exception to this guidance is for the Q10 “While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member’s condition or care?” For this item, the top box numerator is the number of respondents who answer “Never” and the bottom box numerator is the number of respondents who answer “Always” or “Usually.”

For items using a “Yes, definitely/Yes, somewhat/No” response scale, the top box numerator is the number of respondents who answer “Yes, definitely” and the bottom box numerator is the number of respondents who answer “No.”

For items using a “Too Little/Right Amount/Too Much” response scale, the top box numerator is the number of respondents who answer “Right Amount” and the bottom box numerator is the number of respondents who answer “Too little” or “Too much.” (There is no middle box for items using this response scale.)

The top box numerator for the Rating of Hospice item is the number of respondents who answer 9 or 10 for the item (on a scale of 0 to 10, where 10 is the “Best Hospice Care Possible”); the bottom box numerator is the number of respondents who answer 0 to 6.

The top box numerator for the Willingness to Recommend item is the number of respondents who answer “Definitely Yes” (on a scale of “Definitely No/Probably No/Probably Yes/Definitely Yes”); the bottom box numerator is the number of respondents who answer “Probably No” or “Definitely No.”

Calculation of hospice-level multi-item measures

0. Score each item using top- box method, possible values of 0 or 100

1. Calculate mode- adjusted scores for each item for each respondent

2. Calculate case-mix adjusted scores for each item for each hospice

3. Take the unweighted means of the mode- and case-mix-adjusted hospice-level items to form multi-item measures

Here is an example of calculations for the measure “Getting Timely Care.”

0. Score each item using top box method, possible values of 0 or 100

Both items in “Getting Care Quickly” have four response options: Never, Sometimes, Usually, Always. Recode each item as 100 for “Always” and 0 for “Never”, “Sometimes”, or “Usually”.

Item #1. While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?

Item #2. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

1. Calculate mode-adjusted scores for each item for each respondent

2. Calculate case-mix adjusted scores for each item for each hospice

Each item is case mix adjusted separately; this step produces case-mix adjusted item-level scores for each hospice.

3. Take the unweighted means of the case-mix adjusted hospice-level items to form multi-item measures.

If the case-mix adjusted scores for a hospice are 95 for item #1 and 90 for item #2, then the hospice-level ‘Getting Timely Care’ would be calculated as (Item1 + Item2) / 2 = (95 + 90) / 2 = 92.5.

## *Denominator Statement*

### 1623: Bereaved Family Survey

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 (unless the Veteran had a prior hospitalization of at least 24 hours in the last 31 days of life); 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.

### 2651: CAHPS® Hospice Survey (experience with care)

CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection.

The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility.

## *Denominator Details*

### 1623: Bereaved Family Survey

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

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

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

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

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

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

### 2651: CAHPS® Hospice Survey (experience with care)

For each item in a multi-item measure, as well as for the ratings measures, the top box denominator is the number of respondents per hospice who answered the item. For each multi-item measure score, the denominator is the number of respondents who answer at least one item within the multi-item measure. Multi-item measure scores are the average proportion of respondents that gave responses in the most positive category across the items in the multi-item measure (as discussed in S.6).

Survey population: Primary caregivers of patients who died while receiving care from a given hospice in a given month.

Denominator for Multi-Item Measures: The number of respondents who answer at least one item within the multi-item measure.

Denominator for Rating Measures: The number of respondents who answered the item.

## *Exclusions*

### 1623: Bereaved Family Survey

- 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 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.

-

### 2651: CAHPS® Hospice Survey (experience with care)

The eight measures included here are calculated only for hospices that have at least 30 completed surveys over eight quarters of data collection.

The exclusions noted in here are those who are ineligible to participate in the survey. The one exception is caregivers who report on the survey that they “never” oversaw or took part in the decedent’s care; these respondents are instructed to complete the “About You” and “About Your Family Member” sections of the survey only.

Cases are excluded from the survey target population if:

- The hospice patient is still alive
- The decedent’s age at death was less than 18
- The decedent died within 48 hours of his/her last admission to hospice care
- The decedent had no caregiver of record
- The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address
- The decedent had no caregiver other than a nonfamilial legal guardian
- The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted)
- The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased
- The caregiver reports on the survey that he or she “never” oversaw or took part in decedent’s hospice care

## *Exclusion Details*

### 1623: Bereaved Family Survey

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, and including length of stay are also required to determine exclusion.

### 2651: CAHPS® Hospice Survey (experience with care)

Please see S.10.The CAHPS Hospice Survey Quality Assurance Guidelines (available at: http://www.hospicecahpssurvey.org/en/quality-assurance-guidelines/) contain detailed information regarding how to code decedent/caregiver cases, and how to code appropriately and inappropriately skipped items, as well as items with multiple responses.

## *Risk Adjustment*

### 1623: Bereaved Family Survey

Statistical risk model

### 2651: CAHPS® Hospice Survey (experience with care)

Statistical risk model

## *Stratification*

### 1623: Bereaved Family Survey

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.

### 2651: CAHPS® Hospice Survey (experience with care)

CAHPS Hospice Survey measure scores are used for reporting at the hospice-level (i.e., not stratified by region or other characteristics).

## *Type Score*

### 1623: Bereaved Family Survey

Rate/proportion better quality = higher score

### 2651: CAHPS® Hospice Survey (experience with care)

Rate/proportion better quality = higher score

## *Algorithm*

### 1623: Bereaved Family Survey

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

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

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

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

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

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 (Excellent). A score of "0" reflects all other possible responses (Very good, Good, Fair, Poor). Items are coded as missing if respondents cannot or refuse to answer the item. 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).

We then add nonresponse and patient case mix weights to the model. All adjusted scores are reported. 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.

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We then add nonresponse and patient case mix weights to the model. All adjusted scores are reported.

### 2651: CAHPS® Hospice Survey (experience with care)

Top Box Score Calculation:

1) Identify target respondent population (i.e., primary caregivers of hospice patients who died while receiving hospice care from a given hospice in a given month)

2) Identify any exclusions from the respondent population (as described above in S.10)

3) Score each item using top box method, possible values of 0 or 100

4) Calculate mode adjusted top box scores for each item.

5) Calculate case-mix adjusted top box scores for each item for each hospice; case-mix adjustment is a linear regression based approach that adjusts for all variables listed in S.14. Specifically, a regression model predicting item scores is fit using the case-mix adjustor variables and fixed effects for hospices. Adjusted hospice means are then calculated (e.g., using LSMEANS in SAS).

6) Top-box scores are averaged across the items within each multi-item measure, weighting each item equally. If data are missing for a respondent for an item(s) within a multi-item measure, the respondent’s answers to other items within the measure are still used in the calculation of multi-item measure scores. (Please see S.22 below for more details). Top Box Score Calculation:

1) Identify target respondent population (i.e., primary caregivers of hospice patients who died while receiving hospice care from a given hospice in a given month)

2) Identify any exclusions from the respondent population (as described above in S.10)

3) Score each item using top box method, possible values of 0 or 100

4) Calculate mode adjusted top box scores for each item.

5) Calculate case-mix adjusted top box scores for each item for each hospice; case-mix adjustment is a linear regression based approach that adjusts for all variables listed in S.14. Specifically, a regression model predicting item scores is fit using the case-mix adjustor variables and fixed effects for hospices. Adjusted hospice means are then calculated (e.g., using LSMEANS in SAS).

6) Top-box scores are averaged across the items within each multi-item measure, weighting each item equally. If data are missing for a respondent for an item(s) within a multi-item measure, the respondent’s answers to other items within the measure are still used in the calculation of multi-item measure scores. (Please see S.22 below for more details).

## *Submission items*

### 1623: Bereaved Family Survey

5.1 Identified measures: 2651 : CAHPS® Hospice Survey (experience with care)

5a.1 Are specs completely harmonized? No

5a.2 If not completely harmonized, identify difference, rationale, impact: Survey items different as well as coding of items, Target group is also different, We are specifically looking at inpatient Veteran deaths, regardless of hospice use. Currently, the BFS is the only tool assessing enf of life care in a VA inpatient setting. We believe that assessing all deaths, not just hospice deaths, is critical to the VA mission of improving care for all Veterans regardless of choice of level of care at death. We do see any negative impact to interpretability or burden of data collection.

5b.1 If competing, why superior or rationale for additive value: NQF 2651 CAHPS Hospice Survey

Although the Bereaved Family Survey is in many ways similar to the CAHPS Hospice Survey, it provides information on a specific population (Veterans) and measures the quality of care provided a single health care system. Unlike the CAHPS-Hospice, 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 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 the quality data that can be easily and quickly disseminated. The BFS also measures satisfaction of care that are unique to a Veteran population (i.e, survivor and funeral benefits, PTSD). The population 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.

### 2651: CAHPS® Hospice Survey (experience with care)

5.1 Identified measures: 0208 : Family Evaluation of Hospice Care

1623 : Bereaved Family Survey

5a.1 Are specs completely harmonized? Yes

5a.2 If not completely harmonized, identify difference, rationale, impact: N/A

5b.1 If competing, why superior or rationale for additive value: 0208 Family Evaluation of Hospice Care.

The Family Evaluation of Hospice Care Survey (FEHC), developed more than 20 years ago, assesses hospice care experiences from the perspective of bereaved family members. The CAHPS Hospice Survey covers similar domains, but includes important methodological improvements in the response task, and is adjusted for case mix and mode. Additionally, more stringent survey administration guidelines are in place to permit public reporting of the survey results and valid comparison across hospice programs. FEHC measures were maintained by the National Hospice and Palliative Care Organization (NHPCO), which operated a voluntary repository that provided hospice programs with national benchmarks for FEHC measures. With the national implementation of the CAHPS Hospice Survey, NHPCO shut down the voluntary repository. NQF endorsement of FEHC measures was removed in January 2018.

1623 Bereaved Family Survey.

The Department of Veterans Affairs Bereaved Family Survey assesses experiences of veterans' health care in the last month of life from the perspective of bereaved family members. Importantly, the Bereaved Family Survey assesses care for those who die in inpatient settings, regardless of whether they have received hospice care; this is distinct from respondents to the CAHPS Hospice Survey, who include informal caregivers of decedents who received hospice care across a range of care settings (including both inpatient and other settings).

## Appendix F: Pre-Evaluation Comments

No pre-evaluation comments were received.

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