

Business Case: Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain

Project Title: Palliative Care Measures Project

Date: Information included is current on 12/30/20.

Project Overview:

The Centers for Medicare & Medicaid Services (CMS) has entered a cooperative agreement with the American Academy of Hospice and Palliative Medicine (AAHPM) as part of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) to develop two patient-reported measures of ambulatory palliative care experience, broadly in the domains of symptoms and communication. The measures are intended to assess the extent to which patients receiving ambulatory clinic-based palliative care received the help that they wanted for their pain, and that they were heard and understood by their palliative care provider and team. The cooperative agreement name is the "Palliative Care Measures Project." The agreement number is 1V1CMS331639-01-00. AAHPM has partnered with the National Coalition for Hospice and Palliative Care and RAND Health Care to develop the proposed measures.

Measure Description:

This business case describes a quality measure under consideration for use by the Centers for Medicaid and Medicare Services (CMS). The proposed measure, Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain, is the percentage of patients aged 18 and older who had an ambulatory palliative care visit, who identify as having pain and wanting help for their pain and report getting the help they wanted for their pain by their palliative care provider and team during their care in the last six months. The measure will be aggregated over a 12-month period. This measure will be derived from patient-reported data elements (i.e., items) – collected via survey with mixed-mode administration (i.e., mail with phone follow-up).

Numerator Statement:

The percentage of patients meeting the denominator statement (see below) who report getting the help they wanted for their pain by their palliative care provider and team during their care in the last six months.

Numerator options include:

- *Performance met*: receiving desired help for pain achieved [threshold to be specified] within 6 months following an ambulatory palliative care visit
- OR
- *Performance not met*: receiving desired help for pain was not achieved [threshold to be specified] within 6 months following an ambulatory palliative care visit

The data for the measure will be aggregated based on a 12-month reporting period.

The response that defines the numerator will correspond to a survey question that has three response options assessing whether the respondent received the help they wanted for their pain: 1) Yes, Definitely, 2) Yes, Somewhat, and 3) No. Scoring methodology (e.g., top box scoring; linear mean scoring) will be determined using beta test results.

Denominator Statement:

All patients aged 18 years and older who had an ambulatory palliative care visit with a MIPS-eligible provider during the 12-month reporting period, who report having pain AND wanting help for their pain, where:

- Ambulatory palliative care visits are defined as:
 - ICD-10 Z51.5 (Encounter for palliative care) OR Provider Hospice and Palliative Care Specialty Code 17;

AND

- CPT 99201-99205 (New Office Visit); OR CPT 99211-99215 (Established Office Visit); or Place of service (POS) Code 11 – Office

- 2019 MIPS-eligible clinician types include:
 - Physicians (including doctors of medicine, osteopathy, dental surgery, dental medicine, podiatric medicine, and optometry); osteopathic practitioners; chiropractors; physician assistants; nurse practitioners; clinical nurse specialists; certified registered nurse anesthetists; physical therapists; occupational therapists; clinical psychologists; qualified speech-language pathologists; qualified audiologists; registered dietitians or nutrition professionals.

Palliative care providers and/or provider groups should consider all adult ambulatory palliative care patients who receive care during the 12-month reporting period as eligible to be invited to complete the patient experience survey related to their ambulatory palliative care visit, unless they meet further exclusion criteria. Patients should be invited to complete the patient experience survey only once per reporting period (see Denominator Exclusions below).

In order for the visit and experience to remain salient to the patient and ensure successful implementation of the measure, providers should send the patient experience survey to patients within 3-months of their eligible visit to reasonably satisfy the 6-month lookback timeframe referenced in the measure.

Risk-adjustment calculation will be determined after beta testing. During the beta test, we are collecting potential risk-adjustment variables directly from participating programs via their submitted data files. These variables include age, gender, location, and diagnoses, among others, and were identified based on commonly-used risk adjusters from other patient experience surveys. The intention is to minimize burden on the patient respondent by collecting what we can administratively.

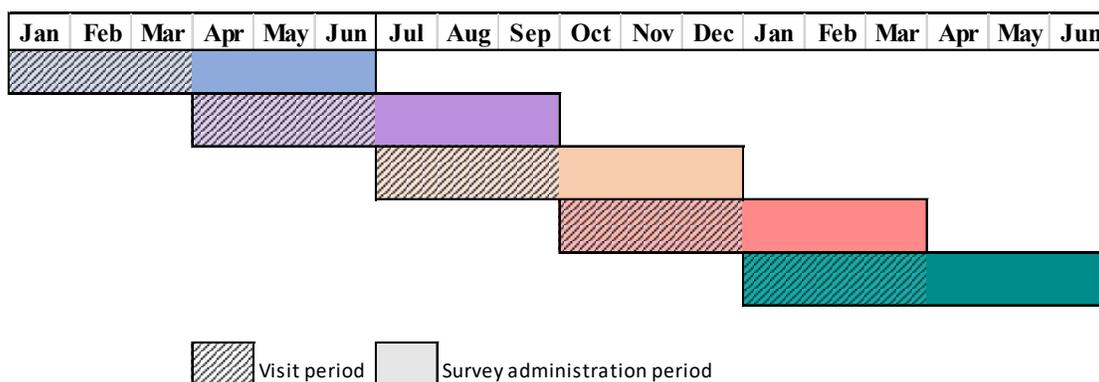
Denominator exclusions include patients who:

- Do not complete and return the patient experience survey within 6 months of the eligible ambulatory palliative care visit (i.e., providers and groups will not be penalized for non-response);
- Are deceased by the time the survey reaches them (i.e., bereaved caregiver responses are excluded);
- Have already completed the patient experience survey once in the 12-month reporting period
- Are unable to complete the patient experience survey due to cognitive impairment (details TBD pending beta results)
- Respond that they did not receive care by the listed ambulatory palliative care provider in the last six months (i.e., disavow the provider/provider group)
- Identify as not speaking English or Spanish

Note: Exact exclusion criteria will be determined after testing.

Based on technical expert clinical user and patient panel (TECUPP) and advisor feedback, we propose that for programs to be eligible to participate in this measure that they demonstrate an ability to field the survey to ambulatory palliative care patients within three-months of eligible visits. Per discussion with the TECUPP, constraining the implementation to ensure that patients are sent surveys within 3-months of their eligible visit provides a sufficiently large pool of eligible patients with visits recent enough to avoid recall bias or loss to follow-up. Surveys must be completed by patients within 6 months of the visit to avoid challenges with recall or loss-to-follow-up which would make the findings less actionable. During the alpha test, we confirmed the feasibility of this eligibility criteria. Given a 12-month reporting period and quarterly surveys, data can be obtained from participating programs with four data pulls, each representing the list of patients receiving care during the previous three months (only unique patients will be surveyed in each round of data collection; patients already surveyed will be deemed ineligible in subsequent data pulls). This is shown in Figure 1 below.

Figure 1. Alignment of palliative care visits and survey administration periods



Business Case Report Executive Summary:

The field of palliative care has grown rapidly in recent years, yet the quality of palliative care delivered in the ambulatory setting is not systematically measured. Existing evidence and expert consensus have highlighted significant unmet need among seriously ill persons and gaps in symptom management and meaningful communication measures, despite the noted importance of these domains to seriously ill patients and their families.¹ These gaps may be particularly pronounced in ambulatory settings, where patients and families have limited access to palliative care services and may struggle to manage their illness and accept their trajectory.

In the last years of life, many patients experience pain and other symptoms that are not adequately managed²⁻⁸ and receive care that is not consistent with their preferences.⁹⁻¹² Pain is highly prevalent among patients with serious illness.¹³⁻¹⁹ The consequences of poorly managed pain in patients with serious illness include reduced quality of life, impaired functional status, and higher acute care utilization.²⁰⁻²³ Systematic reviews have identified longstanding disparities in pain management across various health care settings, including underdiagnosis and undertreatment of pain in Black patients.²⁴

Multiple studies have also reported disparities by race/ethnicity and socioeconomic status in the prevalence of unmet needs for symptom management among patients with serious illness,²⁵⁻²⁷ underscoring the importance of measuring patients' experience of receiving help for pain. While many existing quality measures assess standardized clinical outcomes and processes of care related to pain assessment, the subjective experience of symptoms does not lend itself to a "one size fits all" evaluation approach. Patients with serious illness make important tradeoffs (e.g., some patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects) and hold different preferences for their care that may only be reflected via patient experience measures, that is, from a measure based on patient or proxy report rather than an evaluation conducted by the provider.

The proposed measure will fill identified measure gaps. First, the proposed measure will assess care experience among patients receiving ambulatory palliative care; a population in which existing measures have not been tested or applied. Second, in contrast to existing measures of pain management which focus on reported reductions in pain levels, the proposed "unmet needs" measure is directly tailored to address whether patients are receiving care in accord with their wishes. This is important because it measures a more patient-centered construct rather than a clinically-imposed construct of "improvement" in pain. Third, the proposed measure adds to a small but growing body of measures focused on patient-reported experience in the context of end of life care.

Incidence and Prevalence Data

Pain is one of the most common and distressing symptoms among the seriously ill.¹³⁻¹⁹ Pain is highly prevalent among ambulatory palliative care patients and is one of the most common reasons for referral to palliative care.²⁸⁻³⁰ Receiving help for pain and other symptoms at end of life is one of the top concerns cited by patients with serious illness.⁴ Pain is often the primary symptom at the time of referral to palliative or supportive care services, and pain control typically improves over the course of this care, leaving other symptoms to take precedence at the very end of life or near the time of death.³¹

Several studies have examined prevalence or importance of pain and other symptoms among patients with serious illness across various palliative care settings. In one study of symptom prevalence among hospitalized patients who qualified for palliative care, 31.1 percent reported pain as one of their most bothersome symptoms.³² In a study of hospitalized patients in hospice and palliative care units, pain was among the most common complaints at admission, reported by 11 percent of patients.³³ In another study of patients referred to palliative care services in the hospice, hospital, and ambulatory settings, pain was the most prevalent symptom across settings, reported by 64 percent of patients. Pain was particularly prevalent among patients referred to ambulatory palliative care (reported by 75 percent of patients).²⁸

Other studies have assessed symptoms in the last year or weeks of life, agnostic to care setting. One study that examined decedent data from the Health and Retirement Survey found that among individuals in the last year of life, 60.8 percent reported pain, including 52.4 percent with moderate or severe pain.³⁴ In another study of symptoms reported in the last three months of life among patients still under the care of a primary care provider, 56 percent of patients reported pain.³⁵

In patients with serious illness, pain frequently co-occurs with psychological symptoms such as depression and anxiety.³⁶⁻³⁸ In a prospective study to examine the correlation between physical symptoms and depression in patients with advanced cancer, 27 percent of patients met criteria for major depression, and symptoms of depression were highly correlated with physical symptom burden, including pain severity.³⁸ Given the correlation between pain, depression, and anxiety, addressing pain is important for management of psychological symptoms.

Measure Alignment with [CMS and National Quality Goals](#) :

This measure falls into the “Strengthen person and family engagement as partners in their care” goal of CMS’ Meaningful Measures Initiative, and the domain of Person and Caregiver-Centered Experience and Outcomes within MACRA. The goal of the proposed measure is to improve pain management that is tailored to patient preferences and goals in outpatient palliative care settings. The outcome that is the focus of the proposed quality measure is to ensure that the patient received their preferred level of help for their pain from their outpatient palliative care provider and team, resulting in low level of unmet need for their pain.

The goal of this project is to produce quality measures that can be used by providers eligible for Merit-Based Incentive Payment System (MIPS) who provide palliative care services to their patients, so that the patient experience of core components of high-quality palliative care can be attributed to their providers and used to incentivize quality improvement. Although MIPS applies to all Medicare patients, with no limit or focus on patients with serious illness, a strong portfolio of MIPS quality measures helps ensure measurement is meaningful and relevant to providers and their patients. Following completion of beta testing and data analyses, the two palliative care measures will be submitted for endorsement by the National Quality Forum and for inclusion into CMS’ Quality Payment Programs including MIPS and alternative payment models.

This measure has not yet been implemented in an existing program; however, we believe this measure would receive support as a patient-reported experience of care measure to improve the quality of care that patients with serious illness receive. Our testing results and the feedback we have received from experts indicate that the measure can be successfully implemented to assess clinicians’ performance.

Measure Uses (select all that apply):

- public reporting
- public health/disease surveillance
- payment program
- regulatory and accreditation programs payment and network selection
- professional certification or recognition
- quality improvement with benchmarking (external benchmarking to multiple organizations)
- quality improvement (internal to the specific organization)
- not in use

Current Performance (including any disparities):

The “Help Wanted” data element has been tested and used for research in palliative care and non-palliative care populations in different formats.^{25, 27, 39} The CAHPS Hospice Survey includes several items[†] that ask bereaved family members of hospice patients whether the patient received help wanted for pain and other symptoms at end of life.³⁹ However, this data element has not been incorporated into measurement programs, and the exact wording and structure proposed for this quality measure has not yet been used among ambulatory palliative care populations.

Unmet needs for symptom management, particularly pain, are common among palliative care patients. In one study that compared prevalence of unmet needs among inpatient and outpatient palliative care patients, outpatients presented with more unresolved pain than inpatients (58.5% vs. 4.1%).⁴⁰ In another study to compare unmet needs among community-based palliative care patients with primary diagnoses of heart failure or cancer, patients with cancer presented with more unresolved symptoms overall, including higher prevalence of unresolved moderate to severe pain (32% vs. 19% among patients with heart failure), while patients with heart failure more often presented with unresolved dyspnea (25% versus 18% among patients with cancer).⁴¹

Multiple studies have also reported disparities by race/ethnicity and socioeconomic status in the prevalence of unmet needs for symptom management among patients with serious illness. One study examined the prevalence of unmet needs for symptom management among a nationally representative sample of patients with lung and colorectal cancer.²⁵ Patients were defined as having unmet need if they reported that they wanted help for at least one common symptom (pain, fatigue, depression, nausea/vomiting, cough, dyspnea, diarrhea) in the previous four weeks but did not receive it. Overall, 15 percent (791 of 5,422) of patients had one or more unmet needs for symptom management. Adjusting for sociodemographic and clinical factors, patient characteristics associated with unmet need included African American race, being uninsured or poor, having early-stage lung cancer, and the presence of moderate to severe symptoms.²⁵ Similarly, in a population-based study of newly diagnosed patients with lung cancer, disparities were observed by race/ethnicity and socioeconomic status in patient perceptions of unmet needs for supportive services such as psychological services and pain management.²⁶ Marked disparities persisted for Black, Latino, and Asian/Pacific Islander patients compared to white patients even after controlling for demographic and socioeconomic factors, health system and health care access, and need.²⁶ Being younger, female, never married, uninsured, a current smoker, having comorbid anxiety/depression, and having cost/insurance barriers were also associated with unmet need.²⁶

[†] Getting Help for Symptoms (4 items)

- Did your family member get as much help with pain as he or she needed?
- How often did your family member get the help he or she needed for trouble breathing?
- How often did your family member get the help he or she needed for trouble with constipation?
- How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?

Measure Impact on Care and Health Outcomes:

Current evidence regarding the impact that pain measurement will have on care processes and outcomes in the palliative care context is limited, but promising. A recent large systematic review conducted to inform the 4th edition National Consensus Project Guidelines for Quality Palliative Care⁴² identified a large body of research evaluating the impact of palliative care on symptom management (n=48 systematic reviews), but much of the evidence was of low quality due to inconsistent findings across studies regarding the impact of both pharmacological and non-pharmacological interventions on symptoms.⁴³ Importantly, symptom severity (i.e., reduction in severity) was typically the primary outcome measured across studies, with little attention to the patient's preferences for intervention and goals for management.⁴³ There was moderate-quality evidence demonstrating that an interdisciplinary palliative care team can achieve sustainable and clinically significant reductions in symptom burden,⁴⁴ underscoring the important role that palliative care plays in symptom management at the end of life. The absence of attention to patient goals and values in the current evidence regarding palliative symptom interventions, combined with poor evidence regarding symptom interventions, underscores the importance of a more patient-centered approach to measuring the quality of symptom management that incorporates patient preferences, needs, and goals.

The Integrative Framework of Appraisal and Adaptation in Serious Medical Illness describes the proposed process by which palliative care improves experiences of care for patients with serious illness.⁴⁵ The framework posits that palliative care's focus on symptom management, coping with illness, goals of care, and treatment decisions may be associated with improved patient quality of life in part by increasing patients' use of active (vs. passive) and approach-oriented (vs. avoidant) coping strategies.⁴⁵ For example, palliative care providers can recommend strategies to treat or improve pain, a direct problem-solving coping strategy.⁴⁵ In addition, helping patients set short-term, incremental goals for improvement, such as a goal of being able to manage the pain enough to get some chores done, can improve perceived control and reduce patient feelings of hopelessness or powerlessness.⁴⁵ Patients are constantly appraising and adapting to serious illness, and the one of the roles of palliative care is to assess and respond to patient needs for symptom management.⁴⁵ Symptom management is a core competency for palliative care providers, and the patient's experience in this domain is central to the overall quality of palliative care.^{46, 47}

The proposed measure is expected to have important impacts on health outcomes; however, it is important to note that in a palliative and end of life context, outcomes such as goal-concordant care, emotional and existential well-being, overall satisfaction with care, and quality of the dying process are more relevant than typical clinical outcomes such as mortality. Accordingly, palliative care requires measures that examine whether patients are receiving care that aligns with their goals, rather than meeting clinical outcomes, such as mortality, that may be more appropriate to other conditions.

Receiving desired help for pain and other symptoms is important to patients' experience of serious illness. In the last years of life, most persons face prolonged periods of functional impairment due to multiple comorbid illnesses.⁴⁸ In addition, many patients experience pain and other symptoms that are not adequately managed²⁻⁸ and receive care that is not consistent with their preferences.⁹⁻¹² Palliative care has been shown to improve patient experience and satisfaction with care,^{49, 50} reduce caregiver

burden,⁵¹ and improve symptom management and quality of life.⁵²⁻⁵⁴ It has also been shown to reduce unnecessary hospital admissions and readmissions through effective care coordination and symptom management.^{55, 56} Accordingly, an increasing number of physicians, nurse practitioners, and physician assistants have specialized in providing palliative care in inpatient, ambulatory, and hospice settings.^{35, 57, 58}

While no studies have directly measured the effects of receiving desired help for pain, the expected size of improvement in outcomes for the proposed measure may be inferred based on performance of related measures from the American Society of Clinical Oncology's (ASCO) Quality Oncology Practice Initiative (QOPI). Implemented in 2006, QOPI is a voluntary quality improvement program for oncology practices with a twice-yearly data reporting and analysis cycle. Participating practices receive detailed benchmarking reports on their performance across the continuum of care. QOPI measure 38 is a composite measure for care of pain that includes components from three pain-related measures including assessment of pain, documentation of pain intensity, and the formulation of a specific plan for treating pain during the last two visits before death.⁵⁹ In a study of over 600 practices that participated in QOPI's Fall 2010 measurement cycle, practices that had participated in multiple data collection cycles had better performance on the composite measure for care of pain compared to sites participating for the first time (62.61 percent vs. 46.89 percent).⁵⁹ Compared to first-time QOPI participants, repeat participants also had better performance in rates of documenting discussions of hospice and palliative care (62.42 percent vs. 54.65 percent) and higher rates of hospice enrollment (40.95 percent vs. 31.45 percent).⁵⁹ These findings demonstrate that performance measurement and benchmarking can lead to meaningful improvement in palliative care quality and outcomes for patients with serious illness. Repeat participants had submitted data for multiple six-month performance cycles, suggesting that the expected time frame for improvement in similar performance measures may range from one year to several years.

Multiple RCTs demonstrate that interventions implemented in ambulatory palliative care settings can improve pain management.^{60, 61} In a systematic review of palliative care interventions,⁶² four RCTs in ambulatory palliative care settings demonstrated that patient and caregiver educational interventions for self-management of pain led to reduced pain severity.⁶³⁻⁶⁶ We also expect that routine quality measurement will itself foster improvements in quality of care. Evidence from the oncology literature demonstrates that routine measurement of patient-reported outcomes (PROs) with feedback to providers can enable earlier detection of symptoms and improve patient-provider communication about symptoms.^{67, 68} Several large randomized controlled trials (RCTs) in ambulatory oncology practices have demonstrated that that routine collection of patient-reported symptom and quality of life measures with timely provider feedback led to increased discussion of symptoms and quality of life issues during clinic visits.⁶⁸⁻⁷² Successful interventions occurred in the context of sufficient intensity of feedback (multiple times over a sustained period of time) targeting multiple stakeholders (doctors, nurses, interdisciplinary team members, and patients).⁶⁰ In one RCT, repeated collection of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) and the Hospital Anxiety and Depression Scale during clinic visits over the course of six months led to increased communication about pain and other symptoms, as well as improved health-related quality of life and improved patient perceptions of continuity of care relative to controls.^{67, 68}

Measure Impact on Healthcare Costs (if any):

Measuring the extent to which patients receive desired help for pain from their palliative care team may not directly impact health care costs. However, poorly controlled pain is an important driver of acute care utilization in patients with serious illness.^{22, 23} Among patients with cancer, unmanaged symptom distress, often related to pain, is the most common reason for emergency department visits and often leads to subsequent hospitalizations.^{22, 23} Better management of pain and other symptoms in ambulatory settings may help to prevent acute care utilization related to symptom distress. In a RCT, routine symptom monitoring and reporting among patients receiving outpatient chemotherapy for advanced cancer led to better health-related quality of life at six-month follow-up, in addition to fewer ER visits and fewer hospitalizations.⁵⁴

Palliative care may also help to reduce health care resource use that is inconsistent with patient preferences. Patients in the U.S. who are seriously ill and approaching end of life often receive intensive medical treatment incongruent with their wishes.⁷³⁻⁷⁵ Aggressive medical treatment at end of life is costly; approximately one quarter of Medicare spending for beneficiaries aged 65 and older occurs in the last year of life.⁷⁶ Palliative care interventions in various settings (inpatient, ambulatory, home-based) have been associated with lower health care resource use and, in some cases, lower costs for patients with serious illness.^{44, 49}

Multiple RCTs have demonstrated that ambulatory palliative care interventions can reduce health care utilization, in addition to improving patient satisfaction, symptom management, and quality of life.^{49, 50, 52, 77, 78} In one RCT, early palliative care for patients with metastatic lung cancer led to significant improvements in quality of life and mood, as well as less use of chemotherapy at end of life and longer survival relative to patients receiving usual care.⁵² In a year-long RCT, ambulatory palliative medicine consultation for patients with advanced illness led to fewer urgent care visits and improvements in dyspnea, anxiety, and spiritual wellbeing, but no change in emergency department visits or hospitalizations.⁷⁸ In another RCT, an in-home palliative care intervention for terminally ill patients led to improved patient satisfaction and fewer emergency department visits and hospital admissions compared with patients receiving usual care, resulting in substantially lower costs of care.⁵⁰ While findings related to cost have varied, palliative care interventions have been consistently associated with improved patient outcomes.^{44, 49}

The proposed measures may also be valuable for implementation of innovative payment models for palliative care delivery that may impact emerging models of community-based palliative care (e.g., telehealth, embedded clinic models). Interdisciplinary palliative care team services are often unbillable under a fee-for-service model, and value-based payment models may be an alternative for reimbursement.⁷⁹ However, innovative financial models require quality metrics to ensure accountability for patients as well as payers and providers.^{39, 80} Many emerging models of community-based palliative care are delivered in community settings and may not utilize the same interdisciplinary team nor have the same level of training as programs evaluated in the literature.⁸¹ Palliative care quality measures would hold programs accountable for quality and would allow providers to demonstrate the value of their services.⁸⁰ Currently available measures are generally limited to end of life utilization and process measures and are not consistently used across programs, thus patient reported quality metrics are

needed to assess the impact of community-based palliative care and ensure transparency and accountability for these vulnerable patients.^{80, 81}

Influencing Factors:

Multiple factors may influence adoption, implementation, and endorsement of the proposed measures, as well as outcomes resulting from the measures. These factors include recent legislation, implementation challenges, and the burden of participation in the measures.

As part of our information gathering, we identified two major regulations that have influenced the landscape of quality measurement for patients with serious illness. The first is the Hospice Quality Reporting Program (HQRP) which was created as part of the Affordable Care Act in 2010 and directed the Secretary of the Department of Health and Human Services to establish quality reporting requirements for hospice programs. The regulations that established the HQRP focus on patients who receive palliative care through hospice, but the focus on hospice limits the quality measures—and the data to support the quality measures—to patients who have chosen to forego curative treatment, which is currently a requirement of Medicare’s hospice benefit. In contrast, patients targeted by the quality measures we are developing may receive palliative care and curative care concurrently. However, the HQRP provides an important precedent for collecting data on the experience of seriously ill patients and the use of quality measures in this population for quality improvement and public reporting.

The second regulation that is directly related to the current quality measure development project is the MACRA legislation.⁸² In contrast to the relatively narrow HQRP, MACRA affects many aspects of payment and quality reporting for health care providers. MACRA was signed into law in 2015 with three primary aims: to repeal the sustainable growth rate methodology that calculated payment cuts for providers; to create two tracks for Medicare payment that emphasize value-based payment; and to consolidate three previous quality reporting programs (Physician Quality Reporting System, Value-based Payment Modifier, and Meaningful Use) into a single system through the Merit-Based Incentive Payment System (MIPS).⁸³ MIPS assesses performance[‡] in four categories: quality, cost, promoting interoperability, and improvement activities. MIPS quality measures serve as the mechanism for measuring provider performance. Although MIPS applies to all Medicare patients, with no limit or focus on patients with serious illness, a strong portfolio of MIPS quality measures helps to ensure that measurement is meaningful and relevant to providers and their patients. The goal of this project is to produce quality measures that can be used by MIPS-eligible providers who provide palliative care services to their patients, so that the patient experience of core components of high-quality palliative care can be attributed to their providers and used to incentivize quality improvement.

We identified several potential challenges related to implementation of the proposed measures. In focus groups, palliative care providers expressed concerns about attribution given that patients see multiple providers, though this concern may be addressed by referencing a specific provider and team in

[‡] Beginning in performance year 2019, MIPS-eligible providers include physicians, osteopathic practitioners, chiropractors, physicians assistants, nurse practitioners, clinical nurse specialists, certified nurse anesthetists, physical therapists, occupational therapists, clinical psychologists, qualified speech-language pathologists, qualified audiologists, and registered dietitians or nutrition professionals who exceed the Performance Year 2019 low-volume threshold at the individual-level or at the group-level when reporting as a group.

the patient survey. Another consideration is selection of survey modalities (i.e., mail, email, in-person) that will yield high response rates and thoughtful responses (i.e., after patients have had a chance to think about their experience). Prior work estimating the effect of the mode of survey administration on response rates and response tendencies for the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey, which asks bereaved caregivers to assess patient experiences of hospice and end-of-life care, found that response rates were 42.6 percent for mail-only survey administration, 37.9 percent for telephone-only, and 52.6 percent for mail with telephone follow-up.⁸⁴ To avoid potential gaming of the measure (for example, programs selectively surveying patients whose responses they expect to be positive), a survey vendor or registry will be responsible for identifying patients eligible to complete the survey.

Several factors may influence participation in the proposed measures. The financial and administrative burden to administer the survey may be greater for smaller palliative care practices; therefore, larger practices with more resources may be more likely to participate. It is possible that smaller practices may not have enough patients to generate reliable quality measures.³⁹ In addition, because patients with a single visit are eligible to complete the survey, some providers may be concerned that a single visit is not sufficient to address patients' concerns. For this reason, providers and practices with greater continuity of care with their patients may be more likely to participate.

Resources Required for Measure Implementation:

Various resources will likely be necessary for successful measure implementation and use. Although specific resource requirements to implement patient-experience measures were not clearly-identified in the literature, a survey study of facilitators and barriers to quality improvement in palliative care reported that key barriers cited by clinicians and administrators included lack of infrastructure for goal setting and benchmarking, as well as lack of accountability or rewards.⁸⁵ To identify resource requirements, AAHPM conducted interviews with palliative care programs that participated in the alpha and beta tests to better understand how the proposed measures may be used to facilitate quality improvement, as well as the perceived financial and administrative burden of measure implementation and associated quality improvement activities. Resources required to implement the measure would likely include IT staff hours to extract patient visit data from the electronic health record and the cost of hiring a survey vendor to administer the survey to eligible patients. As a point of reference, CMS has estimated that hospices pay approximately \$4000 per year to their survey vendors to administer the 47-item CAHPS Hospice Survey on a monthly rolling basis (typically via mail-only mode of administration). Most programs had previously worked with a vendor to administer patient surveys. Important factors cited in the decision to invest in support from a survey vendor included cost, sensitivity and tracking issues (i.e., concerns about sending surveys to deceased patients), patient survey fatigue, ability to compare measure performance with other programs, and unstable patient mailing addresses (although, in light of COVID-19, one program noted that they now consistently collect patient emails for telehealth). Finally, another consideration is the cost of quality improvement associated with the measure. Anticipated quality improvement activities related to measure implementation were explored in program interviews. Potential quality improvement activities included provider workshops and training to ensure that providers have the skillset to manage all types of pain; encouraging providers to establish expectations for pain management and set realistic goals with patients; review of pain

management strategies and treatment plans; and encouraging a comprehensive pain management approach by partnering with interventional pain and integrative medicine teams, as well as spiritual counselors and chaplains, when necessary.

AAHPM also conducted informational calls with five CMS-approved survey vendors to better understand the financial burden to practices to hire a vendor to administer the patient surveys, as well as vendors' analytic capabilities to calculate scores on the proposed measures. The five vendors ranged in size, cost, and capabilities. All vendors had experience administering a range of CAHPS surveys (e.g., hospice, hospital, home health, CAHPS for MIPS). All vendors employed biostatisticians or analysts and routinely reported performance benchmarking data to clients for CAHPS surveys, although analytic capabilities varied. In general, vendors thought it would be feasible to calculate scores on the proposed palliative care measures if they were given specific guidelines such as a technical manual and programming code. All vendors reported that they typically receive sampling data in the form of a client-provided extract file. Estimated costs to administer the mixed mode patient surveys on a monthly rolling basis varied from approximately \$2,500 to \$12,500 per year. Cost estimates varied widely depending on the vendor, the volume of eligible patients, and the data analytics requested. Vendors noted that telephone is the most expensive survey mode, and costs will vary depending on the number of follow-up calls to survey non-respondents.

Costs of Clinical Care:

Systematic reviews of the cost and cost-effectiveness of palliative care interventions in various settings (hospice, hospital-based, home-based) have identified a lack of cost-effectiveness data as a major gap in the research.⁸⁶⁻⁹⁰ In particular, there is a dearth of research on the cost of palliative care in ambulatory settings. The absence of these data make calculating the additional costs to provide ambulatory palliative care services difficult.

Potential Unintended Consequences of the Measure (if any):

In focus groups and interviews with palliative care providers, patients, caregivers, and family members during both the alpha and beta tests of this project, several concerns emerged regarding measurement of whether patients received the help they wanted for pain. Although many of these concerns relate to more typical pain measures that focus on reducing symptom severity rather than ensuring that patient needs are met, they could reflect potential unintended consequences of the proposed measure.

The first concern is that providers may be held accountable for a symptom experience over which they may have little impact. Providers noted there are multiple types of pain that patients experience beyond physical, such as emotional, existential, psychological, social, and spiritual, that might conflate with the pain experience. While patients might want to experience physical pain relief, there might be underlying issues such as a "psychosocial crisis or ongoing long-term issues they've had in their life, or a spiritual crisis" that impact their experience of pain. Further limiting their ability to impact the pain experience is the stigma associated with taking opioids, with providers in one focus group noting that "A lot of [patients] are afraid to say that they're in pain. They don't want to be labeled as being [drug] seeking." Providers from three separate focus groups also mentioned that patients might have unrealistic expectations about pain control, with some patients wanting to be completely pain free when that might not be feasible for their clinical situation. Because of these issues related to the measurement of

pain, some providers voiced concern that truly addressing patient pain is a complex endeavor, and providers may not always be able to meet patient needs. This may be particularly true if there are underlying issues that patients do not communicate, either because they are unaware or uncomfortable in doing so, and/or have expectations that are inconsistent with what providers can actually meet (i.e., pain reduction from seven to three on a ten point scale might be possible but reduction from seven to zero might be impossible).

Another concern related to pain measures was around opioid prescribing. It is possible that a measure focused on pain could incentivize providers to prescribe more opioids, or unfairly penalize them for not prescribing opioids. One provider commented that some of the negative feedback on pain management may have come from patients whose providers cut back on opioids (in light of growing concerns regarding unsafe or over-prescribing) to treat their pain. Many ambulatory palliative care programs have implemented opioid prescribing policies in an attempt to prevent opioid misuse and diversion. As a precaution to avoid unintended consequences related to opioid prescribing, programs should consider implementing opioid prescribing policies as part of this quality measure.

Another potential concern is that implementation of a measure focused on receiving help wanted for pain may result in less attention to other symptoms. However, as mentioned above, in patients with serious illness pain frequently co-occurs with other symptoms, particularly psychological symptoms such as depression and anxiety.³⁶⁻³⁸ Receiving help wanted for pain may improve other symptoms that commonly co-occur with pain.

Other concerns included: i) inadequate insurance coverage may limit providers' ability to fully manage pain; ii) comparison across palliative care programs may be challenging because patient populations and needs for pain management vary; and iii) patients may receive pain management from other services in addition to palliative care, so their responses could possibly reflect care received from other providers. Strategies to address some of the stated concerns included implementing protocols for opioid prescribing, encouraging providers to discuss expectations with patients up front, and setting realistic goals for pain management.

These considerations were taken into account in development of the measure and the choice to focus on patients' experience of receiving desired help for pain. Individuals with serious illness make important tradeoffs (e.g., patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects) and hold different preferences for their care that may only be reflected via patient experience measures. Although providers do not have control over patients' symptoms, the palliative care team can help to ensure that symptom management is consistent with patient preferences and values.

Finally, it is possible that patients who have died may be contacted to complete the survey, potentially causing distress for families. Our current data collection approach is to first send eligible patients a letter notifying them of the upcoming survey with a stamped postcard that can be returned in the event of death or a move/new address. As we continue data collection and analyses, we will have data on the numbers of patients who were mistakenly contacted after death and how we were notified (e.g., returned postcard, telephone).

Description of Model(s) and Formulas Used:

This measure will use a rate/proportion score type where a higher score resulting from this measure should be interpreted, relative to a lower score, as representing better quality of care. The calculation algorithm/measure logic will be finalized based on analyses of beta test data. The current steps are to:

- Identify eligibility within target respondent population
- Check patient age
- Check whether patient received ambulatory palliative care
- Identify any exclusions (i.e., non-completes for the patient experience survey; previous completion of survey in a given reporting period; individuals who have died or are unable to complete the survey due to cognitive impairment)
- Consider patients who return the survey for the denominator
- Apply numerator information and scoring methodology (e.g., top box scoring; linear mean scoring) which will be determined pending testing results
- Report results at the provider or group/practice level over a 12-month period
- Apply case-mix adjustment approach (pending further information from planned beta test)

The target population for sampling includes adult patients aged 18 years or older who have received ambulatory palliative care services. The sample will be drawn by the provider or group based on eligibility criteria. A vendor should be used to field the survey to eligible patients. Survey administration will be mixed-mode, including mail (hard-copy or emailed link to online survey) followed up with phone (CATI) survey if needed. Information about minimum response rate will be available after beta testing complete. Proxy responses are not allowed, but proxy assistance is allowed. The level of proxy assistance that will be allowed ultimately will be determined following beta testing.

The measure is to be comprised of survey data representing patient report of care and collected over a one-year period. The survey will include questions for both of the proposed measures of palliative care experience, including the heard and understood data elements and a question to assess the extent to which patients received the help that they wanted for their pain. The survey also includes other items related to patient experiences of care, patient demographics, health status, primary diagnosis, and proxy assistance in completing the survey. The beta survey instrument includes 43 items. Looking to implementation, the overall survey is not expected to include all 43 items, since many are included solely for testing and analytic purposes. The data should be collected from either a sample that is representative of the palliative care provider or group or a census of eligible palliative care patients within the designated timeframe. The minimum response rate for participating within the measure will be determined during beta testing. Response rates at the program level should be calculated with respect to key items and reported to determine the sufficiency of the data to calculate the measure prior to imputation. The threshold for these minimum response rate will be determined following the beta testing period. For survey responses that contain missing data, imputation procedures may be used *where appropriate* to handling missing response values. This procedure will be documented following beta testing.

Within palliative care providers and/or groups with high enough response rates, the current plan is to assess the distribution of missing data (i.e., not responding to specific questions) and nonresponse (i.e., not responding to the survey) to assess their impact on utilizing the proposed measure. The first concern is that responders and non-responders differ in the distributions of case-mix variables, i.e., informative missingness. While we will not know how the non-responders “would have responded” regarding their care, we can be certain that if the distributions of case-mix variables are different then there is a potential for bias. We will use available patient data to characterize the differences between responders and non-responders to assess potential impact non-response may have on the representativeness of the study population. A lesser concern is of missing data, i.e., not responding to individual items or demographic questions. To handle this, we will again assess the distributions and patterns of missing data, but here we will perform an assessment to see if a missing-at-random assumption seems plausible and if so impute data where necessary to keep as many survey responses within the pool of data as possible. A multiple imputation strategy and either distributional assumptions or alternative strategies will be used to fill in the missing data.

Patient-reported data will be collected via survey instrument. The instrument was developed for this measure and is meant to be completed on paper and via telephone and possibly via web-link (based on beta testing results and evidence of feasibility) in English or Spanish.

Limitations of Analysis:

The study team limited the literature for this business case to articles written in English and published between 2000 and 2019 to present recent statistics, interventions, and cost projections. Our literature search focused on identifying studies related to symptom management experience and communication or patient-provider relational experience in palliative care populations and other patients with serious illness. We used a purposive “snowball” approach to identify relevant studies, first identifying key studies, then reviewing citations to identify findings in related papers. Although the focus of the proposed measure is ambulatory palliative care, the palliative care settings represented within the search specifications also included hospital-based (inpatient or outpatient), hospice, and home-based settings. Although a large volume of historical literature was not incorporated into this analysis, studies referenced in internal project documents (i.e., the MACRA Palliative Care Measure Development Project Environmental Scan [completed June 2019] and Information Gathering Report [completed October 2019]) were also reviewed. These documents incorporated a longer time span of literature.

For the alpha and beta tests, patient surveys were administered by the RAND Survey Research Group. Palliative care programs’ experiences with other survey vendors may differ.

Net Benefit:

Net benefits from the proposed measure of *Ambulatory Palliative Care Patients’ Experience of Receiving Desired Help for Pain* include:

- Improved patient experience and satisfaction with care,^{44, 49}
- Improved symptom management and quality of life.^{44, 49}

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