2020 Technical Expert Panels: Hospice Quality Reporting Program Summary Report

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Table of Contents

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 currently rests on:

- Submission by hospices of both Hospice Item Set (HIS) [1] and Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey data
- Development of hospice quality measures using the data submitted to CMS
- Public reporting of these quality measures on the CMS webpage

CMS seeks to define, measure, and incentivize high-quality hospice care by prioritizing high-impact quality measure areas that are meaningful to patients, their families and caregivers, in line with the priorities in the Meaningful Measures Framework (MMF)[2]. Over the next several years, CMS anticipates expanding the HQRP to include additional meaningful quality measures.

Abt Associates and its subcontractors (the Abt team), under contract with CMS, have been developing the new hospice clinical assessment instrument, known as the Hospice Outcomes & Patient Evaluation (HOPE), which will support hospice quality measurement. HOPE is expected to replace the current HIS data collection tool. The primary goals for HOPE are to reflect the care needs of people through the dying process, prioritize the safety and comfort of individuals enrolled in hospice nationwide, and promote person-centered care that prioritizes psychosocial, spiritual, and emotional support.

The Abt team solicited applicants for a Technical Expert Panel (TEP) to help develop and refine new hospice quality measures, focusing on measures derived from HOPE. The TEP first convened in November 2019 and was chartered for three years. The TEP convened again in March and November 2020, and a subset of TEP members convened between May and June 2020 as a workgroup. This report provides a summary of the TEP activities that occurred in 2020, and the recommendations from each.

1.2 *Development and Objectives of the Hospice Outcomes & Patient Evaluation*

CMS is developing HOPE to include key HIS items, supplemented with new items for enhanced quality reporting and evaluation. HOPE is intended to provide hospices with real-time patient assessment data, so they can better understand patients' care needs throughout the hospice stay and improve their plans of care. HOPE will also support developing important outcome-based quality measures and process measures that can help support or complement the outcome

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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

2 Centers for Medicare & Medicaid Services (2019). Meaningful Measures Hub. Retrieved from: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/MMF/General-info-Sub-Page

measures. Currently, through the HIS, hospices only report data collected at two time points: admission and discharge. A key aspect of HOPE is that patient assessment data collection can occur during routine 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 robust and useful dataset for measuring quality outcomes.

Note that HOPE development has no impact on the CAHPS® Hospice Survey, which is a caregiver 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.

HOPE is designed to support hospices, patients and their families/caregivers, and CMS by collecting clinical assessment data at multiple time points throughout a hospice stay. HOPE will support hospice care delivery workflow by focusing on domains and times where and 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 through three stakeholder groups: 1) hospice clinical staff, 2) hospice patients, including their families and caregivers, and 3) CMS. Specifically, HOPE will support hospice staff by improving their understanding of the patient's holistic needs and informing 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 hospice care delivery. 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, HOPE-based quality measures that reflect critical care outcomes and care processes throughout the hospice stay will enable CMS to meet the Meaningful Measures Framework objectives of identifying 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. Project information gathering activities identified and validated HOPE data collection domains through literature reviews, key informant interviews, and focus groups. The details of the information gathering activities and findings are discussed in the "Base Year Information Gathering Report"[3] and "HOPE Focus Group Addendum,"[4] accessible on the CMS webpage. The domains currently being tested for inclusion in HOPE are:

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[3] 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

[4] Abt Associates (2019). Information Gathering Report Focus Group Addendum: Hospice Quality Reporting Program, Base Year. Retrieved from: https://www.cms.gov/files/document/hopefocusgroupaddendumhqrp508pdf.pdf

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

1.3 *Future Vision for HQRP*

Currently, the HQRP leverages 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 HQRP quality measures. CMS is also developing measures based on administrative claims data, such as the Hospice Visits in the Last Days of Life measure. In the future, CMS will draw upon three complementary sources of data for the HQRP (as depicted in the graphic below): 1) administrative data (e.g., claims); 2) standardized HOPE data; and 3) CAHPS® Hospice Survey data.

HOPE and administrative data will enhance the HQRP through new process and 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. In addition, CMS intends to explore a combination of administrative and HOPE data, and composite measures—measures that use two or more individual quality measures to produce a single measure score[5] – to further support a robust set of meaningful quality measures.

[5] 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

2. TEP Responsibilities and Composition

2.1 *TEP Responsibilities*

The HQRP TEP was convened to provide thoughtful input to the Abt team during the quality measure conceptualization and development process. The HQRP TEP has committed to do the following:

- Serve the needs of the hospice population by seeking to improve the quality of care provided to hospice patients while also improving their quality of life.
- Ensure that quality measures developed, whether 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 focused on the following objectives:

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

In Year 2, the TEP focus is on providing input on revised measure and technical specifications of a measures calculated from assessment data, as well as risk adjustment and exclusions.

In Year 3, the TEP will focus on refined measure specifications, preliminary measure calculation, and testing results from early HOPE alpha data.

2.2 *TEP Composition*

Using the CMS Measures Management System Blueprint (v15.0)[6] 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 solicited TEP nominations and initiated recruitment by posting a 30-day Call for the HQRP TEP and a TEP nomination form on the CMS website. 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.

[6] 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 (Note: the Blueprint has been updated since this time, and Version 16.0 is now available)

After 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 Appendix A.

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 – Urban Kirkland, WA
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 – Rural Saint Michael, MN
Teresa Craig, BBA, CPA, Director, Client Strategy	Netsmart (Retired 2020)	Past Executive Director of non-profit, for-profit, urban and rural hospices; worked with hospice and home care programs, software, reporting tools and technology	N/A	N/A	South Atlantic - Urban 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 - Urban Grand Rapids, MI
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 - Urban Sandy, UT
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 – Urban New York, NY
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 – Urban Sarasota, FL
Jeff McNally, MD, Medical Director	Intermountain Homecare	Physician; focus on standardizing workflow and identify metrics for quality measures	Medium	Non-profit	West – Rural Charleston, UT
Sean Morrison, MD, Physician	Mt Sinai	Palliative medicine physician and geriatrician; Clinical and health services researcher	N/A	N/A	Middle Atlantic – Urban New York, NY
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 – Urban Timonium, MD
Janell Solomon, Director of Compliance	Sangre de Cristo Hospice	Participant in CMS Pilot A; audits quality measure documentation; EHR implementation	Large	Non-profit	Mountain – Rural Pueblo, CO

3. Spring 2020 TEP Webinar

3.1 *Meeting Purpose*

Abt held a webinar with the TEP on March 30, 2020 to solicit input on quality measures calculated from existing data, including administrative claims data. Specifically, the Abt team sought feedback on draft measure concepts referred to as the Care Composite Measure (now called the Hospice Care Index) and the Weekend Visits Measure. Ten TEP members participated in the webinar. Dr. Sean Morrison was unable to attend so he provided feedback during a separate call with the Abt team on June 29, 2020.

3.2 *Topics and Discussion Questions*

The March 2020 meeting began with a review of the project and TEP goals. The Abt team then provided context on measuring the quality of hospice care, touching on the present and future state of HQRP measures.

The Abt team presented two concepts for claims-based quality measures, based on Medicare Fee-for-Service administrative claims data. The measure concepts discussed are described in the section below. Abt sought input on these concepts to inform whether CMS should pursue further development of these concepts as claims-based quality measures.

3.3 *Claims-Based Hospice Care Composite Measure*

3.3.1 Background

Previously, CMS developed and implemented a composite of population metrics calculated using Medicare Fee-for-Service claims data, to help monitor hospice benefit utilization as part of hospice payment reform. Separately, during Abt's information-gathering efforts, many of the metrics used in this composite emerged as measure concepts identified as potentially useful for hospice quality reporting. CMS became interested in whether this existing composite could be leveraged to report information on hospice quality.

The composite was identified as potentially helpful in measuring quality because its construction allows CMS to identify hospices that consistently exhibit multiple concerning patterns of care as identified by CMS's informational gathering activities. Abt presented to the TEP specifications for 11 individual indicators, as well as details on how the composite measure is constructed from these 11. Abt sought TEP input for two reasons:

1. The composite is based on an approved National Quality Forum (NQF) approach, but it differs from most quality measures in that while the indicators have their own numerators and denominators, the index score is not composed of a numerator and denominator. Abt sought TEP input on how well consumers would understand and interpret the composite measure's score.
2. Abt has explored which individual measures to include in the composite to produce the most meaningful measure results. Abt sought TEP input on whether all individual indicators included in the composite used in payment reform also should be included in the composite when used for quality measurement.

To calculate the current draft quality measure composite, Abt identified hospices within each individual measure category that met a defined criterion. A hospice's composite score was then

calculated as the total number of instances across the 11 individual indicators in which the hospice was identified as meeting the criteria. Abt also shared the draft measure testing results with the TEP, demonstrating that considerable variation existed for the composite score across hospices, with notable patterns of variation by hospice size and profit status. Abt also demonstrated that the Care Composite Measure was correlated with existing CAHPS® Hospice Survey scores, further validating its use. In addition, CMS submitted the measure to the NQF's Measures Under Consideration for public comment and received conditional support for rulemaking, contingent on endorsement by NQF's Measure Applications Partnership.

3.3.2 Discussion

The TEP showed general support for the Care Composite Measure, while noting that providers (hospices) and consumers (patients and caregivers) may interpret and act on this information differently.

For providers, the Care Composite Measure could provide actionable feedback. A Care Composite Measure could help highlight potential areas for intervention or improvement. "If I presented this to my hospice leadership team, they'd be excited," one TEP member noted, and added that "granular detail would… be helpful only for providers." Another TEP member inquired about the measurement of specific indicators, such as "live discharges," for which "there doesn't seem to be an industry standard."

While most TEP members agreed that the Care Composite Measure would provide actionable information for the providers, they noted reporting this measure publicly would require additional context to meaningfully inform consumer choice. Because patients and caregivers may not "always understand the importance [of indicators]," the Care Composite Measure may be "overwhelming." For instance, "most people don't even understand why there would be a live discharge within the first seven days" — a confusion that might undermine an element of the composite measure.

To address consumer needs, several TEP members recommended reporting all of the composite indicators to providers, but "streamlining" the information that is publicly reported and/or providing additional, accessible information to help consumers contextualize and correctly interpret the information. A TEP member suggested that, ideally, a consumer should be able to "hover over each component [on a webpage] and get the lay description." The TEP concluded that with a clear and concise presentation, the Care Composite Measure could benefit consumers. Caution should be taken to prevent ambiguity in interpretation.

In addition to general concerns about consumers' interpretation of the Care Composite Measure, several TEP members raised questions about the measure's individual components. One TEP member expressed a belief that not all of the 11 individual measures belong in the same composite, and that further consideration is needed regarding the selection of sub-measures. For consumers, "some of these measures are far more important than others"; some, like weekend visits, are "critical to know about," while other measures are "more dependent on the community and their [specific] expectations."

The TEP had mixed feedback regarding the use of CAHPS® Hospice Survey scores to validate the measure. First, there was concern that the Care Composite Measure would simply repeat the information already collected by CAHPS® scores if CAHPS® scores were used to validate the

indicators and exclude indicators that were not strongly correlated. The Abt team clarified that, rather than being redundant, the different nature of the two sources of data (Medicare hospice claims compared to caregiver accounts) would make the measures complementary rather than redundant. Also, similar to the HIS-based Comprehensive Assessment Measure, the claims-based Care Composite Measure could highlight areas for clinical intervention, and thus give providers additional insight to help them improve their CAHPS® scores. Finally, because claims data are already collected for payment purposes, the care composite measure would not impose additional burden on providers.

Some TEP members also questioned the fundamental usefulness of CAHPS® Hospice Survey data as a validator for a Care Composite Measure, because of their concerns that the CAHPS® data themselves may not be valid in some cases. Several TEP members reported that in some instances, caregivers of people in assisted living facilities (ALFs) have confused hospice staff with ALF staff, and used the CAHPS® survey to provide feedback on the ALF's quality of care rather than the quality of the hospice care received while residing at the ALF. These TEP members expressed concern that this potential validity issue would be most acute in areas where ALFs are abundant, though respondents in ALFs represent a small proportion of all survey respondents.

The TEP also discussed the value of a "long length of stay" metric — a component of the Care Composite Measure shared with the TEP. Several TEP members noted that interpretations of this metric may differ between providers and consumers; a long length of stay could appear "negative" for a hospice provider, but "a consumer might prefer a hospice with a long length of stay." One TEP member recommended removing this component altogether, in recognition that it may perpetuate a certain stigma around end-of-life care. Because hospice is already viewed by many as a "death sentence," consumers "will not resonate with a QM [quality measure] that promotes enrolling in a hospice that 'kills you faster.'" In this case, patients and caregivers might opt for, rather than avoid, a hospice known for its long lengths of stay. This member also stated that this measure is appropriate for payment monitoring but not for quality measurement. Meanwhile, another TEP member noted that nursing visits typically decrease as length of stay increases and encouraged further research regarding this correlation.

3.3.3 Recommendations

- Analyze visit minutes by all staffing types in the first 7 days of hospice service
- Consider changing 'early live discharge' to 'live discharge within 7 days of hospice' and 'readmission to hospice within 30 days'
- Consider whether or not 'hospice length of stay greater than or equal to 180 days' has value for consumers
- Further research was suggested regarding a correlation noted between nursing visits decreasing as length of stay increases
- Discuss evidence around the use of CAHPS® Hospice Survey data as a validator for measures under development

3.4 *Weekend Visits Measure*

3.4.1 Background

The Hospice Conditions of Participation (CoP) at 418.100(b)(2) state: "Nursing services, physician services, and drugs and biologicals (as specified in §418.106) must be made routinely available on a 24-hour basis 7 days a week. Other covered services must be available on a 24-hour basis when reasonable and necessary to meet the needs of the patient and family." Thus, the Office of Inspector General (OIG) has recommended that CMS develop claims-based measures focusing on how often hospice visits on the weekends occur.

In a previous analysis of hospice visits by a nurse or social worker in the last three days of life, Abt found patients dying on Monday have the lowest rates of these visits (i.e., when the last three days included two weekend days)[7]. In addition, the average rate of hospice visits is much lower on weekends than on weekdays, and some holidays have lower rates than others.

In light of these observations, Abt developed two potential ways to conceptualize "weekend visits" as a measure for hospice providers: 1) weekend days without any visits, and 2) percentage of patients that never had a weekend visit. Both concepts would encompass all the time a patient spent receiving hospice care, and would not be isolated to the last days of life.

Abt acknowledged several potential drawbacks to these measure concepts. Notably, the weekend visits measure does not account for patient need. In other words, providing fewer visits on weekends does not necessarily mean that the services were not available when patients had an urgent need, or that the hospice did not come during an emergency. In fact, visits might be lower on weekends because caregivers or extended family/friends may be more likely to be around (and the presence of hospice staff could be seen as intrusive).

3.4.2 Discussion

Most TEP members stated that a "weekend visits" measure would provide valuable and "concrete" information to patients and caregivers. According to one TEP clinician, hospices tend to receive more calls during weekends, when family caregivers are likely to be at home. Meanwhile, many TEP-member proponents of the measure alluded to their own experiences as family caregivers. One TEP member recalled the "horrible" experience of convincing a pharmacy to dispense necessary seizure medication, because she "did not have access to a hospice" during that weekend; another described the frustration around not being able to get a weekend visit for her mother-in-law during her last days of life. The desire among many caregivers for around-the-clock care, combined with the increased prevalence of reported symptoms during weekends, suggests that a "weekend visits" measure would be well-received by consumers.

However, a few TEP members acknowledged that the provision of weekend visits does not always correlate with patient satisfaction. One TEP member stated: "sometimes, visits go up on weekends when patient needs are not able to be met during the week — so, it's not really a useful measure." According to one TEP member, the existing "visits at the end of life" measure is sufficient, without the itemization of weekend visits.

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[7] Abt Associates (2019, November 6-7). *Hospice Quality Reporting Program: Measure Development Technical Expert Panel* [Presentation], Linthicum, MD, United States.

In addition to the existing "visits at the end of life" measure and the proposed "weekend visits measure," one TEP clinician recommended "immediate bereavement visits" as an additional claims-based measure, particularly because many families "get distressed about not having an immediate post-death visit." One TEP member voiced concerns that some hospices have a hands-off mentality after a patient dies, at which point they no longer think it's their responsibility to check in on the family. A measure regarding post-death follow-up may be well-received by caregivers, whose experiences with hospice extend beyond their loved one's death.

3.4.3 Recommendations

- Consider a post-death follow-up measure that captures immediate bereavement visits to caregivers/families.

4. Spring 2020 TEP Pain Workgroup

4.1 *Meeting Purpose*

As the Abt Team was finalizing the alpha test version of HOPE items, the team realized there was an important need to obtain feedback on several HOPE assessment items before alpha testing began. It was not possible to delay seeking feedback until the next scheduled TEP meeting while still meeting the timeline for HOPE alpha testing and future measure development. Therefore, Abt convened three hour-long workgroups with a subset of TEP members on May 18, May 28, and June 6, 2020 to solicit informal input regarding quality measure concepts and instrument assessment items focused on pain. In particular, the team sought to refine pain QM concepts — as well as items in the HOPE alpha test version that would be used to calculate those measures — and discuss research questions related to pain in general. The timing of these workgroups allowed the team to get interim feedback on the quality measure concepts in development, and in particular at a crucial time prior to the start of alpha testing that allowed related preliminary HOPE items to be included. Four TEP members — William Matthews, Sean Morrison, Janell Solomon, and Maureen Henry — were invited to participate in these workgroups in order to represent a range of expertise relevant to the discussion of pain QMs. They are, respectively a physician, a hospice nurse, a hospice professional with knowledge of electronic health record (EHR) systems and finance, and a hospice research methodologist.

4.2 *Topics and Discussion Questions*

Each workgroup session was intended to foster discussion among the TEP members on a prepared set of questions that were distributed in advance of the scheduled meetings. Topics discussed included pain quality measure concepts, implications for HOPE items, and general considerations to guide future information-gathering.

4.3 *Pain QM Concepts*

4.3.1 Background

Developing an outcome quality measure using HOPE information that addresses patients' pain and symptoms is a leading priority for CMS to fill measure gaps in the HQRP. TEP workgroup participants commented on the feasibility and structure of three potential pain outcome quality measures that could satisfy this need: of a: 1) timely reduction in pain, 2) reduction in pain severity, and 3) prevention of severe pain. These three measures were designed by the Abt team with clinical input.

4.3.2 Discussion

All participating workgroup members confirmed the importance of (and potential for variability in) measuring pain within and across hospice organizations. For example, one workgroup clinician emphasized the importance of measuring not just severity of pain, but the extent to which pain interferes with quality of life and the ability to perform key functions. Other participants described using different measurement approaches, depending on patients' ability to self-report.

Timely Reduction in Pain. Workgroup members expressed mixed enthusiasm about a Timely Reduction in Pain QM concept. Primarily, the participating clinicians noted the importance of customized care planning — something that, ideally, should be informed by patient's preferences

for pain management and acceptable threshold of pain. In fact, because "it's so important to recognize that one patient's acceptable pain level is not the same as another's," one TEP member oversaw a quality improvement project that systematically tracked patient preferences around pain to achieve more individualized and personalized care. Meanwhile, another clinician was concerned that because "some patients are entirely tolerant" of high pain levels, a Timely Reduction in Pain QM could unfairly penalize hospices that do not reduce pain within a certain time frame even though they are respecting patients' preferences.

Reduction in Pain Severity. Workgroup members expressed general support for a Reduction in Pain Severity QM concept. However, there was some hesitation around assigning a lookback period. One TEP clinician noted the difficulty in operationalizing "active pain": is it pain that is present at the time of assessment, or pain that occurred within a certain timeframe? Determining "active" pain, for the purposes of tracking pain severity reduction over time, is particularly difficult for patients who are non-communicative.

Prevention of Severe Pain. Lastly, there were some reservations about a Prevention of Severe Pain QM concept. For instance, one workgroup member raised concerns about sedation and over-sedation, and that pain may occur due to the progression of a disease, even when the care is excellent.

Reassessment timeframe. Two participants noted that they would apply the same reassessment standards for both pain impact and pain severity. Most agreed that a pain impact reassessment timeframe would be more appropriate if it were at least 72 hours, rather than 48 hours, particularly when considering logistical constraints around medication delivery and adjustments. This is especially true for rural areas where "drug delivery may take longer" and when the time frame includes a weekend, given that some patients refuse phone calls and visits over the weekend. One participant also suggested using different reassessment timeframes depending on the severity of pain: five days was suggested for patients with mild pain, while 72 hours would be appropriate for severe and moderate pain.

Multi-symptom quality measure. There was general support for a multi-symptom outcome measure including pain and other symptoms. Workgroup members agreed that all symptoms (not just pain, shortness of breath and anxiety) causing moderate or extreme distress should have a reassessment within 3-5 days. There was disagreement as to whether fatigue should be considered a symptom that impacts daily function: specifically, one participating clinician noted that there is limited evidence regarding the potential to improve fatigue through healthcare interventions. For a multi-symptom outcome measure, two clinicians recommended using the Edmonton Symptom Assessment System (ESAS), which is validated across multiple settings and already used by many hospices.

4.3.3 Recommendations

- Account for potential abrupt changes during general inpatient care, particularly in the length of time before reassessment.
- Distinguish between variable and consistent pain.
- Lengthen the reassessment period to be at least 72 hours (and potentially longer for less severe pain levels).

- Consider using the Edmonton Symptom Assessment System (ESAS), which is validated across multiple settings and already used by many hospices, for a multi-symptom outcome measure.

4.4 *Items in the HOPE Alpha Test Used for Pain QM Concepts*

4.4.1 Background

TEP workgroup participants provided feedback on draft HOPE items intended to measure medication management, falls, and wounds among hospice patients.

4.4.2 Discussion

Medication management. Collecting data on safe and appropriate medication management could allow hospices to track changes in patient function, while better understanding and predicting hospice resource use. Currently, this proposed item has no associated quality measure. Workgroup participants agreed that an item around medication management is appropriate for a hospice assessment. For instance, it could help inform advance care planning, particularly regarding changes to a patient's location. However, members raised concerns about its feasibility as a quality measure, considering that "staff may not have control over the patients' or caregivers' ability to take medications safely," particularly for patients with fast-changing disease trajectories.

Falls. Given the post-acute care quality measure that captures the percentage of care episodes in which the patient experienced one or more falls with major injury (NQF: 0674, CMS ID: N013.01)[8], workgroup participants discussed whether it would be appropriate to have a similar falls measure for hospice. Overall, workgroup participants did not support a falls measure for hospice, in part because "there's not necessarily a deficiency in care" across hospices that needs to be elucidated. Moreover, hospices do not necessarily have control over patients' falls. One clinician noted that due to the patient-centered nature of hospice care, hospices must "ensure that patients have autonomy," even if that means allowing patients to go against clinical recommendations. Simply put, "patients have the right to fall." Another workgroup member agreed that "staff can be well-meaning, but patients still do what they want"; a measure of falls may have unintended consequences if it penalizes hospices for allowing patients to move freely.

Wounds. Workgroup participants agreed that a process QM related to wounds should be considered, namely because some wounds are unavoidable. Moreover, hospices would need to recognize that patients' risk of skin breakdown fluctuates over long stays. Overall, workgroup participants acknowledged that process measures can be challenging if they are high performing, but that a wound-related process measure would be a reasonable indicator of quality nonetheless. They also recommended having the measure address all types of wounds and not just pressure ulcers.

4.4.3 Recommendations

- Account for differences in medication management across locations of care.

[8] Centers for Medicare & Medicaid Services (2019). MDS 3.0 Quality Measures User's Manual (v12.1). Retrieved from: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Downloads/MDS-30-QM-USERS-MANUAL-v121.pdf

- Consider all types of wounds, not just pressure ulcers, as part of a wound-related process measure.
- Consider including process measures to hold hospices accountable to standards of care.

4.5 *Research Questions for Future Information Gathering and Other Considerations*

4.5.1 Background

During the discussion of quality measure concepts and assessment items, workgroup members considered the following topics: how to accommodate unresponsive or cognitively impaired patients, caregiver/proxy report validity, the importance of patient and caregiver preferences, measuring patient and caregiver preferences, the pros and cons of a singular pain measurement tool, multidisciplinary assessment structure, and how to operationalize spiritual care.

4.5.2 Discussion

Unresponsive or cognitively impaired patients. Workgroup members recognized the challenge of quality measurement for unresponsive or cognitively impaired patients. They described using different measurement approaches depending on patients' responsiveness: typically, numeric severity scales for patients who are able to self-report, and other scales that "utilize standard nursing measures" for patients who are non-communicative. However, one clinician noted that most observational scales can be translated to numeric, and vice versa, to standardize responses between patients who can and cannot self-report.

Another clinician proposed a categorization approach to facilitate quality measurement. Namely, patients should be grouped into those "able to respond" and those "unable to respond." In the "unable to respond" category, there may be some cognitively-impaired patients. Meanwhile, actively dying patients could fall into either of those categories, but have their own set of treatment considerations. Two participants, however, noted that clinicians should be careful about assuming that anyone with cognitive impairment would not be able to respond. For instance, data on patients with dementia suggests that if someone can respond, their responses are valid.

Two workgroup members mentioned that their own hospices use the PAINAD (Pain Assessment in Advanced Dementia Scale), which is a validated tool. Because the "path of least resistance" among hospice staff is to not record answers for patients who are unable to respond, staff must be well-trained in order to use any tool for pain measurement.

Patient versus proxy report. All workgroup members agreed that measures based on patient report are preferable to those based on proxy report. One participant had concerns about the validity of using multiple reports (patient and proxy, or multiple proxies). Similarly, a clinician agreed that the concordance between proxy and patient-reported pain is not perfect: proxies tend to overrate or overestimate pain when compared to patients. Other participants, while acknowledging some validity concerns, felt comfortable with proxy reports as long as 1) the proxy was a primary caregiver or nurse familiar with the patient over the course of the hospice stay and 2) the EHR clearly distinguishes proxy report from patient report.

Patient and caregiver preferences. Workgroup members did not support a measure related to advance care planning preferences. One clinician argued that advance directives have not helped

ensure that patients get their preferences met, in part because the decisions are complex and hard to anticipate. If measured, this concept would be appropriate as a patient (or caregiver) reported outcome measure — albeit, with additional considerations and limitations.

For example, one participant noted the common discrepancies between patient and caregiver preferences. Sometimes, a patient is very specific about their preferences, only for proxies to make contradictory decisions when the patient becomes unable to communicate. She recounted a time in her own hospice when a patient went unresponsive very quickly, only to wake up in the hospital ("very angry") after a proxy made a decision counter to his wishes. In this case, the answer to "Were the patient's needs met?" is "No," even though the hospice successfully carried out the orders of the caregiver. Which one should be prioritized?

One participant noted that there would be "serious actionability issues" if patient/caregiver preferences were incorporated into an outcome measure, even if there were exclusions. "It's really hard to do anything that will be fair to the hospice, and not have unintended consequences."

Measurement scales. The workgroup discussed whether it is better to have a tool embedded into HOPE, or to indicate that the pain was assessed using an external validated tool (and let that tool be up to the discretion of the staff).

Some participants urged the use of multiple tools. For instance, two currently use "all the scales" at their respective organizations, depending on the patient's profile and the extent to which staff have been trained. One clinician summarized the usability and applicability of different scale types, reporting that broadly speaking, categorical scales are easiest for patients to use, and just as reliable as numerical; numerical scales are the "norm," although patients have trouble identifying pain in the middle of the range; visual scales have varied reliability and user-friendliness, and are appropriate for children, but not for cognitively impaired adults.

Meanwhile, other workgroup members emphasized the importance of abstracting the measurements of different scales into one standardized assessment, embedded within the EHR. One participant, who admits that there is "no one-size-fits-all tool," is a proponent of an embedded prompt within the EHR that 1) asks which tool was used to assess a patient's pain, and 2) opens that specific tool upon selection. The various tools used by her hospice "link up to the corresponding HIS answer," and she appreciates the "consistency" of translating scores from various scales into an HIS record.

Nonetheless, in a follow-up email, one participant wrote: "With respect to a specific tool, I appreciated hearing from the clinicians about how they use a multitude of tools to measure symptoms. But from a measure development perspective, I know of no way to have an outcome measure that is not measured in a standardized manner across the entity type being measured."

Spiritual care. Abt described its goal of incorporating spiritual assessment items into HOPE from validated tools in a way that is meaningful and not burdensome. The resulting measurement considerations include whether it is appropriate to credit any effort by a hospice to address spiritual needs, regardless of its impact. For instance, is it meaningful to measure that a patient had a spiritual need, and that the hospice took action by referring to a chaplain?

One clinician noted that despite the emphasis on spiritual care within hospice, there is "no intervention that is proven to improve spiritual distress"; thus, it seems unproductive to measure spiritual care, particularly when "sending in a chaplain may not be enough." Ultimately, once a hospice identifies a need, the challenge is determining that the response meets that need. Another workgroup member agreed that a hospice cannot be held accountable for not meeting someone's spiritual needs.

In contrast, another clinician affirmed that "asking whether a patient has distress, and whether it was addressed, is appropriate." Due to patients' varying perceptions of (and ability to communicate) distress, all measurements are technically subjective, even with standardized scales. For a potential HOPE item on spiritual care, this participant recommended fusing question 9 on the IPOS (Patient version and Staff Version), "Have any practical problems resulting from your illness been addressed? (such as financial or personal)," with the question "Is your religion challenged by what is happening to you?" on the Spiritual Distress Assessment Tool.

4.5.3 Recommendations

- Consider different measurement pathways for verbal, cognitively impaired non-verbal, and actively dying populations.
- Conduct a literature review of recent studies looking at the concordance between patient and proxy report.
- Prioritize patient reports over proxy reports.
- Consider merging question 9 on the IPOS with the question "Is your religion challenged by what is happening to you?" on the Spiritual Distress Assessment Tool, to achieve a spiritual assessment item for HOPE.

5. Fall 2020 TEP

5.1 *Meeting Purpose*

The Abt team hosted an all-day virtual TEP meeting on November 10, 2020. The purpose was to discuss candidate outcome measures assessing pain and symptom management, based on HOPE items, and to identify priorities for measure development. Prior to this all-day meeting, the Abt team met with TEP members on November 5, 2020 to present background information in preparation for the full TEP meeting. During the pre-TEP meeting, Abt team members Jennifer Riggs and Marian Essey provided an update on HOPE development, including an overview of the assessment items currently being tested, and introduced three candidate outcome quality measures addressing pain and symptom management that could be calculated using information collected by HOPE.

To facilitate productive discussion during a full-day virtual meeting, the TEP meeting included three breakout sessions to inform full group discussion. Each individual measure discussion began with TEP members divided into two breakout groups (one group with five TEP members, the other with six TEP members, with small group composition changing over the three breakout sessions), where TEP members participated in a guided discussion of the measure, facilitated by Abt team members, T.J. Christian and Marian Essey. The groups then reconvened, shared the main small group discussion points, and explored areas of differing opinion. Abt team members, Sara Galantowicz and David Stevenson, facilitated the TEP meeting overall, including the full group discussions following the breakout sessions.

All eleven TEP members attended both the November 5 pre-TEP meeting and the November 10 full-day meeting.

5.2 *Topics and Discussion Questions*

The TEP meeting focused on identifying and prioritizing candidate pain and symptom outcome measures that could be calculated using HOPE data. TEP members were asked to identify which of the candidate outcome measures should be further developed. TEP members engaged in a facilitated discussion, based on an interview guide distributed in advance, of each candidate measure: (1) Timely Reduction of Pain Impact, (2) Reduction in Pain Severity, and (3) Timely Reduction of Symptoms. The draft HOPE items associated with these measures are included in Appendix B. A number of discussion questions were consistent across measures:

1. What are your thoughts/initial reactions to this measure? Are there any concerns with this measure?
2. What is the role of neuropathic pain in this measure?
    a. Should neuropathic pain be included in the measure for the measure to include all pain? Or should it be a measure exclusion?
    b. Should it be considered a risk factor only and not a measure exclusion? Or is neuropathic pain not a consideration in calculating this measure?
3. Would you recommend using the identified HOPE item in developing the measure? Would you recommend any changes to this item or is there another item that would better meet the intent of this measure?

Some questions were optional, and only discussed time permitting:

4. The draft measure is calculated using an item collecting information on patient/caregiver desired tolerance and on preferences for treatment. Two items are under consideration for use in this measure.
    a. Which item better meets the intent of this measure?
    b. Are there any concerns with either item?
    c. Would you recommend any changes to either item (Patient Desired Tolerance Level for Symptoms vs. Patient Preferences for Symptom Management) or is there another item that would better meet the intent of this measure that should be considered as we continue to test/refine HOPE?

Each measure discussion also included measure-specific questions:

Timely Reduction of Pain Impact

1. CMS is considering a re-assessment time point of 2 days instead of 3 days.
    a. Do you agree that a high-quality hospice should be expected to achieve symptom control within 2 days?
    b. If there are concerns with a re-assessment within 2 days, is the concern related to getting the symptom under control OR is the concern related to having this outcome reported?
2. What is your experience with neuropathic pain? How much of an issue is neuropathic pain at your hospice or with the patients you encounter?
3. Are there concerns that the Timely Reduction in Pain Impact HOPE measure would have any of the issues that led to the retirement of NQF #0209 Comfortable Dying Measure (Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment)? Why or why not?
4. Would counting quality episodes for the Timely Reduction in Pain Impact measure at all time points prevent reportability issues that occurred with the retired measure?
5. Does allowing a caregiver response and not just the patient response for the HOPE symptom impact prevent reportability issues with the Timely Reduction in Pain Impact measure?

Reduction in Pain Severity

1. If patients with neuropathic pain are excluded from this measure, are there concerns with reportability of the measure?
    a. By excluding patients with neuropathic pain, would the population of patients included in the measure denominator/population be too low?
    b. If patients with neuropathic pain are excluded from the measure, are there concerns with gaming the measure? For example, would more patients be identified as having neuropathic pain than are likely to truly have neuropathic pain?

Timely Reduction of Symptoms

1. Which symptoms should be included in the measure?

2. Should pain be included as a symptom in this measure as it is also in measure #1 Timely Reduction of Pain Impact?
3. If pain is included in the measure, should it have equal weight as the other symptoms?

TEP Polling and General Feedback

At the end of each measure discussion, TEP members responded ("Yes,", "No," or "Unsure") to three poll questions:

1. Will the measure distinguish between high-quality and low-quality hospices?
2. Will this measure be useful to hospice providers in their quality improvement efforts?
3. Will this measure be useful to consumers in helping to select a hospice?

The day concluded with a discussion of measure development priorities. TEP members responded to a final polling question ranking the three measures in order of importance. They also considered the following questions:

1. Are there other measures that should be considered that we haven't discussed today?
2. Based on the discussion today, what is the TEP's opinion about the feasibility of a pain outcome measure to be developed for the HQRP? Are any of the three measures viable?
3. Should CMS discontinue development of any of the three measure constructs? If so, why?
4. If the TEP were to design a measure from scratch to address pain in hospice patients, what would that measure look like?

5.3 *Timely Reduction of Pain Impact*

5.3.1 Background

The candidate measure Timely Reduction of Pain Impact reports the percentage of patients who experience a reduction in the impact of their pain. The reduction must have occurred within 3 days of identifying pain that had a moderate or severe impact on the patient. The primary HOPE items used to calculate this measure are Symptom Impact and either Patient Desired Tolerance Level for Symptoms or Patient Preferences for Symptom Management, as reported at Admission, Interdisciplinary Group (IDG) assessment, Symptom Reassessment, Level of Care Change, and Recertification (see Appendix B for items). Patients meeting the measure criteria are identified as follows:

1. For patients whose pain impact is rated as moderate or severe, and
2. For whom patients (or caregivers) preferred pain reduction,
3. That pain impact was re-assessed within 3 days of the pain assessment indicating moderate or severe pain, and
4. There was a decrease in pain impact rating.

5.3.2 Discussion

Overall, TEP members supported this candidate measure. There was some concern that incorporating both individual patient preference for pain reduction and pain tolerance would make it difficult to interpret, given patients' varying pain preferences and tolerances. Some TEP members questioned whether this measure was sufficient to address pain crisis episodes; they suggested focusing the measure on severe pain, or including different considerations for severe

pain. There was also discussion around consolidating pain impact and severity in one measure. A few TEP members questioned whether including only pain impact or severity would be more meaningful, and whether reporting both impact and severity would be confusing for patients or clinicians. However, other TEP members felt it was reasonable to capture both impact and severity. One noted that there are a large number of pain studies that use instruments assessing both severity and impact, and in those studies patients do not have difficulty in distinguishing the two. Another shared experience with patients living with serious illness who would contextualize the severity of their pain by citing its impact. After this discussion, the group was more comfortable with how the measure captured pain impact and severity. There were no changes recommended to HOPE item Symptom Impact, and no concerns about caregiver report or reportability issues.

2-day versus 3-day re-assessment

Each breakout group initially reached a different conclusion about the optimal time frame for reassessing symptoms, including pain. The group preferring 3 days was more concerned about special circumstances that would make 2 days insufficient to reduce pain. They cited issues such as access to patients (e.g., patients not wanting a provider visit), and were concerned that rural hospices would be more impacted by these issues. They noted that some hospices could have more patients with difficult-to-manage pain, affecting their score on this measure, and were concerned that hospices might refuse patients if they thought they would be unable to manage their pain within 2 days. They also questioned how the measure would account for changes in patient preferences over time so that hospices would not be penalized for these changes. The group preferring 2 days noted that population-based measures would mitigate many of these concerns. They recognized that there will inevitably be some patients whose pain impact cannot be reduced in 2 days, but expected such patients would be evenly distributed across hospices; they did not anticipate hospices refusing patients perceived as having unmanageable pain. While acknowledging concerns about incentives to over-medicate, they felt that 3 days would be a long time for a patient to wait for pain palliation, and 2 days was enough time to get pain under control.

Neuropathic pain

TEP members recognized that neuropathic pain is difficult to treat and discussed how a pain measure should address this type of pain. There was consensus that neuropathic pain should not be a measure exclusion, but rather considered for potential risk adjustment. Many TEP members favored risk adjustment because they thought neuropathic pain was too prevalent to exclude. The TEP commented that alpha testing data could be used to inform a decision (e.g., whether certain hospices have a higher proportion of patients with neuropathic pain, or whether the presence of neuropathic pain is related to a patient less likely to achieve timely pain reduction). Prior to HOPE data availability, the TEP suggested information gathering could assess the prevalence of ICD-10 codes indicating neuropathic pain (M79.2) prior to hospice admission.

5.3.3 Recommendations

- Timely Reduction of Pain Impact is a viable measure for further development.
- A 2-day (vs. 3-day) reassessment would be appropriate for severe pain, not necessarily moderate pain.
- A neuropathic pain exclusion is not needed in the measures, but risk adjustment should be considered.

5.4 *Reduction in Pain Severity*

5.4.1 Background

The candidate measure Reduction in Pain Severity is the percentage of patients who have a reduction in reported pain severity. The primary HOPE items used to calculate this measure are Pain Screening, Pain Active Problem, and Patient Desired Tolerance Level for Symptoms or Patient Preferences for Symptom Management, as reported at Admission, IDG, Symptom Reassessment, Level of Care Change, and Recertification (see Appendix B for items). Patients meeting the measure criteria are identified as follows:

1. For patients who screened positive for pain, and
2. For whom the pain severity was moderate or severe,
3. For whom pain is an active problem,
4. For whom patients (or caregivers) preferred pain reduction,
5. That pain severity was re-assessed within 3 days of the pain screening, and
6. There was a decrease in pain severity rating from the most recent HOPE assessment.

5.4.2 Discussion

Overall, the TEP supported this candidate measure and supported including patient preferences. Most TEP members noted that patients may be satisfied even without a reduction in pain, so it is important to determine whether the patient even wants pain management and account for these preferences in measurement. One TEP member emphasized, "Patients have the right *not* to treat their pain." However, another member stated reducing pain severity is imperative and was concerned that clinicians' warnings around opioid misuse could influence patient preferences for pain management. This individual explained, "We do have the clinical acumen to demonstrate that most somatic pain can be reduced without major opioid-related side effects, and I think we should hold clinicians accountable to that."

TEP members suggested considering risk adjustment for neuropathic pain. There was some discussion around revising the neuropathic pain item in HOPE to capture more information. Currently the item is binary ("Does the patient have neuropathic pain (e.g., pain with burning, tingling, pins and needles, hypersensitivity to touch)?" with response options limited to "Yes" or "No"). One TEP member suggested additional questions about neuropathic pain would be informative (e.g., to examine whether neuropathic pain contributes to the patient's overall pain, or capture how long they have lived with this neuropathic pain). However, the overall consensus was that identifying the presence of neuropathic pain was sufficient for the purpose of this measure.

5.4.3 Recommendations

- Reduction in Pain Severity is a viable measure for further development.
- Explore risk adjustment for neuropathic pain.

5.5 *Timely Reduction of Symptoms*

5.5.1 Background

The candidate measure Timely Reduction of Symptoms is the percentage of patients who experience a reduction the impact of their pain and/or other symptoms. Reduction must have occurred within 3 days of identification of pain and/or other symptoms that had a moderate or

severe impact on the patient. The primary HOPE items used to calculate this measure are Symptom Impact and Patient Desired Tolerance Level for Symptoms or Patient Preferences for Symptom Management, as reported at Admission, IDG, Symptom Reassessment, Level of Care Change, and Recertification (see Appendix B for items). Patients meeting the measure criteria are identified as follows:

1. For patients whose pain, shortness of breath, anxiety, nausea, vomiting, diarrhea, constipation, and/or agitation impact is moderate or severe, and
2. For whom patients (or caregivers) preferred symptom reduction,
3. That symptom impact was re-assessed within 3 days of the initial assessment, and
4. There was a decrease in symptom impact rating (total score decrease for all symptoms).

5.5.2 Discussion

The TEP members agreed that this was a viable candidate measure. They recommended removing pain from the measure to avoid overlap with the Timely Reduction of Pain Impact measure, but supported including all other symptoms. A few TEP members suggested separating out breathlessness, anxiety, and agitation rather than including them with the other symptoms. They noted that managing shortness of breath within 2 or 3 days can be difficult, and similarly believed that anxiety and agitation were difficult to control. While others agreed that there could be challenges to managing these symptoms in some patients during a 2 or 3-day timeframe, they felt these would be exceptions. Therefore, it was reasonable to assess symptom reduction within 2-3 days. There was also some discussion about data collection timeframes. Some TEP members preferred a 2-day reassessment, reiterating that 3 days is a long time for patients to suffer, while others felt 3 days was more reasonable for hospices. Regardless, TEP members felt the reassessment time period should be consistent between this measure and Timely Reduction of Pain Impact. Some TEP members were also concerned that hospices would perceive the reassessments as burdensome to collect, but others felt that having assessments aligned with IDG meetings would not be a burden, as they would align with the hospice's existing operational processes.

5.5.3 Recommendations

- Remove pain from Timely Reduction of Symptoms.

5.6 *Symptom Management*

5.6.1 Background

The HOPE item Follow-up Symptom Control is a nurse's assessment of whether the patient has achieved symptom control (*yes, no, not applicable*) on a number of symptoms: pain, shortness of breath, anxiety, nausea, vomiting, diarrhea, constipation, and agitation. The item was developed in response to the TEP discussion in November 2019, and is part of the HOPE alpha test. TEP members were asked about using this item to calculate a quality measure related to symptom management of one or more symptoms.

5.6.2 Discussion

TEP members noted this item was not well-defined. Specifically, members commented that the language "under control" was unclear and would be easy for hospices to game. One TEP member shared that their whole hospice team struggled to interpret the question. There was consensus that the Symptom Impact item was preferable for measuring quality.

5.6.3 Recommendations

- Do not use HOPE item Follow-up Symptom Control for quality measurement.

5.7 *Measure Priorities*

5.7.1 Background

After discussing each of the candidate outcome measures, the Abt team sought feedback on the appropriateness of the measures, development priorities, and whether there were other pain management measure constructs the team should consider.

5.7.2 Discussion

The TEP had a few suggestions for other pain management measures. One TEP member suggested a measure that would assess overutilization versus underutilization of pain medication, perhaps using claims data. Similarly, another TEP member supported a medication management measure.

All TEP members believed all three candidate outcome measures were viable. There was some concern that the measures Timely Reduction of Pain Impact and Reduction in Pain Severity would be duplicative if both were implemented, but no one recommended discontinuing development of any of the measures. When asked to rank the three measures in order of importance, Timely Reduction of Pain Impact was ranked the highest, followed by Timely Reduction of Symptoms, then Reduction in Pain Severity.

5.7.3 Recommendations

- Continue development of all three candidate measures, prioritizing Timely Reduction of Pain Impact, followed by Timely Reduction of Symptoms, then Reduction in Pain Severity.

5.8 *Federal Stakeholder Debrief*

On December 9, 2020, Abt team members debriefed federal stakeholders. This included a high-level review of measure development activities and a summary of the discussion and input provided during the TEP meetings. There was also opportunity for questions and reactions from federal staff. The federal staff discussion included:

- Conceptual differences between “Timely reduction in pain” vs. “Reduction in pain severity”, how much overlap there is, and whether input was received from the TEP (particularly as which would be more helpful to patients and/or caregivers).
- A two-day reassessment for a timely reduction of pain (candidate measure #1) or non-pain symptoms (candidate measure #3) was more than enough time, and 24 hours might be preferable for reassessment (although more as a process-check, to ensure the hospice was taking steps to address the pain, rather than the pain being controlled).
- That despite design challenges, the Federal staff were pleased on development progress.

6. Conclusions

6.1 *Key Recommendations*

Since their inaugural November 2019 meeting, the TEP has provided feedback to the Abt team on a range of measure concepts for development. Below we summarize key recommendations from the Spring 2020 TEP Webinar, Spring 2020 TEP Pain Workgroup, and Fall 2020 TEP.

- Claims-Based Hospice Care Composite Measure
  - Analyze visit minutes by all staffing types in the first 7 days of hospice service.
  - Consider changing 'early live discharge' to 'live discharge within 7 days of hospice' and 'readmission to hospice within 30 days.'
  - Consider whether or not 'hospice length of stay greater than or equal to 180 days' has value for consumers.
  - Discuss evidence around using CAHPS® Hospice Survey data to validate measures under development.
- Weekend Visits Measure
  - Consider a post-death follow-up measure that captures immediate bereavement visits to caregivers/families.
- Candidate Pain and Symptom Outcome Measures
  - Continue developing all three candidate quality measures, prioritizing Timely Reduction of Pain (Impact), then Timely Reduction of Symptoms, and Reduction in Pain Severity.
  - Remove pain from the symptoms included in Timely Reduction of Symptoms; all other symptoms are reasonable for inclusion.
  - A 2-day (vs. 3-day) reassessment would be appropriate for severe pain, not necessarily moderate pain.
  - Including patient preferences is an important and valuable component to these quality measures. However, there was no clear preference for the HOPE item by which this information would be collected (Desired Tolerance Level for Symptoms vs. Preferences for Symptom Management).
  - Neuropathic pain should be evaluated as a risk adjustor, not a denominator exclusion.
  - Distinguish between variable and consistent pain.

As the Abt team and CMS continue to develop and refine measures, these recommendations will be considered alongside additional input from the TEP and public comments.

6.2 *Future Directions for Analysis and Research*

In addition to the recommendations raised in the sections above, the TEP raised a number of topics for further research or consideration. These include:

- The correlation found between decreased nursing visits and increased length of stay
- Recent studies on the concordance between patient and proxy report.
- Prevalence of neuropathic pain prior to hospice admission
- Support for the feasibility of improving pain within 2 days

The TEP also recommended considering the following:

- Different measurement approaches for verbal, cognitively impaired non-verbal, and actively dying populations.
- Prioritizing patient reports over proxy reports.
- Merging question 9 on the IPOS ("Have any practical problems resulting from your illness been addressed? (such as financial or personal)), with the Spiritual Distress Assessment Tool question, "Is your religion challenged by what is happening to you?", to achieve a spiritual assessment item for HOPE.

6.3 *Next Steps*

As a follow-up to the November 2020 TEP, additional collaboration with the TEP is anticipated to further define the HOPE-based measure concepts discussed. The Abt team will begin internal planning for 2021 TEP activities in January-February 2021, and will hold a Spring TEP webinar in May or June 2021. Current proposed topics for the Spring TEP webinar include a measure update, review of preliminary HOPE alpha test data, and any information gathering updates.

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 former Director of Client Strategy at NetSmart, an electronic health record (EHR) vendor for post-acute care communities. Ms. Craig retired from this position in 2020, after 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: Draft HOPE Items Used in Candidate Quality Measures

This section displays the draft HOPE items related to the candidate quality measures discussed during the Fall 2020 TEP. These items are currently being tested and thus are still in draft form. Note that the items included here have been excerpted from HOPE and do not represent the complete assessment tool. Each item includes instructions on coding (selecting the response) and the time points at which the item is collected.

Draft Time Points

HOPE data are collected at the following time points:

1. Admission (ADM)
2. Interdisciplinary Group (IDG) assessment
3. Level of care change (LOC) assessment
4. Recertification (RC)
5. Symptom Reassessment (RES)
6. Planned Discharge (PD)
7. Unplanned Discharge (UNPD)
8. Discharge: Expired (EXP)

Draft HOPE Items

DRAFT Symptom Impact

Based on your clinical assessment (including input from patient and/or caregiver) - Enter one code that best describes **how the patient has been affected by each of the following symptoms over the past 2 days.** *Symptoms may impact multiple patient activities including, but not limited to, sleep, concentration, day to day activities, or ability to interact with others*.

Coding:

0. Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment
1. Slight
2. Moderate
3. Severe
9. Not applicable – the patient is not experiencing the symptom

	2. Admission	**3. Symptom Reassessment**	**4. IDG**	**5. LOC**	**6. Recertification**	**7. Planned Discharge**
	Enter code ↓	**Enter code ↓**	**Enter code ↓**	**Enter code ↓**	**Enter code ↓**	**Enter code ↓**
A. Pain	☐	☐	☐	☐	☐	☐
B. Shortness of breath	☐	☐	☐	☐	☐	☐
C. Anxiety	☐	☐	☐	☐	☐	☐
D. Nausea	☐	☐	☐	☐	☐	☐
E. Vomiting	☐	☐	☐	☐	☐	☐
F. Diarrhea	☐	☐	☐	☐	☐	☐
G. Constipation	☐	☐	☐	☐	☐	☐
H. Agitation	☐	☐	☐	☐	☐	☐

During the assessment for Symptom Impact, indicate if the patient contributed to the assessment

Enter code ☐	1. **Yes,** the patient contributed. 2. **No,** the patient was unable to respond; responses were provided by caregiver. 3. **No**, the patient was unable to respond and no caregiver was available.

DRAFT Patient Desired Tolerance Level for Symptoms

Based on your clinical assessment (including input from patient and/or caregiver) - Enter one code that best describes the patient's **desired tolerance level for each of the following symptoms.**

Coding:

0. None – patient prefers not to experience the symptom at all
1. Slight
2. Moderate
3. High
9. Not applicable – the patient is not experiencing the symptom

	3. Admission	**4. IDG**	**5. LOC**	**6. Recertification**	**7. Planned Discharge**
	Enter code ↓	**Enter code ↓**	**Enter code ↓**	**Enter code ↓**	**Enter code ↓**
A. Pain	☐	☐	☐	☐	☐
B. Shortness of breath	☐	☐	☐	☐	☐
C. Anxiety	☐	☐	☐	☐	☐
D. Nausea	☐	☐	☐	☐	☐
E. Vomiting	☐	☐	☐	☐	☐
F. Diarrhea	☐	☐	☐	☐	☐
G. Constipation	☐	☐	☐	☐	☐
H. Agitation	☐	☐	☐	☐	☐

During the assessment of Patient Desired Tolerance Level for Symptoms, indicate if the patient contributed to the assessment

Enter code	
☐	0. **Yes,** the patient contributed 1. **No,** the patient was unable to respond; responses were provided by caregiver 2. **No**, the patient was unable to respond and no caregiver was available

DRAFT Patient Preferences for Symptom Management

Based on your clinical assessment (including input from patient and/or caregiver) - Does the patient prioritize reduction in their symptoms, even with potential treatment side- effects or inconveniences?					
Coding: **0.** No **1.** Yes **1. Not applicable –** the patient is not experiencing the symptom					
	2. Admission	**3. IDG**	**4. LOC**	**5. Recertification**	**6. Planned Discharge**
	Enter code ↓	**Enter code** ↓	**Enter code** ↓	**Enter code** ↓	**Enter code** ↓
A. Pain	☐	☐	☐	☐	☐
B. Shortness of breath	☐	☐	☐	☐	☐
C. Anxiety	☐	☐	☐	☐	☐
D. Nausea	☐	☐	☐	☐	☐
E. Vomiting	☐	☐	☐	☐	☐
F. Diarrhea	☐	☐	☐	☐	☐
G. Constipation	☐	☐	☐	☐	☐
H. Agitation	☐	☐	☐	☐	☐

DRAFT Neuropathic Pain

Does the patient have neuropathic pain? (e.g., pain with burning, tingling, pins and needles, hypersensitivity to touch)	
Enter code ☐	0. **No** 1. **Yes**

DRAFT Pain Screening

A. Was the patient screened for pain?

☐ 0. **No** →Skip to *xxx*
☐ 1. **Yes**

C. The patient's pain severity was:

☐ 0. None
☐ 1. Mild
☐ 2. Moderate
☐ 3. Severe
☐ 9. Pain not rated

D. Type of standardized pain tool used:

☐ 1. Numeric
☐ 2. Verbal descriptor
☐ 3. Patient visual
☐ 4. Staff observation
☐ 9. No standardized tool used

DRAFT Pain Active Problem

Is pain an active problem for the patient?

☐ 0. **No** →Skip to *xxx*
☐ 1**. Yes**