



November 2019 Technical Expert Panel: Hospice Quality Reporting Program Summary Report

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Executive Summary

The Centers for Medicare & Medicaid Services (CMS) contracted with Abt Associates under a Measure & Instrument Development Support (MIDS) Task Order to support the overall Hospice Quality Reporting Program (HQRP) including the development, maintenance, implementation and re-evaluation of structural, process, outcome and composite measures that are reflective of the quality of hospice care provided through Medicare. The HQRP promotes delivery of patient-centered, high-quality, and safe care, and is currently comprised of the Hospice Item Set (HIS) and the Hospice Consumer Assessment of Healthcare Providers and Systems (CAHPS).

Currently, HQRP measures are based on information collected at admission and discharge, with no information being collected in real time on patient conditions and needs during their hospice stay for the purpose of quality measures. Furthermore, there is limited information of physical, social, emotional, and spiritual needs of the hospice patient in the HQRP quality measures. In response to this, CMS is investing in the development of a new hospice assessment instrument, called the Hospice Outcomes & Patient Evaluation (HOPE) to improve care and care planning in real-time and to provide aggregate data on the quality of care provided by a hospice. Data from HOPE will also inform development of new quality measures that will be publically reported by CMS. Abt solicited input on potential new hospice quality measures from a Technical Expert Panel (TEP).

The TEP met in November 2019 to discuss concepts for new quality measures for HQRP. For each measure concept, the TEP was provided a rationale based on information-gathering and policy considerations for each concept. Abt also shared concepts on target populations and exclusions for the measures. The TEP provided thoughtful feedback on HOPE-based measures and claims-based measure concepts; this feedback informs quality measures (QMs) to be developed for HQRP. Measure concepts discussed included pain, dyspnea, caregiver wellbeing, patient preferences, and claims-based measures.

The Abt team and CMS will consider TEP feedback towards these measure concepts that emphasize the importance of patient preferences, reducing provider burden, and changes in patient data if changes in condition occur.

Section 1 – Background and Overview

1.1 *The Hospice Quality Reporting Program (HQRP)*

The Centers for Medicare & Medicaid Services (CMS) is committed to the provision of high quality care for Medicare beneficiaries enrolled in hospice. As part of the Hospice Quality Reporting Program (HQRP) established under section 1814(i)(5) of the Social Security Act, CMS requires Medicare-certified hospices to submit quality data for public reporting and evaluation. The foundation of HQRP includes:

- Data submission by hospices through both the Hospice Item Set (HIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey
- Development of hospice quality measures using the data submitted to CMS
- Public reporting of the quality measures on the CMS webpage
- A two percentage point reduction in the Annual Payment Update (APU) for hospices failing to meet the HQRP requirements.

CMS continues to strengthen the HQRP, and has invested resources in the development of a new hospice assessment instrument and quality measures that can be derived from that instrument. Abt Associates and its subcontractors, under contract with CMS, have been developing the new hospice clinical assessment instrument the Hospice Outcomes & Patient Evaluation (HOPE) that will support hospice quality measurement. At the same time, the Abt team has been engaged in a strategic efforts to solicit input from a variety of stakeholders on clinical assessment and quality measurement. The process is iterative and overlapping, with each activity in this effort providing additional information that is used in subsequent activities.

To help develop and refine hospice quality measures, the Abt team solicited volunteers for a Technical Expert Panel (TEP) and convened that TEP to provide feedback on development of the new hospice clinical assessment instrument and quality measure that might be derived from that instrument. This report provides a summary of the first in-person meeting of the TEP in November 2019. This report also provides background on the purpose of the hospice assessment instrument, its role in quality measurement, and some quality measurement considerations that Abt and CMS have identified.

1.2 *Development of the Hospice Outcomes & Patient Evaluation (HOPE)*

CMS is developing the HOPE assessment instrument to include key items currently in the Hospice Item Set (HIS)¹. In addition to new items for enhanced quality reporting and evaluation. HOPE is intended to provide hospices with real-time patient assessment data to better understand care needs throughout the hospice stay and improve the patient's plan of care. HOPE also supports the development of important outcome-based quality measures. Currently, hospices are only reporting data collected at two time points: admission and discharge. A key aspect of HOPE is data collection during regular encounters with patients throughout the hospice stay. By incorporating real-time assessments of patient and family needs throughout the hospice stay, HOPE will provide a useful dataset for measuring quality outcomes.

¹ Centers for Medicare & Medicaid Services (2020). Hospice Item Set. Retrieved from: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Hospice-Item-Set-HIS>

Note that the development of HOPE has no impact on the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey, which is a survey designed to measure and assess the experiences of patients who died while receiving hospice care, as well as the experience of their informal caregiver. The CAHPS® Hospice Survey samples the primary caregivers of deceased hospice patients who meet specific criteria and asks them about help with symptoms, communication with the hospice team, and their overall rating of the hospice.

1.3 HOPE Objectives

The HOPE assessment instrument is designed to support hospices, patients and their families/caregivers, and CMS by collecting clinical assessment data at multiple time points throughout a hospice episode; HOPE will support hospice care delivery workflow by focusing on domains and times when hospices already assess the patient. HOPE data will be standardized, as all Medicare-certified hospices will be collecting the same information for all patients. The standardized data from HOPE will also be used to develop quality measures, support patient choice of a hospice, support hospice research, and potentially to inform future payment reform.

HOPE is intended to improve the quality of care in hospices for the most vulnerable populations by impacting three stakeholder groups, including hospice clinical staff, hospice patients that includes their family and caregivers, and CMS. HOPE will support hospice staff by improving their understanding of the patient's holistic needs and inform the development of the plan of care. The quality measures derived from HOPE data are intended to help hospices identify opportunities to improve patient- and agency-level experience with hospice care. HOPE is also intended to improve patient and family/caregiver engagement. The publicly reported quality measures will inform and differentiate hospices to assist consumers in selecting a hospice.

Finally, CMS seeks to use HOPE assessment data to develop quality measures that are useful to stakeholders and reflect critical outcomes of care throughout the hospice stay. The quality measures will meet the Meaningful Measures Framework objectives to identify high-priority areas for development while seeking to reduce burden on hospice providers.

Hospice care honors patient, family, and caregiver needs by addressing physical, social, emotional, and spiritual well-being throughout the hospice stay. The following domains were identified through project information gathering activities to be included in HOPE. These domains were identified and validated through literature reviews, key informant interviews, and focus groups. The details of the information gathering activities and findings are discussed in the "HOPE Information Gathering Report"² and "HOPE Focus Group Addendum"³, accessible on the CMS webpage. The domains currently being tested for inclusion in HOPE are:

² Abt Associates (2019). Information Gathering Report: Hospice Quality Reporting Program, Base Year. Retrieved from: <https://www.cms.gov/files/document/hope-information-gathering-report-508pdf.pdf>

³ Abt Associates (2019). Information Gathering Report Focus Group Addendum: Hospice Quality Reporting Program, Base Year. Retrieved from: <https://www.cms.gov/files/document/hopefocusgroupaddendumhgrp508pdf.pdf>

- Actively Dying
- Physical Symptoms
- Function
- Prognosis and Performance Status
- Caregiver Well-Being
- Social and Emotional Needs
- Spirituality
- Shared Decision-Making & Advance Care Planning

1.4 *Future Vision for HQR*

Currently, the HQR is composed of data from both the HIS and CAHPS® Hospice Survey. CMS is developing HOPE to encompass key HIS items, and expand upon them. Ultimately, HOPE will replace the HIS as a data source for HQR quality measures. Thus, CMS will draw upon three complementary sources of data for the HQR (as depicted in the graphic below): 1) administrative claims; 2) standardized HOPE data; and 3) CAHPS® Hospice Survey data.



HOPE and claims data will enhance existing CAHPS® and HIS-based measures by including new outcome-based measures. Quality measures based on HOPE data are expected to be person-centered and reflect the domains of care that are important to CMS, hospices, and patients and their families/caregivers. CMS is also considering developing measures based on administrative claims, a combination of administrative claims and HOPE data, and composite measures—measures that use two or more individual quality measures to produce a single measure score⁴—to further support a robust set of meaningful quality measures.

1.5 *Considerations for Data Collection and Quality Measurement*

As part of the quality measure concept development process, the Abt team also identified a series of foundational considerations based on information gathering activities, such as expert interviews and focus groups. The foundational considerations below provide a general guide for the development of HOPE and outcome-based quality measures.

1.5.1 *Data Collection Considerations*

The foundation of quality measures is based on collecting robust standardized data. These data would be used in calculations necessary to test a quality measure’s validity, reliability, and variability. The Abt team identified two key considerations for data collection that impact the

⁴ National Quality Forum (2009). Composite Measure Evaluation Framework and National Voluntary Consensus Standards for Mortality and Safety— Composite Measures: A Consensus Report. Washington, DC. Retrieved from: https://www.qualityforum.org/Publications/2009/08/Composite_full.aspx

development of HOPE and HOPE-based quality measures: 1) the data collection burden on providers, patients, and caregivers; and 2) whether the data collected supports outcome quality measure calculations necessary for National Quality Forum (NQF) measure endorsement. The Abt team considers NQF requirements necessary to ensure quality measures align with NQF goals.

When considering the burden of data collection, the Abt team takes into account the workflow of the hospice. For example, the hospice workflow adapts to unforeseen changes (e.g. a patient's condition or preferences) on a patient-by-patient basis that may require truncating the amount of data collected to accommodate immediate changes and to ensure that data collection does not interrupt the delivery of high-quality care. Testing HOPE may determine how best to collect information and the optimal timing of data collection to minimize burden and align with the hospice workflow.

Data collection must also support the calculation of outcome quality measures to test validity, reliability, and variability. For example, quality measure concepts may need data that differentiates short- and long-stay patients, captures patient population characteristics, and includes assessment items needed to risk adjust outcome quality measures. Therefore, HOPE items would be tested for reliability and validity to determine whether specific items could be used in outcome quality measure concepts.

1.5.2 *Quality Measurement Considerations*

The Abt team also identified several quality measure development considerations, such as the setting of care, patient and family/caregiver preferences, and length of stay. The Abt team is interested in whether these factors may influence the design of an outcome measure concept to account for differences when testing validity, reliability, and variability in an outcome measure.

Hospice care is provided primarily in a traditional home but can also include nursing homes, assisted-living facilities (ALFs), group homes, and other congregate settings. For example, there are measure concepts that may only be applicable to patients living in the traditional home. Some measure concepts may require accounting for differences in resource intensity, communication pathways, and caregiver education needs. Another important difference in care experiences could result from the more proximate availability of other (non-hospice) professional staff, such as facility staff for hospice residents of nursing homes, in addition to hospice staff, versus patients in their own homes, where care relies more on informal caregivers. Some hospice patients may transition through multiple settings during their hospice enrollment – for example, from home to a hospital – while others will remain in one setting throughout their entire hospice stay. Outcomes which may be affected by the setting of care should be adjusted to account for these differences.

As a requirement of the Medicare hospice benefit, hospices are required to provide emotional and spiritual support for the patient and their family members or unpaid caregivers, as well as bereavement services for the family and caregivers. Thus, potential process quality measure concepts (e.g., whether persons or family with distress are offered treatment and/or visits by social workers, bereavement staff, or spiritual counselors) should consider whether the hospice seeks to address family and caregiver concerns.

Hospice patients present with a variety of terminal conditions and comorbidities, with varying disease trajectories. Variability among hospice beneficiaries in length of stay and disease trajectory complicates efforts to uniformly measure quality, which requires the collection of standardized data for all beneficiaries. For example, patients with longer stays inevitably require

more assessments of pain, symptoms, and psychological needs as a function of the length of stay, increasing the opportunities for data collection, compared with their short-stay counterparts.

1.6 Quality Measurement Concepts

The Abt team developed a list of measure concepts based on findings from the information gathering activities, which included expert interviews and focus group discussions. The Abt team presented information for CMS consideration and prioritization that included concepts based on data to potentially be collected from HOPE and from administrative claims. CMS prioritized measure concepts to closely align with the following principles of CMS's Meaningful Measures Framework:

- Meaningful to patients, clinicians, and providers
- Outcome based where possible
- Minimize level of burden for providers
- Creates opportunity for improvement

Based on findings from the information gathering activities and recognizing quality measure development priorities, Abt and CMS identified four quality measure concepts to discuss at the November 2019 (Year 1) HQRTP TEP meeting convened by the Abt team. These were:

- Pain
- Shortness of breath (dyspnea)
- Caregiver well-being
- Patient preferences

Other measure concepts emerging from the information-gathering process will be revisited at a later date. These include:

- Preventable hospitalization of persons with a do-not-hospitalize (DNH) order
- Falls
- Skin integrity
- Addressing spiritual and religious beliefs

1.7 Organization of the Report

The remainder of this report summarizes the TEP proceedings for the development of hospice quality measures. Section 2 details the TEP responsibilities, composition, and federal stakeholder debrief. Section 3 provides a background of the purpose of the 2019 TEP meeting, meeting topics, and discussion questions. Section 4 summarizes the TEP discussions on specific measure concepts including background, key takeaways, and recommendations. Section 5 provides the main takeaways from the TEP and next steps for hospice measure development.

Section 2 – TEP Responsibilities, Composition, and Federal Stakeholders

2.1 TEP Responsibilities

The HQRP TEP will serve for a three-year period to provide thoughtful input to the Abt team during the process of conceptualization and developing quality measures. The HQRP TEP has committed to do the following:

- Serve the needs of the hospice population, seeking to improve the quality of care provided to hospice patients while also improving their quality of life.
- Ensure that quality measures developed (instrument- or claims-based) are meaningful for the hospice beneficiaries and their families and caregivers, transparent to hospice providers, and useful to consumers.
- Be responsive to project timelines and provide timely responses to requests for input, insights, and feedback.
- Consider quality measures based on HOPE or claims data as a key focus area for their work.

In Year 1 of the project, the TEP will focus on the following objectives:

- Measure conceptualization, input on topics and relative importance
- Refinement of candidate measure list
- Applying measure evaluation criteria to candidate quality measures

In Year 2, the TEP will focus on reviewing revised instrument-based quality measure concepts, instrument testing results, and specifications of quality measures calculated from administrative data.

In Year 3, the TEP focus will be on measure testing, analyzing test results, and reviewing updated measure evaluations and specifications, as well as measure implementation, including responding to questions or suggestions from public comments and stakeholder input.

2.2 TEP Composition

Using the CMS Measures Management System Blueprint (v15.0)⁵ process, Abt solicited nominations for and then formed a TEP to provide input into the development of HOPE and related quality measures.

On August 30, 2019, Abt posted a 30-day Call for the HQRP TEP and a TEP nomination form on the CMS website to solicit TEP nominations and initiate recruitment. The Call for TEP was disseminated through national hospice provider associations, individuals who participated in information-gathering activity expert interviews, and through the CMS regional offices in order to seek a diverse representation of hospice experience (e.g., geographic, sociodemographic, clinical expertise, and technical expertise). The Abt team received nominations from people with a broad range of skills (i.e., clinical and non-clinical); nominees knowledgeable about serving vulnerable populations experiencing limited access to hospice; and geographic diversity.

⁵ Centers for Medicare & Medicaid Services. (2019). CMS Measures Management System Blueprint Version 15.0. Retrieved from: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/Blueprint.pdf>

At the close of the nomination period, Abt selected 12 nominees with diverse backgrounds and a range of perspectives and expertise. One nominee stepped down from the TEP before the first meeting, resulting in 11 HQRP TEP members. Table 1 presents the name and profile of these TEP members; for a detailed background of each TEP member, please see the Appendices.

Table 1. List of HQRP TEP members

Name, Credentials, Professional Role	Organizational Affiliation	Areas of Expertise/Experience; Stakeholder Group/s	Hospice Size (if pertinent)	Hospice Corporate Status (if pertinent)	Geographic Breakdown, City, State of the organization
Connie Anderson, BSN, MBA (former) VP of Clinical Operations	Northwest Kidney Centers	Quality measure development expert	N/A	N/A	Pacific - Kirkland, Washington (Urban)
Ashley Arnold, BSN, Executive Director of Quality	St. Croix Hospice	Hospice and palliative care nurse; trains and manages field staff on data collection for quality measures	Large	For-profit	West North Central - Saint Michael, Minnesota (Rural)
Teresa Craig, BBA, CPA, Director, Client Strategy	Netsmart	Past Executive Director of non-profit, for-profit, urban and rural hospices; works with hospice and home care programs, software, reporting tools and technology	N/A	N/A	South Atlantic - Overland Park, KS/ Dunedin, FL
Kathleen Feeney, JD Chief Judge Pro Tem	Kent County Circuit Court	Pediatric hospice patient caregiver; experience with quality improvement strategies to improve public service	N/A	N/A	Midwest - Grand Rapids, Michigan (Urban)
Maureen Henry, PhD, JD, Senior Manager	University of Utah; Customer Value Partners	Previously a Research Scientist at the National Committee for Quality Assurance	N/A	N/A	West - Sandy, Utah
Bonnie Lauder, RN, PMHNP, MIS, CPHQ, Director of Quality	Visiting Nurse Services of New York	Nurse and healthcare informatics expertise across settings	Large	Non-profit	Middle Atlantic - New York, New York (Urban)
William Matthews, RN, Quality Specialist	Tidewell Hospice (Stratum Health System)	Nurse and responsible for cross organizational collaboration to achieve quality improvement goals	Large	Non-profit	South Atlantic - Sarasota, Florida (Urban)
Jeff McNally, MD, Medical Director	Intermountain Homecare	Physician; focus on standardizing workflow and identify metrics for quality measures	Medium	Non-profit	West - Charleston, Utah (Rural)

Name, Credentials, Professional Role	Organizational Affiliation	Areas of Expertise/Experience; Stakeholder Group/s	Hospice Size (if pertinent)	Hospice Corporate Status (if pertinent)	Geographic Breakdown, City, State of the organization
Sean Morrison, MD, Physician	Mt Sinai	Palliative medicine physician and geriatrician; Clinical and health services researcher	N/A	N/A	Middle Atlantic - New York, New York (Urban)
Bethany Myers, BSN, RN Quality Assurance Nurse	Stella Maris Hospice	Nurse; oversees all aspects of data submission, audits data, and trains staff on quality reporting requirements	Large	Other	Middle Atlantic - Timonium, Maryland (Urban)
Janell Solomon, Director of Compliance	Sangre de Cristo Hospice	Participant in CMS Pilot A; audits quality measure documentation; EHR implementation	Large	Non-profit	Mountain - Pueblo, Colorado (Rural)

2.3 Federal Stakeholder Debrief Session

Following the TEP meeting in November, Abt convened a two-hour federal stakeholder debrief session on January 9, 2020. During this session, Abt summarized the slides from the in-person TEP meeting on November 6 and 7, 2019 (see Section 4), and discussed the key takeaways from the meeting (see Section 5). The federal stakeholders participating in the debrief session agreed that the TEP raised important points for consideration.

Section 3 – TEP Background

3.1 *November 2019 TEP Meeting Purpose*

In Year 1, all members attended a pre-TEP meeting webinar held on November 1, 2019, to introduce themselves to each other, discuss the objectives of the TEP, and review concepts foundational to the instrument and quality measure development work. The foundational background includes principles from the Meaningful Measures Framework and CMS Measures Management System Blueprint. Abt also emphasized that TEP members were being asked to express their views and not (necessarily) the views of their organizations. The Abt team also presented findings from information-gathering activities conducted to date.

On November 6 and 7, 2019, the Abt team hosted the first in-person HQRP TEP meeting to explore the quality measure concepts. The HQRP TEP Charter (see Appendix B) was reviewed by the TEP in advance and ratified on November 6, 2019. The TEP also received the CMS Meaningful Measures Framework Fact Sheet⁶ as a reference regarding the principles of identifying meaningful quality measures for development.

All of the TEP members listed above attended the November 6 (all day) and 7 (half day) meeting in-person except for Kathleen Feeney, who attended much of the meeting via conference call. Both the pre-TEP webinar meeting and the in-person TEP meeting were facilitated by Abt team members Sara Galantowicz and David Stevenson.

3.2 *Topics and Discussion Questions*

The November 2019 meeting began with a review of project background, reaffirmation of the TEP Mandate and Charter, and a presentation on information gathering activities to-date. The Abt team then provided context on measuring the quality of hospice care, touching on the present and future state of instrument-based hospice measures and challenges in measuring hospice quality.

The TEP began discussing a series of concepts for quality measures. Concepts included assessment instrument based- and claims-based quality measures. The concepts discussed were:

- Pain
- Shortness of breath
- Caregiver well-being and preferences
- Claims-based measures/visits provided at the end of life

For each measure concept, the Abt team first presented a rationale for proposing the concept, including the background based on information gathering findings and policy context. The Abt team also presented one or more potential concepts, with details on the target population and potential exclusions and risk-adjustment that would apply to the quality measure specifications. The Abt team shared considerations for deciding how to specify a potential measure, based on some initial testing related to a claims-based measure concept. Following each presentation, TEP

⁶ Centers for Medicare Services (CMS.gov). Meaningful Measures Initiative. Retrieved from: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Meaningful-Measures_Overview-Fact-Sheet_508_2018-02-28.pdf

members engaged in a facilitated discussion, informed by a series of discussion questions, listed below.

Discussion Questions:

1. Do you see this as an important/relevant indicator of quality hospice care?
2. What concerns do you have about this concept?
 - a. Unintended consequences regarding care delivery? Patient experience? Provider behavior?
3. What concerns might you have about attribution of results to individual providers?
4. How would providers in your organization likely perceive this measure? Favorably? What concerns might they have?
5. How might consumers perceive or use this measure? Would it be meaningful?
6. How would your organization use this information for quality improvement?
7. What are your thoughts, recommendations or concerns about future public reporting for this measure? What additional, contextual information would support public reporting? Relative measure values vs. thresholds? State vs. national comparisons?
8. What kind of information would be valuable to stakeholders (providers, patients and caregivers, associations, etc.) in interpreting the results of this measure?
9. How might this concept help address the experience of minority and underserved populations? Other subpopulations, such as rural patients?

Each measure concept summary section below includes a table with a high-level summary of the TEP response and key discussion topics related to:

- The importance of the concept
- Whether the concept is actionable or applicable
- Whether the results of the quality measure are attributable to providers
- Whether the consumer perceives the concept as valuable when publicly reported
- Whether the concept addresses underserved populations' experience with hospice

Section 4 – TEP Discussions and Summary

This section captures the TEP discussion by measure concept topic. Each measure concept topic includes a background discussion to provide context to the measure concept and highlights salient points raised to support the discussion. This section also captures the overarching themes of each measure concept followed by key takeaways and recommendations.

4.1 Measure Concept: Pain

4.1.1 Background

Providing person-centered pain palliation is a hallmark of high quality hospice care. Numerous studies have reported concerns with management of severe pain that impact the quality of life at the end-of-life.^{7,8} One randomized controlled trial involving hospices noted important opportunities to improve pain management.⁹ Although the TEP did not discuss the Calendar Year 2019 final rule that implements provisions of the Comprehensive Addition and Recovery Act (CARA) of 2016, the Abt team recognizes that hospice patients are exempt from opioid restrictions.

The key processes in high quality symptom palliation include: 1) screening; 2) comprehensive assessment that characterizes the etiology and impact of the symptom, and ascertains the patient's desired level of symptom control; 3) initiation of treatment; 4) anticipation and prevention of symptom crises; and 5) continued monitoring of the treatment and adjusting as needed to meet the patient stated goals. In HQR, there are two existing process measures based on the HIS that indicate whether or not a pain screening and assessment have been performed.¹⁰ The pain measure concept discussed during the TEP meeting relates to whether the patient has achieved his or her desired level of pain control.

In listening sessions and expert interviews comprising hospice, palliative care, and end of life experts, there was general support for a quality measure on mitigating or addressing persistent, severe and overwhelming pain. The NQF previously endorsed measure #0209 “*Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment.*” The endorsement of the measure was ultimately withdrawn in part due to implementation challenges specific to reliance on patient report in a population where patients are often unable to report whether their pain was at a comfortable level 48 hours after their initial assessment. There was consensus among TEP members that the management of pain is foundational to palliative care and to move beyond the current HIS-based process measures that document if a pain assessment was completed and whether treatment was initiated. The TEP opined that a pain outcome quality

⁷ Cassell, E. and Rich, B. (2010). Intractable End-of-Life Suffering and the Ethics of Palliative Sedation. *Pain Medicine*, Volume 11, Issue 3, Pages 435–438. Retrieved from: <https://academic.oup.com/painmedicine/article/11/3/435/1886391>

⁸ Parker-Oliver et al. (2008). Barriers to Pain Management: Caregiver Perceptions and Pain Talk by Hospice Interdisciplinary Teams. *Journal of Pain and Symptom Management*, Volume 36, Issue 4, Pages 374–382. Retrieved from: [https://www.jpmsjournal.com/article/S0885-3924\(08\)00200-5/fulltext](https://www.jpmsjournal.com/article/S0885-3924(08)00200-5/fulltext)

⁹ Federal Register Vol. 83 No. 73 16440, Contract Year 2019 Policy and Technical Changes. Retrieved from: <https://www.govinfo.gov/content/pkg/FR-2018-04-16/pdf/2018-07179.pdf>

¹⁰ Centers for Medicare & Medicaid Services (2020). Hospice Quality Reporting Program: Current Measures. Retrieved from: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Current-Measures>

measure concept was of high importance, which echoes the Abt team's information gathering findings.

4.1.2 Discussion

Different types of pain – The TEP discussed different types of pain experienced by hospice patients and how pain may vary across the hospice episode. Specifically, multiple TEP members noted that different types of pain may merit different approaches to measuring outcomes. For instance, several clinicians on the TEP raised considerations such as distinguishing between pain crises, managing and/or reducing severe or moderate chronic pain, and pain etiology that is difficult to address. The TEP noted many hospice patients experience “chronic, ongoing, consistent pain,” which requires a different set of goals in pain management. In addition to distinguishing among the different types of pain, the TEP also discussed the complexities of patients with an opioid use disorder or drug-seeking behavior and how that may impact the measure design. It was noted that patients who are opioid naïve, or have a history with long-term opioid therapy, may require different thresholds for what is considered to be reduction in pain, or defined as a “moderate” level of pain. Although the TEP recognized these complexities, it did not diminish their focus on the importance of developing a pain outcome quality measure.

Assessing pain – TEP members raised several discussion topics related to the assessment of pain and how both the clinical workflow and the timing of the assessment could impact an outcome measure. One TEP member emphasized that the fluidity of pain assessment may make it challenging to capture a decrease in pain within a specific timeframe, as they may experience fluctuation from one past assessment to another. TEP members explored what would be a reasonable measurement timeframe to mitigate or address severe or overwhelming pain. Some TEP members agreed that a 24-hour period was appropriate for assessing whether or not pain has been addressed, but others suggested that the measure concept may need to consider tying types of pain to a variety of thresholds to reduce pain. For example, there were multiple suggestions for determining the threshold for assessing reduction in pain, including limiting the measure to only capture: i) reductions in severe pain and above; ii) pain crises; and (iii) whether or not pain has been reduced from “overwhelming” in a fixed period of time.

Patient preferences for pain control and treatment was also an important theme raised by the TEP. There was a discussion on how to balance the side effects of medication as it relates to pain, drug interactions, and patient and caregiver/ family preferences, including sedation. Some TEP members suggested that the measure concept focus more on whether or not the patient can do the things they want given their pain and focus on a function and Quality of Life (QoL) measure to allow for these type of patient preferences. Similarly, one TEP member suggested focusing on whether a patient's goal was achieved, rather than specifying an absolute target. This TEP member further emphasized that patients often prefer to work towards their own goals of pain management. Members acknowledged that some patients may not be able to reach their goal despite concerted efforts by the hospice, and CMS should avoid penalizing hospices in these cases, such as unmanageable neuropathic pain.

Data Collection - The TEP was supportive of using a type of scale that can reflect a variety of assessments, such as a modification of the Integrated Palliative Outcome Scale (IPOS)¹¹ to

¹¹ Cicely Saunders Institute. (2012). Palliative Care Outcome Scale. Retrieved from: <https://pos-pal.org/maix/pos-in-english.php>

measure pain and symptom outcomes. The modified IPOS currently being tested would align with the TEP's suggestion to include patient preferences and goal attainment as part of the measure. Several of the TEP members supported using an outcome scale to accommodate a wide range of pain assessment scales and suggested that this approach would facilitate implementation of the measure. One TEP member familiar with electronic health record (EHR) development commented that EHRs currently have various embedded pain assessment scales, which may be used to create flags or alerts to drive behavior, such as conducting a follow-up visit. Depending on the measure threshold and timeframe, triggers could be developed to determine the need for follow-up on the assessment of pain or the outcome of the palliation.

Unintended consequences and exclusions specific to the outcome of pain management were considered at length. With respect to the different types of pain and corresponding treatment, there was additional concern voiced about neuropathic pain and whether or not to exclude it from the measure concept. Several clinicians on the TEP suggested that including neuropathic pain in an outcome measure would be difficult, as the timeframe for achieving desired pain relief may be longer than 24 - 48 hours. However, one TEP member expressed that failing to include neuropathic pain may leave it to be included in the next round of measures. In addition, there was concern about how this outcome measure may translate across different settings. For example, assisted living facilities may have unique considerations in terms of state licensure or policies that influence how much assistance is provided to patients for taking medications. Availability of caregivers and how patients make choices about their desired outcomes were important considerations, specifically as they relate to determining whether a medication regimen has been followed. Finally, members expressed concern about unintentionally incentivizing hospices to avoid taking certain patients because their pain levels and medication needs may not fit with the hospice's predetermined formulary.

4.1.3 Key Takeaways and Implications

The TEP discussion articulated several key points for consideration in further development and refinement of the pain measure concept and HOPE. In addition, two areas of further analysis and research were identified to support the refinement efforts.

- Review evidence base and determine the desired outcome or outcome(s) for measurement: pain crisis management; reduction of patient pain; or alignment to patient/caregiver preferences and goals.
- Refine treatment in a measure or measures, including the potential for the exclusion of specific types of pain, such as neuropathic or intentional (i.e., patient preference to tolerate some pain in order to avoid unwanted medication side effects, such as drowsiness).

The TEP suggested further analysis and research specific to neuropathic pain, and to test the IPOS response options to ensure they address considerations related to patient preferences.

Considerations for the draft HOPE assessment include collecting data on types of pain and the relationship between preferences, goals, and the desired outcomes. Finally, it was emphasized by multiple members of the TEP that the guidance for HOPE should include clear instructions on how the lookback period timeframe and type of pain impact scoring.

4.1.4 Recommendations

The discussion on the pain measure concept discussion resulted in several considerations that will be used to inform refinement of the measure concept during development. The TEP suggested that the measure developer consider exploring concepts related to:

- Timely resolution of pain crises
- Achieving patient preferences regarding pain treatment; and
- Impact on quality of life.

TEP members also recommended refining the exclusions to acknowledge the unique nature of neuropathic pain. Based on pending follow-up research on neuropathic pain, the TEP encouraged the measure developer to also consider how this type of pain is either addressed in exclusions or via risk-adjustment. Further, TEP members recommended careful consideration of how location of care is addressed in the measure.

4.2 Measure Concept: Shortness of Breath/Dyspnea

4.2.1 Background

Shortness of breath or dyspnea is a prevalent concern among hospice patients attributed to multiple causes, and thus different treatment approaches depend on the patient's physical condition, emotional well-being, and spiritual needs. Two out of three persons experience dyspnea with diagnoses commonly managed in hospice, such as cancer with lung involvement, chronic obstructive pulmonary disease (COPD), heart failure, and dementia.¹² Dyspnea may also result from chemical imbalances or a low hemoglobin that causes severe tachypnea and the sensation of dyspnea. In addition to the physical needs of the patient, hospice clinicians also work to teach patients and their caregivers how to manage episodes of dyspnea using relaxation and breathing techniques, repositioning, improving airflow with fans, and proper use of oxygen and medications.

The TEP also discussed the effects of pharmacologic treatment, such as opiates, for severe dyspnea. Although the use of oxygen and other medications can help to alleviate the anxiety and feeling of breathlessness, the use of opiates is often necessary, which in combination with benzodiazepines can lead to respiratory depression. In addition to respiratory depression from pharmacologic management, other physiological changes may be mistaken for shortness of breath, particularly by the caregivers, if the patient appears in distress. The TEP recognized the challenges of developing a dyspnea outcome measure when considering the complexities of accounting for multiple causes of dyspnea and effects of treatment from a variety or combination of modalities.

The proposed measure concept discussed with the TEP considers: 1) focus on symptom severity of shortness of breath at rest; and 2) focus on exacerbation of dyspnea during the hospice stay.

4.2.2 Discussion

Evidence Base – TEP members discussed the multiple causes of dyspnea and the varying evidence base for different treatment approaches. TEP clinicians noted that effective treatment of dyspnea requires a considerable amount of training based on varying etiologies. In addition, the TEP members agreed that for the hospice population it is important to consider patient preferences for dyspnea treatment and/or sedation. The TEP also discussed focusing the measure concept on specific diagnoses associated with dyspnea where there is a stronger evidence base

¹² Kamal, A., Maguire, J., Wheeler, J., Currow, D., Abernethy, A. Dyspnea Review for the Palliative Care Professional: Assessment, Burdens, and Etiologies. *Journal of Palliative Medicine*, 14(10): 1167–1172. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3189385/>

for treatment including Chronic Obstructive Pulmonary Disease (COPD), Congestive Heart Failure (CHF), lung cancer, pneumonia, and pulmonary fibrosis.

Several TEP clinicians suggested further research is needed to determine the best approach for the measure concept given all the considerations that impact palliation and management of dyspnea. They suggested one idea for additional research is to explore whether a dyspnea measure could best support the delivery of quality care and avoid unintended consequences caused by medication side effects, by focusing only on disabling dyspnea as a trigger, and considering a time period such as the last few days of life. The TEP suggested restricting the measure denominator to diagnoses with a good evidence base for treatment. In addition, TEP members discussed when to assess for dyspnea and appropriate timeframes associated with any dyspnea measure.

Regarding Patient Preferences, several TEP members discussed whether a patient would indicate treatment intervention preferences that account for the side effects of dyspnea treatment to balance addressing or mitigating the symptom while preserving their end of life wishes. The TEP expressed the importance of preserving patient preferences because meaningful quality measures must reflect the delivery of evidence-based treatment that aligns with the patient's wishes. This discussion supported an initial focus on specific diagnoses where patients may have a better understanding of their preferred or expected comfort levels associated with dyspnea. Several TEP members recommended that patient preference for non-treatment of dyspnea be included in the measure so as to not penalize providers who were unable to bring the symptoms to the patient's desired level.

Unintended consequences were discussed by the TEP to recognize the possibility of medication overuse for patients experiencing dyspnea. The TEP explored ways to identify whether there is medication overuse or appropriate symptom management. Several TEP members suggested capturing medication information from provider self-report to inform the measure, but subsequent discussion raised concerns about the accuracy of these data. As the TEP indicated that dyspnea may be one of the most distressing conditions for the patient's caregiver and/or family members, they raised concern the measure may have unintended consequences such as uninformed decision making and/or unnecessary treatment that may exacerbate the patient's symptoms. For example, intubation of a dyspneic patient has long-term repercussions for care and treatment. Additional considerations raised by members of the TEP included the existing safety evidence for medication combinations leading to respiratory depression. However, there was no conclusion on how to identify these practices or behaviors through measurement without collecting detailed information about a patient's medication regimen and response to the medications with minimal reporting burden.

The topic of Population Differences was raised in a more general nature when considering developing any outcome measure. In the context of dyspnea, geographic differences (e.g., urban or rural) were discussed with regard to the follow-up period to assess and treat dyspnea in a timely matter while considering patient preferences at each follow up. Several members of the TEP highlighted differences between rural and urban locales such as the distance required to conduct follow up visits and the patient's desire for privacy. Oftentimes, rural hospices were unable to conduct prompt follow up visits due to the time it took to travel. Furthermore, rural patients and their caregivers are often more independent, refusing care in certain situations. In contrast, those living in urban locales were identified as often expecting prompt responses and more frequent follow-up visits. Several TEP members also encouraged more thought about risk adjustment or stratification for different populations to account for differences when the measure

is publicly reported. The TEP suggested exploring patient choice when comparing outcomes and to exclude or adjust for patients who have stated their preferences for less communication or fewer visits.

4.2.3 Key Takeaways and Implications

The TEP discussion identified several key areas for further development and refinement of the dyspnea measure concept and HOPE. For the measure concept, the TEP encouraged the exploration of ways to ensure that the measure construct supports the delivery of quality care and avoids unintended consequences, including one construct restricting the inclusion of cases to those patients experiencing disabling dyspnea during the last few weeks of life. This would recognize hospices that are actively addressing the symptoms, while acknowledging that responses to treatment could be unpredictable. The TEP conveyed that hospices want to focus on addressing all symptoms to ensure the patient is comfortable and provide the appropriate level of support to the patient and caregivers. In addition, the TEP suggested the developer consider including patient and caregiver preferences, such as a desire for fewer visits. The measure concept should be restricted to diagnoses with an evidence base for the denominator without bias for patient selection and determining the best mechanism to address patient characteristics.

TEP members identified further analysis and research efforts to support key areas for further development and refinement. To address the reliability of symptom assessment for dyspnea, several TEP members suggested that the measure developer conduct inter-rater analysis on existing symptom assessment data for dyspnea in the draft HOPE field testing. Additional research to identify diagnoses associated with dyspnea with adequate evidence for symptom management was also recommended.

Based on the proposed items, the TEP suggested that the draft HOPE assessment undergo further testing of the response options for a symptom severity scale to determine accuracy for identifying the severity of dyspnea within specific diagnostic cohorts.

4.2.4 Recommendations

The dyspnea measure concept discussion resulted in several suggestions that will be considered to refine the measure concept during development. The TEP recognized the challenges of addressing dyspnea for hospice patients while holding hospices to a higher standard of care by addressing shortness of breath at the end of life and honoring patient and family preferences. To best support hospices in delivering holistic quality care and avoid unintended consequences, the TEP recommended that the measure developer consider these areas for measure concept refinement:

- Address patient preferences for symptom management;
- Address patient preferences for visits;
- Restrict to evidence-based diagnoses for the denominator; and
- Set threshold at “overwhelming”.

Other areas for the measure developer to consider include determining how to address anxiety versus dyspnea, or anxiety accompanying dyspnea, as well as stratifying or risk adjusting the measure to account for rural versus urban locales.

4.3 Measure Concept: Caregiver Well-Being

4.3.1 Background

Medicare defines hospice care as a comprehensive set of services coordinated by an interdisciplinary team tasked with assessing the needs of the patient and caregiver, developing an appropriate plan of care, and updating the patient's plan of care on a regular basis. As part of this process, the interdisciplinary team considers the caregiver's and family's willingness and ability to care for the patient. In addition, Medicare's definition of palliative care includes patient- and family-centered care that involves addressing physical, psychosocial, emotional, and spiritual needs and to facilitate patient autonomy, access to information, and choice. Hospice care also addresses the bereavement needs of the family following the death of the patient. Hospices are required to have structured bereavement programs that recognize and address the needs of family and caregivers after the patient's death. The NQF's framework and preferred practices for palliative and hospice care also recognizes that communication, addressing educational needs, and providing support for caregivers are priorities. In some instances, caregivers are designated to make proxy decisions about preferences and goals of care if the patient is not able or defers to the designated medical power of attorney. Surveys of caregivers show that they experience physical, emotional, financial stress, and burn-out when caring for a loved one, which can also directly impact the care experience for a hospice patient.¹³

In 2019, the OIG issued two reports on the vulnerabilities in hospice care, highlighting patient and caregiver complaints, needs that were not addressed, ineffective symptom management, and hospices providing poor quality of care.¹⁴ These reports highlight issues pertaining to patients, their families, or caregivers not receiving critical information to help them with decision making, or education related to hospice benefits and available services. For example, the Medicare hospice benefit includes inpatient respite care in a Medicare-approved facility to provide relief for the unpaid caregiver for up to five days. The report highlights issues with hospices not making respite care available to caregivers or using the general inpatient benefit in place of respite services.

CMS currently requires hospices to contract with a vendor to collect data from primary caregivers of deceased hospice patients regarding their experience of care using the CAHPS® Hospice Survey. This survey yields a set of standardized metrics that are publicly reported on the Hospice Compare website. Respondents are the primary caregiver, most typically family members. The hospice identifies the primary caregiver from their administrative records, and data collection is initiated two months following the month of the decedent's death. The CAHPS® Hospice Survey supports calculation of the following quality measures:

- Hospice Team Communication
- Getting Timely Care
- Treating Family Member with Respect

¹³ Schulz R, Beach S. (1999). Caregiving as a risk factor for mortality: the caregiver health effects study. *JAMA*. 282(23):2215-2219. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/10605972>

¹⁴ U.S. Department of Health and Human Services Office of Inspector General. (2019). Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity. Retrieved from: <https://oig.hhs.gov/oei/reports/oei-02-16-00570.pdf>

- Getting Emotional and Religious Support
- Getting Help for Symptoms
- Getting Hospice Training
- Rating of the Hospice Care
- Willingness to Recommend the Hospice

Information on CAHPS® Hospice Survey and associated measures was provided to the TEP to offer context regarding current quality measures related to the caregiver's experience. Abt clarified that HOPE implementation will not impact the CAHPS® Hospice Survey or related quality measures. The caregiver well-being measure concept discussion with the TEP began by considering whether there is an opportunity for HOPE to address any gaps in the HQRP related to the caregiver experience. The TEP was asked to consider whether a caregiver well-being measure concept could promote overall caregiver well-being, in particular the assessment of caregivers in real time, their educational needs, emotional or psychological stress, and associated coping or distress.

4.3.2 Discussion

Assessing Caregivers is an important component and standard practice, particularly for hospice. However, the TEP questioned which caregiver outcome/s might be appropriate for a quality measure. TEP members raised the question of defining the issues a caregiver measure might address and what a hospice might be able to address during the relatively short length of stay for many hospice patients. They noted the CAHPS® Hospice Survey already offers retrospective feedback on the patient and caregiver experience of care, but is missing some information regarding caregiver education and the quality of communication with the hospice. Furthermore, TEP members reported that caregivers are often unsure of what services they received. Members of the TEP noted that not all caregivers receive the CAHPS® Hospice Survey - there are size exemptions for participation and exclusion criteria. Some TEP members cited the importance of obtaining feedback throughout the hospice stay and not just after death. One TEP member further suggested that hospices reach out to caregivers at the very beginning of hospice care. However, members had difficulty identifying relevant and actionable real-time metrics for success or a measureable outcome of interest related to the assessment of caregiver well-being, other than identifying whether specific needs are identified, thereby yielding information about processes rather than outcomes.

Communication and Education measure concepts were discussed by the TEP, and several members noted that while good caregiver communication and education do improve patient outcomes, the evidence is currently not sufficient to support a quality metric. TEP members noted that a publicly reported communication metric could encourage hospices to be more consistent in educating and communicating with caregivers on what to expect in hospice, or what is in the hospice benefit. One TEP member noted that, from a caregiver perspective, this type of transparency through public reporting would be valuable. TEP members also noted that, generally, a higher rate of communication with caregivers is correlated with higher caregiver satisfaction.

Well-Being and Burden are interrelated when assessing caregivers for hospice. Caregivers' well-being will directly impact the quality of care for the hospice patient. If a caregiver has difficulty with providing assistance due to stressors of caregiver, it reduces the effectiveness and quality of hospice. A TEP clinician emphasized that training caregivers is paramount in allowing

caregivers to be effective in their roles, but they also need to be able to act on their training based education provided by the hospice. One member also noted that data are currently collected on caregiver bereavement risk and burn-out; therefore, collecting well-being data via HOPE would be reasonable and not unduly burdensome.

Definitions of who is a caregiver can vary, and there are also considerations pertaining to the location of care. The TEP noted that a caregiver measure concept should take into account the differences between the settings where hospice is provided and the role of a caregiver in each of those settings. For example, burn-out of unpaid caregivers in the home has different implications than in the inpatient settings, where paid care is also furnished. It was also emphasized that when multiple family members are caregivers there can be variability amongst the caregivers regarding needs and preferences.

4.3.3 Key Takeaways and Implications

The TEP discussion identified several key areas for further research and refinement of the measure concepts and HOPE. The TEP expressed interest in measuring caregiver well-being and communication. Specifically, there was support to measure caregiver understanding of the hospice benefit. However, overall, TEP members agreed that it would be challenging to measure outcomes for both of these concepts.

There was little analysis and research recommended other than learning of any planned changes for the CAHPS® Hospice Survey. The TEP collectively agreed that a quality measure gap does not exist when the CAHPS® Hospice Survey captures the caregiver experience of holistic person- and family-centered care, which is under its own contract.

Considerations for the draft HOPE assessment include reviewing field testing data from caregiver-specific items and determining if they should be retained in the absence of application to a quality metric.

4.3.4 Recommendations

The caregiver well-being measure concept discussion resulted in a recommendation to not develop a HOPE-based measure at this time. The TEP emphasized that caregiver well-being is important, but struggled to articulate a feasible or meaningful outcome of interest for a quality measure that can be derived from assessment data.

4.4 Measure Concept: Preferences

4.4.1 Background

The National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care (4th Edition) recommendations include that the patient's symptoms (including physical, psychological, spiritual, and social) should be addressed during the dying process and that preferences should be honored.¹⁵ There is broad legal and ethical consensus that the treatment of seriously ill patients and those at the end-of-life should be guided by their values and preferences regarding life-sustaining treatments.¹⁶ Failure to elicit and communicate these preferences can

¹⁵ National Coalition for Hospice and Palliative Care. (2018). Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Retrieved from: https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf

¹⁶ Lorenz et al. (2004). End of Life Care and Outcomes: A Summary. *AHRQ Evidence Report Summaries*. Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK11874/>

result in the intermediate outcome of treatment that is contradictory to patient and family/caregiver values which in turn decreases patient and caregiver satisfaction. High-quality hospice care should include timely advance care planning that captures patient and caregiver preferences for life sustaining treatment, resuscitation, hospitalizations, desire to maintain alertness, and other end of life interventions. Evidence shows that the frequency and quality of communication between hospices and patients/caregivers have positive effects that include alignment of treatment with preferences.¹⁷

CMS currently publicly reports a HIS-based process measure on Hospice Compare regarding treatment preferences. The goal of this measure is to ensure that hospice providers are eliciting and documenting patient treatment preferences. However, this measure has high performance rates and limited variability. In addition, it does not identify meaningful preferences and measureable outcomes.

A measure concept that includes asking a hospice to update patient preferences on a timely basis could help ensure that hospitalizations and revocations from hospice are consistent with patient/family treatment preferences and goals of care. A current quality concern related to capturing and documenting patient and family/caregiver preferences is live discharge. Updating patient preferences on a timely basis may help determine whether the behavior leading to live discharges and/or multiple readmission is hospice- or patient-driven. These live discharges could reflect patient choice or provider behavior. Additionally, such a measure, developed using HOPE assessment data, could also indicate whether the goals of care in regards to hospitalization were addressed early and consistently throughout the care episode. Another important preference to capture and measure is the patient's desired sedation level. Sedation preferences could also be correlated to medication information to monitor dosing.

4.4.2 Discussion

Communication and the quality of a conversation are linked to successful advance care planning. TEP members agreed that hospices need to be held accountable for staff training on care planning conversations to elicit patient preferences. However, they acknowledged that it is difficult, if not impossible, to measure the quality of a conversation. Measuring “did you have the conversation” or documenting the preferences does not provide the level of data needed to develop an outcome measure. It was also emphasized by one TEP member that conversations about preferences are only effective if the patient/caregiver has been prepared for their prognosis. This underscores the importance of education for patients and caregivers about the patient's condition and care.

The topic of Assessing Preferences, including when and how to assess, as well as how to capture changing preferences, was also explored by the TEP. TEP members agreed that early collection of preferences at admission is an important quality goal, but communication challenges presented feasibility issues for updating and capturing changes in preferences. Some TEP members suggested continuous and ongoing collection of preferences that could be updated at interdisciplinary team meetings would be a reasonable metric to capture. There were other TEP members who indicated the difficulty of assessing whether or not preferences had been met for a patient. Many members of the TEP agreed that preferences should be patient-centered and

¹⁷ Hancock et al. (2007). Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliative Medicine*, 21(6), 507–517. <https://doi.org/10.1177/0269216307080823>

customizable. TEP members also suggested that patient and caregiver preferences may differ, so capturing both may be effective. For example, members agreed that measuring whether hospices met patient preferences for the medication management of symptoms and possible sedation is important. They noted that patients should be educated on the side effects of any medications that result in sedation. This should be considered when addressing symptom treatment/management.

Important to Measure – A member of the TEP shared concern that some hospices may not be asking patients and caregivers questions about preferences and goals, and instead are focused on processes for clinical care. A preference measure would incentivize behavior to discuss and collect preferences from the caregiver and patient. The current HIS-based measure concept could be enhanced to include additional preferences as well as the frequency of collection through HOPE.

4.4.3 Key Takeaways and Implications

The TEP discussion identified areas for further research and refinement of the measure concept and HOPE, including:

- Expanding the scope of preferences currently collected (e.g., tube feeding, antibiotics, IV hydration, sedation)
- Stratifying by care setting specifically related to sedation preferences (e.g., Assisted Living Facility vs. Skilled Nursing Facility vs. patients' traditional homes)
- Accounting for shifting patient preferences

Several members of the TEP shared best practices from their organizations. For example, Visiting Nurse Service of New York (VNSNY) uses a script called “Respecting Choices®” for conversations to elicit and document patient preferences.

Considerations for the draft HOPE assessment include review of field testing data from modified IPOS items to determine if sedation preferences can be linked to medical information. In addition, there was a recommendation to include new items for future HOPE versions that indicate (either by a drop down list or free test) whether conversations are happening and the content of those conversations.

4.4.4 Recommendations

The patient preferences measure concept discussion resulted in a series of recommendations for consideration that include several new measure concepts:

- Document patient and caregiver goals in their own words and link to interdisciplinary team updates
- Link symptom management preferences to how and what medication is prescribed
- Link patient preferences measure to paid and unpaid caregiver availability
- Consider structural measures that indicate staff training on meaningful conversations

Other areas for the measure developer to consider include stratifying the measure by care setting.

4.5 Claims-Based Measures Overview

4.5.1 Background

To date, the HQRP has calculated quality measures based on data from the HIS and CAHPS® Hospice Survey. There are opportunities to calculate quality measures with other sources such as

administrative claims. Claims data in particular has minimal collection burden and can be used to assess service utilization. Claims-based measures generally only indicate that care processes occurred, and lack information on the quality of the service or the interaction. Linking claims-based measure results with caregiver experience measures from the CAHPS® Hospice Survey data can help test for validity, reliability, and variability.

The OIG¹⁸ and MedPAC¹⁹ have expressed concerns regarding the HQRP in their recent reports. OIG suggested that CMS develop claims-based information to include in the Hospice Compare or successor website. In response to the recommendation, CMS agreed to develop claims-based measures that may enable beneficiaries and their caregivers to make more informed choices and to hold hospices more accountable for the care they provide.

In response to the concerns raised by OIG and MedPAC, CMS recently completed development of a claims-based measure capturing visits by a nurse or social worker at the end of life, called the “Hospice Visits in the Last Days of Life” (HVLDDL) measure. This measure is based on an existing HIS-based measure pair. This newer claims-based version was submitted to the Measure Application Partnership (MAP) in December 2019, hosted by the NQF, for deliberation.²⁰ Efforts to re-specify the measure began with testing to improve the HIS-based measure pair, one of which had not met CMS’s readiness standards for public reporting. Initial testing results indicated that claims could be used to re-specify the measure, thus reducing burden on hospice providers. CMS is also considering developing hybrid quality measures, which would be calculated using both claims and assessment (HOPE) information. Hybrid quality measures allow for a more comprehensive set of information about care processes and outcomes than claims, and assessment data can be used to support risk-adjustment. One challenge with hybrid quality measures is that they are more complicated to design and test. TEP members were asked to provide feedback on the HVLDDL measure concept and hybrid quality measures in general.

4.5.2 Discussion

The TEP agreed that claims-based measures in some cases are able to capture meaningful utilization rates, as with the HVLDDL measure. There was some concern expressed about claims-based measures’ inability to reflect patient preferences or the quality of services provided. In addition, there was also a comment by one TEP member about the importance of messaging that the goal for a HVLDDL measure was not to achieve “100% compliance,” but rather to perform well relative to peers. The TEP raised a series of general questions about the mechanics of using claims data for quality measurement and how missing and/or late claims would affect measure rates.

¹⁸ U.S. Department of Health and Human Services (DHHS) Office of the Inspector General (OIG). *Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity: An OIG Portfolio*. July 2018. <https://oig.hhs.gov/oei/reports/oei-02-16-00570.pdf>

¹⁹ Medicare Payment Advisory Commission (2019). Report to the Congress: Medicare Payment Policy. Retrieved from: http://www.medpac.gov/docs/default-source/reports/mar19_medpac_entirereport_sec.pdf

²⁰ National Quality Forum Measure Application Partnership. (2019). Retrieved from: <http://public.qualityforum.org/MAP/Forms/AllItems.aspx?RootFolder=%2FMAP%2FMAP%20Post%2DAcute%20Care%20Long%2DTerm%20Care%20Workgroup%2F2019%2D2020%20MAP%20PAC%2DLTC%20Workgroup>

The TEP expressed support for the HVLDDL measure presented, based on a review of analyses including correlation to CAHPS® Hospice Survey data. In particular, they supported the focus on the last days of life using claims as a data source. There was agreement that the measure's focus on visits in the last days of life was a good indicator of quality. However, there were some concerns raised about the level of resources a hospice would need in order to perform well on the measure. One TEP member suggested considering phone calls in addition to in-person visits, as hospices are often unable to conduct follow up visits with remote patients. The correlation analysis between visits at the end of life and satisfaction with care was well received by the TEP as a way to validate the claims-based measure concept. One TEP member shared that a similar measure had been implemented in their hospice organization was met with little resistance. The measure in this specific case focused on comparisons of rates and not thresholds. One TEP member suggested comparing hospices that successfully receive service intensity add-on (SIA) payments with measure performance. In regard to the messaging of the measure to align with the SIA payment as finalized in the FY 2016 Hospice Wage Index and Payment Update final rule, there was no consensus for or against.

Hybrid measure concepts in general were well received by the TEP. The TEP agreed that it would be valuable to focus on utilization events such as hospitalizations and whether such events were concordant with patients' preferences and goals. Claims data paired with HOPE data would provide more context.

4.5.3 Recommendations

As next steps for the Visits measure, the TEP suggested that the measure developer consider the public reporting values for the measure to determine whether the measure should report rates or comparative performance (e.g., "better than" or "worse than"). It was also suggested that the measure developer conduct further analysis and research to examine the relationship between SIA payments and Visits measure performance.

Section 5 – Conclusions

5.1 Key TEP Recommendations

During a summary discussion at the conclusion of the meeting, the TEP identified the pain measure concept as a priority for development, indicating that symptom management of pain is critically important in hospice, and it is what hospice patients, families, and caregivers typically care about most. On the consumer side, the TEP agreed that the preference measure concept along with goal setting is important from a public reporting standpoint. Reporting whether or not a hospice meets patient goals on Hospice Compare or successor website would be valuable to consumers, hospice patients, families, caregivers, and other stakeholders. The TEP's discussion on the dyspnea measure concept indicated that CMS and the measure developer would need to consider the complex issues raised by the TEP surrounding denominator restrictions and geographic considerations. There was little support from the TEP for pursuing a caregiver well-being measure concept at this time.

There were several overarching themes that emerged from the individual measure concept discussions that could be considered across the development of all new hospice measure concepts.

1. Location of care: The TEP encouraged the measure developer to consider ways, either by stratification or limiting a measure's target setting, to account for differences across locations of hospice services and the distance providers must travel to patients.
2. Communication and education are fundamental part of hospice, specifically for helping patients and caregivers understand what to expect in the dying process. Education on symptoms and what patients and families and caregivers should expect was identified as a priority topic.
3. Capturing patient and caregiver preferences not only supports advanced care planning, but it is also an integral part of symptom management and goal setting. Effective hospice care includes capturing preferences early on and at regular intervals.

Similar to the overarching themes, there were a series of general recommendations made by the TEP that have direct implications for the timing of HOPE data collection:

1. Meaningful changes in patient status should trigger data collection. This is especially important when there is a change such as a fall, or any event that might change the patient's trajectory. The TEP suggested that there be integration with other data collection, such as EHR, so that relevant changes in patient status prompt an update.
2. Account for changing patient preferences and goals through a living document that can be updated at appropriate times.
3. Reduce provider burden of updates to HOPE by itemizing so that completion of the whole instrument is not required at each data collection time point.
4. Align the collection of HOPE data with regular updates such as bi-weekly IDG, and the 90 and 60 day recertification. It is important to note that there was one TEP member who disagreed with collecting HOPE data for each IDG meeting.

In addition to measure concept priorities, cross-cutting recommendations, and HOPE time-point collection, there were two additional measure concepts suggested by the TEP for future exploration. These included:

1. Skin integrity and prevention of wounds.
2. Prevention of falls, which is a safety concern for all hospice patients, across all settings of care. The TEP recommended adding this measure to the priority measure concept list.

5.2 *Further Analysis and Research*

The Abt team considered the TEP recommendations and identified priority areas of further analysis and research in 2020 and 2021 to support refinement of the measure concepts and HOPE:

Measure Concept: Pain

- Review evidence base and determine the desired outcome or outcome(s) for measurement: pain crisis management; reduction of patient pain; or alignment to patient/caregiver preferences.
- Test assessment items that address considerations related to patient preferences.
- Conduct research into the rationale for use of a modified Integrated Palliative Outcome Scale (IPOS) as part of patient assessment.
- Refine treatment in a measure or measures, including potential exclusion, of specific types of pain, such as neuropathic or intentional.
 - Conduct a review of recent literature on neuropathic pain in the context of hospice.

Measure Concept: Shortness of Breath/Dyspnea

- Conduct inter-rater reliability analysis on HOPE testing data from item(s) related to dyspnea.
- Test feasibility and reliability of follow-up in 48 hours/2-days after a report of “overwhelming” impact of dyspnea.
- Identify diagnoses associated with dyspnea.

Measure Concept: Caregiver Well-Being

- Explore measurement of caregiver well-being and communication.
- Explore measurement of caregiver understanding of the hospice benefit.

Measure Concept: Preferences

- Analyze differences by care setting specifically related to patient preference for sedation in management of symptoms (e.g., Assisted Living Facility vs. Skilled Nursing Facility vs. patients’ personal homes).
 - Review HOPE field testing data of modified IPOS items to describe association of patient preferences to prioritize symptom reduction over potential treatment side effects (e.g., sedation) with patient characteristics and assessment information.
 - Consider including new items for future HOPE versions that indicate (e.g., via pick-list or free text) whether or not conversations are happening and the content of those conversations.
- Research how best to account for shifting and evolving patient preferences.
 - Review existing frameworks regarding preferences and goal-setting, including the Visiting Nurse Service of New York (VNSNY) evidence-based script, “Respecting Choices®.”

Lastly, in the context of the claims-based measures overview discussion, the TEP suggested that the measure developer consider the public reporting values for the measure to determine whether the measure should report rates or comparative performance (e.g., “better than” or “worse than”).

Appendices

Appendix A: TEP Bios

Connie Anderson is the former Vice President of Clinical Operations at Northwest Kidney Centers, where she spent forty-four years working extensively in quality measure development. Ms. Anderson is currently the Co-Chair of the End Stage Renal Disease Standing Committee for quality measures and has been actively involved with the National Quality Forum (NQF) for fifteen years. She is also an international resource for those interested in home hemodialysis and is known for her humane care of renal disease patients. Ms. Anderson received her BSN from University of Washington and currently lives in Kirkland, WA.

Ashley Arnold is the Executive Director of Quality at St. Croix Hospice, which is a large, for-profit facility located in Oakdale, Minnesota. As a certified hospice and palliative care nurse, Ms. Arnold has a combination of clinical and managerial experience. At St. Croix Hospice, she has delivered hospice care directly, while also training and managing field staff on data collection for quality measurement. Ms. Arnold received her BSN from Saint Catherine University and currently lives in Saint Michael, Minnesota.

Teresa Craig is the Director of Client Strategy at NetSmart, an electronic health record (EHR) vendor for post-acute care communities. Ms. Craig has twenty-six years of experience working with hospice and home care programs, software, and technology. She has served as Executive Director, CIO, CFO, and Vice President for both non-profit and for-profit hospice providers across multiple states and in both urban and rural locations. She has also served on the Quality Council for these hospice providers, while overseeing the development of home care software and reporting tools. Ms. Craig received her BBA from Wichita State University and currently lives in Tampa, Florida.

Kathleen Feeney is the Chief Judge Pro Tem of the Kent County Circuit Court in Grand Rapids, Michigan, where she routinely employs quality improvement strategies in evaluating and improving public service. Ms. Feeney serves on numerous statewide workgroups to improve child protection proceedings and the provision of care to medically fragile children. Following the death of her one-year-old daughter in 2000, Ms. Feeney and her husband joined the Family Center Care Advisory Council at the Helen DeVos Children's Hospital to support clinicians in making hospice care more patient-centered. Ms. Feeney received her JD from The University of Illinois and currently lives in Grand Rapids, Michigan.

Maureen Henry is a Senior Manager at Customer Value Partners, a management consulting company. In her previous role as Research Scientist at the National Committee for Quality Assurance (NCQA), Ms. Henry led a learning collaborative of palliative care organizations to use quality improvement techniques to evaluate patient-defined measures in serious illness care, as well as a project to develop care coordination measures for the Medicare Advantage Program. Ms. Henry has also served as the President of the Utah Hospice and Palliative Care Organization, the Executive Director of the Utah Commission on Aging, and the Director of Utah's Aging and Disability Resource Connection (ADRC). Ms. Henry received her PhD from the University of Utah, her JD from The University of California at Berkeley, and her BA from the University of Delaware. She currently lives in Sandy, Utah.

Bonnie Lauder is the Director of Quality at the Visiting Nurse Service of New York's Hospice and Palliative Program and a registered nurse. Ms. Lauder has twenty-five years of experience in the field of healthcare informatics and quality, with a focus on interpretation and implementation of regulatory standards and measures. Since 2005, she has successfully designed and

implemented core clinical and management delivery systems across hospital, home care, and hospice continuums using the Institute for Healthcare Improvement's (IHI) Collaborative Model for Achieving Breakthrough Improvement. Ms. Lauder is also a published author on topics related to evidence-based care implemented at the interdisciplinary care team level. She received her BSN from the State University of New York at Downstate and her Master's in Information Systems from Pace University. Ms. Lauder currently lives in New York, NY.

William Matthews is a Quality Specialist Nurse for Tidewell Hospice, a large for-profit facility in southeast Florida. He is regularly involved in the process of abstracting, submitting, and analyzing the Hospice Item Set (HIS) and Consumer Assessment of Healthcare Providers & Systems (CAHPS) data that is currently required by the Hospice Quality Reporting Program (HQRP), and is familiar with providing the bedside care that quality measures assess. He also collaborates with clinical management, the education department, and the IT department to ensure a comprehensive approach to achieving quality improvement goals. Mr. Matthews received his RN from Manatee Community College and his BA from the University of South Florida. He currently lives in Sarasota, FL.

Jeff McNally is the Senior Medical Director of Homecare/Hospice/Palliative Care/Post-Acute Care at Intermountain Healthcare, a Utah-based, not-for-profit system of hospitals and other health service entities. After twenty-three years of providing emergency medicine care, Dr. McNally transitioned to hospice care. Currently, he works on standardizing workflows and determining metrics to accurately measure the quality and experience of care. Dr. McNally received his MD from the University of Washington and his BA from Stanford University. He currently lives in Salt Lake City, UT.

Sean Morrison is a practicing palliative medicine physician and geriatrician, clinical and health services researcher, and recently-appointed Chair of the Brookdale Department of Geriatrics and Palliative Medicine at the Icahn School of Medicine at Mount Sinai. Dr. Morrison has published over 200 research articles, most of which focus on improving the management of pain in older adults and on developing and evaluating models of palliative care delivery in hospitals and the community. Dr. Morrison received his BA from Brown University and his MD from the University of Chicago. He currently lives in New York, NY.

Bethany Myers is a Quality Assurance Nurse at Stella Maris Hospice, a large facility in Timonium, Maryland. In her current role as a practicing clinician, Ms. Myers transmits completed HIS to CMS for hospice homecare and inpatient units, while reviewing CASPER report for errors or warnings, compiles quality assurance data, audits admission charts, and educates staff about reporting and patient care issues. She also monitors hospice quality data and synthesizes results for other nurses. Ms. Myers received her BSN from Messiah College and currently lives in Timonium, MD.

Janell Solomon is the Director of Compliance at Sangre de Cristo Hospice, a large non-profit facility in rural Colorado. In her current role, Ms. Solomon performs audits of quality measurement documentation and trains staff on how to improve documentation of responses for HIS elements. She ensures the integration of other necessary elements such as payroll, pharmacy, and clinical supply needs. Ms. Solomon was a participant in the Centers for Medicare Services (CMS) HEART Pilot A Test, while also leading numerous beta tests in coordination with Sangre de Cristo's electronic health record (EHR) vendor to improve the efficiency and capability of new software. She currently resides in Pueblo, CO.

Appendix B: TEP Charter

Technical Expert Panel (TEP) Charter

Project Title:

CMS Hospice Quality Reporting Program Patient Assessment Instrument and Quality Measure Development

Project Overview:

The Centers for Medicare & Medicaid Services (CMS) has contracted with Abt Associates to develop a hospice assessment instrument and corresponding set of Quality Measures in support of the Hospice Quality Reporting Program. The instrument and development work is under CMS contract number 75FCMC18D0014, and the task order number is 75FCMC19F0001. For purposes of receiving a broad range of input and engagement throughout the course of its tasks, Abt Associates will convene groups of stakeholders and subject matter experts who can contribute direction and thoughtful input during measure development and implementation.

Project Objectives:

1. Develop an assessment instrument that supports quality measurement for hospice care.
2. Develop quality measures based on the assessment instrument for the CMS Hospice Quality Reporting Program.
3. This work will address patient, family, and caregiver needs, as well as electronic health record (EHR) and other health information technology (HIT) requirements/issues.

TEP Objectives:

Objectives of the TEP will change over the course of the project period.

- Year one:

Measure conceptualization, including input on topics and importance; refinement of candidate measure list; applying measure evaluation criteria to candidate measures; and assessing feasibility.

- Year two:

Measure specification, including technical specifications and risk adjustment.

- Year three:

Measure testing, including analyzing test results and reviewing updated measure evaluations and specifications.

Measure implementation, including responding to questions or suggestions from public comments and stakeholder input.

Guiding Principles:

This TEP serves the needs of the hospice population. Its members are committed to improving the quality of care given to these patients while also improving their quality of life.

This TEP will ensure that the developed hospice assessment instrument is meaningful for the hospice population and transparent to hospice providers.

This TEP will be responsive to project timelines. Its members will provide timely responses to requests for input, insights, and feedback.

This TEP will consider quality measures based on the hospice assessment instrument as a key focus area for their work.

Scope of Responsibilities:

Standing TEP Structure with a three-year term of membership. The first year focus will be primarily on discussions about the importance and usability of measure concepts and potential measures. The TEP will review literature reviews and environmental scans and discuss quality concerns such as measure gaps and alignment across programs and settings and overarching goals for improvement.

The second year will focus on the feasibility of measures based on alpha testing, evidence base, and adequacy of measure specifications.

The third year focus will include input on beta testing and measure evaluation criteria and implementation issues.

Estimated Number and Frequency of Meetings:

One annual in-person TEP meeting and up to three annual teleconferences. The total project duration is November 2019 – November 2022.

Date Approved by TEP:

November 7, 2019