

Business Case: Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood

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 Feeling Heard and Understood, is the percentage of patients aged 18 years and older who had an ambulatory palliative care visit, who report feeling heard and understood 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., web, mail, and phone follow-up). We anticipate this will be a multi-item measure (including the heard and understood item, as well as items measuring related concepts such as trust in provider, whole-person orientation), with exact items to be determined after testing.

Numerator Statement:

The percentage of patients meeting the denominator statement (see below) who report feeling heard and understood by their palliative care provider and team during their care in the last six months.

Numerator options include:

- *Performance met*: feeling heard and understood achieved [threshold to be specified] within 6 months following an ambulatory palliative care visit

OR

- *Performance not met*: feeling heard and understood 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.

We anticipate this will be a multi-item measure (heard and understood, trust in provider, whole-person orientation), with exact items to be determined after testing. Scoring methodology (e.g., top box scoring; linear mean scoring) will also be determined using 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, 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 testing. During the beta test, we are collecting potential risk-adjustment variables directly from participating sites via their submitted data files. These variables include age, gender, location, 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:

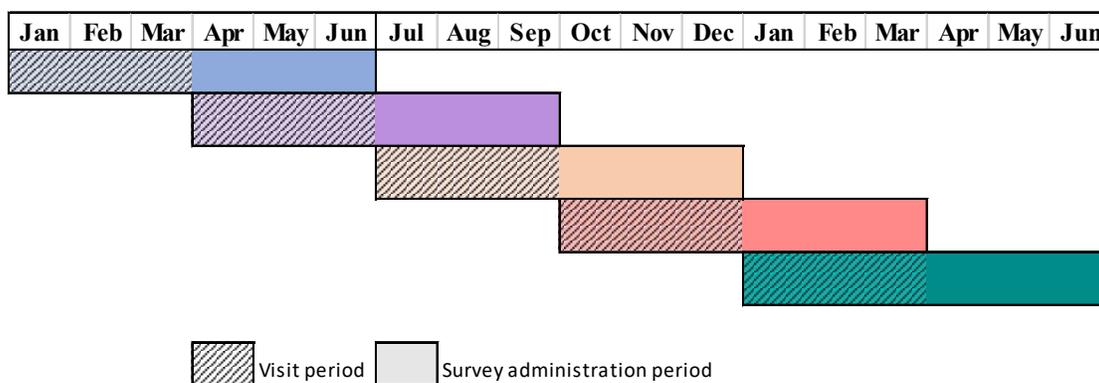
- Do not complete and return the patient experience survey within 6 months of the eligible ambulatory palliative care visit (i.e., providers and groups will not be penalized for non-response);
- Are deceased by the time the survey reaches them (i.e., bereaved caregiver responses are excluded);
- Have 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 testing 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 implementation guidance. 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.

Seriously ill persons often report feeling silenced, ignored, and misunderstood in medical institutions.²⁻⁴ Therefore systematically monitoring, reporting, and responding to how well patients feel heard and understood are crucial to creating and sustaining a health care environment that excels in caring for those who are seriously ill.⁵ The quality of provider communication in serious illness is built on at least four mutually reinforcing processes: information gathering, information sharing, responding to emotion, and fostering relationships.⁶ These elements directly shape patient experience and, when done well, can help patients feel known, informed, in control, and satisfied, potentially improving well-being and

quality of life.⁶⁻⁸ Assessing the extent to which the patient felt heard and understood can improve communication about prognosis and treatment options and adherence to the treatment plan.^{5,9}

The proposed measure will fill clearly-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 current measures, the proposed measure addresses the very important interpersonal nature of patient-provider communication in palliative care that undergirds patient-centered care; i.e., whether the patient felt that their provider truly understood them, their wishes, values, preferences, worries and fears. Third, the proposed measure adds to a small but growing body of measurement focused on patient-reported experience in the context of end of life care.

Incidence and Prevalence Data

Prior research suggests that patients with serious illness may not feel heard and understood by their providers. Two studies by Gramling et al. and Ingersoll et al. examined this outcome among hospitalized patients with serious illness.^{5,10} Both studies evaluated the extent to which patients felt heard and understood by providers immediately before and the day after receiving an initial inpatient palliative care consultation. Patients were asked, “Over the past two days [‘24 hours’ for the post-consultation version], how much have you felt heard and understood by the doctors, nurses, and hospital staff? (Completely /quite a bit /moderately /slightly /not at all).” In both studies, the majority (approximately two-thirds) of seriously ill inpatients reported less than optimal scores on the heard and understood measure prior to palliative care consultation (i.e., not “completely” heard and understood), but many patients’ scores improved following palliative care consultations. Gramling et al. found that over 80 percent of respondents who reported feeling “not at all” heard and understood before palliative care consultation reported feeling more heard and understood at the post-consultation assessment, with 23 percent increasing their rating to “completely.”⁵ Similarly, Ingersoll et al. found that among the two-thirds of palliative care patients who did not report feeling “completely” heard and understood at baseline, 56 percent showed improvement in the heard and understood measure following the palliative care consultation.¹⁰

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 facilitate and improve effective patient-provider communication that engenders trust, acknowledgement, and a whole-person orientation to the care that is provided. The outcome that is the focus of the proposed quality measure is that the patient feels heard and understood by the outpatient palliative care provider and team.

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 "Heard and Understood" data element has been used in palliative care research studies – but not in measurement programs - in different formats.^{5, 10} The exact wording and structure for the proposed quality measure have not yet been used among ambulatory palliative care populations.

Among seriously ill patients, several patient-level characteristics have been associated with feeling incompletely heard and understood by health care providers. In a cross-sectional analysis of advanced cancer patients at two U.S. medical centers, Ingersoll et al.¹⁰ evaluated the extent to which patients felt heard and understood by providers immediately before and the day after receiving an initial inpatient palliative care consultation. Patient-level factors associated with feeling incompletely heard and understood included lower levels of financial security, younger age, high emotional distress, patient uncertainty regarding one-year prognosis, and not endorsing a preference for comfort over longevity. Upon re-assessment the day after inpatient palliative care consultation, many patients had substantial improvement in feeling heard and understood by their health care team. All patient-level factors associated with feeling incompletely heard and understood were substantially attenuated in the post-assessment, suggesting that palliative care consultation helps to improve health care communication globally.¹⁰

Other studies have examined disparities by race and ethnicity in satisfaction with provider communication among patients with serious illness (a different but related concept to feeling heard and understood), but findings have varied. In a national survey of bereaved family members, surrogates of Black patients reported lower satisfaction with the quality of end-of-life care and reported more concerns about provider communication.¹¹ Another study found that terminally ill Black patients reported lower satisfaction than White patients with the overall quality of patient-physician relationships, with greater disparities observed in racially discordant patient-provider relationships.¹²

Other studies have reported conflicting findings. In a multicenter study to examine quality of communication and trust in patients with serious illness, patient characteristics associated with higher ratings of clinician communication included belong to a racial/ethnic minority group, lower income, and higher religiosity.¹³ Another study found that patients from racial/ethnic minority groups, patients with lower income, and patients with lower educational attainment gave physicians in training higher ratings on end of life care communication; however, family members of non-white patients gave trainees lower ratings on communication.¹⁴ A possible explanation for these conflicting findings is that various patient characteristics and contextual factors may impact patients' experience of clinician communication. For example, socioeconomic status has also been associated with quality of patient-provider communication and may mediate associations by race and ethnicity.^{13, 15}

Measure Impact on Care and Health Outcomes:

Current evidence suggests that clear patient-provider communication in palliative care settings has an important and significant impact on care processes and outcomes. A recent large systematic review¹⁶ conducted to inform the 4th edition National Consensus Project Guidelines for Quality Palliative Care¹⁷ found moderate quality evidence that interventions such as ethics consultations and care planning discussions improve consensus around clinical decisions and lead to preference-concordant care, patient-family agreement regarding treatment decisions, and advance care planning documentation.¹⁸⁻²⁰ In a multicenter randomized controlled trial (RCT), a patient-specific communication-priming intervention targeting patients with serious illness and clinicians was associated with higher patient-reported quality of goals-of-care discussions during clinic visits.²¹

There are various conceptual frameworks and theoretical models to help explain how patient-provider communication in the palliative care context can improve patient experience. The Integrative Framework of Appraisal and Adaptation in Serious Medical Illness²² posits that patients are constantly appraising and adapting to serious illness, and their health and emotional needs change throughout the course of their illness. The role of palliative care is to assess and respond to patient needs by providing expert medical knowledge tailored to the patient's specific informational needs, facilitating disease understanding and prognostic awareness, discussing options for management, and suggesting active coping strategies.²² Good communication and interpersonal skills are thus a core competency for palliative care providers, and the patient's experience in this domain is central to the overall quality of palliative care.^{23, 24} By evaluating the extent to which patients feel heard and understood by their palliative care team, the proposed measure is also expected to capture the overall quality of palliative care.

The proposed measure is also 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.

Improving provider communication can improve overall satisfaction with care among patients with serious illness.^{25, 26} In the last years of life, most people face prolonged periods of functional impairment due to multiple comorbid illnesses.²⁷ In addition, many patients experience inadequate communication from their health care providers about prognosis and treatment options^{26, 28-31} and receive care that is not consistent with their preferences.^{29, 31-33} Palliative care consultations can improve patients' perceptions of feeling heard and understood by providers.^{25, 26} In multiple studies, patients with serious illness who received palliative care consultations showed improvement in feeling heard and understood following the consultation.^{5, 10} Palliative care has been shown to improve patient experience and satisfaction with care,^{34, 35} reduce caregiver burden,³⁶ and improve symptom management and quality of life.³⁷⁻³⁹ It has also been shown to reduce unnecessary hospital admissions and readmissions through effective care coordination and symptom management.^{40, 41} Accordingly, an increasing number of physicians, nurse practitioners, and physician assistants have specialized in providing palliative care in inpatient, ambulatory, and hospice settings.⁴²⁻⁴⁴

The potential for improvement and extent of improvement in patient experiences of care can be inferred based on the effect sizes shown in previous studies of patient experience measures in palliative care settings. Evidence from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) literature suggests that data from patient experience measures can inform quality improvement for providers and practices.⁴⁵ Multiple public reporting and pay-for-performance programs incorporate patient experience data from the CAHPS surveys. In California, patient experiences of care improved over the course of three years following implementation of a statewide pay-for-performance program based on Clinician & Groups CAHPS (CG-CAHPS) scores.⁴⁶ Between 2003 and 2006, primary care physicians improved performance on the physician-patient communication (0.62 point annual increase), care coordination (0.48 point annual increase), and office staff interaction (0.22 point annual increase) measures, with the greatest improvement observed among physicians with lower baseline performance.⁴⁶ These changes represent clinically meaningful improvement in the quality of provider communication.⁴⁷

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 improve communication between clinicians and patients.^{48, 49} Several large RCTs in ambulatory oncology practices have demonstrated that that routine collection of patient-reported symptom and quality of life measures with timely provider feedback leads to increased discussion of symptoms and quality of life issues during clinic visits.⁵⁰⁻⁵⁴ 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 improved communication about symptoms, improved health-related quality of life, and improved patient perceptions of continuity of care relative to controls.^{51, 55}

Evidence from the American Society of Clinical Oncology's (ASCO) Quality Oncology Practice Initiative (QOPI) demonstrates that performance measurement and benchmarking can lead to meaningful improvement in palliative care quality and outcomes for patients with serious illness. 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. 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 a composite measure for care of pain compared to sites participating for the first time (62.61 percent vs. 46.89 percent).⁵⁶ 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).⁵⁶ 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.

Measure Impact on Healthcare Costs (if any):

Measuring the extent to which patients with serious illness feel heard and understood by their palliative care team may not directly impact health care costs. However, skilled communication about goals of care may 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.⁵⁷⁻⁵⁹ 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.⁶⁰ 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.^{34, 61}

Multiple RCTs have demonstrated that ambulatory palliative care interventions that incorporate skilled communication about goals of care can reduce health care utilization, in addition to improving patient satisfaction, symptom management, and quality of life.^{34, 35, 37, 62, 63} 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.³⁷ 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.⁶³ 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.³⁵ While findings related to cost have varied, palliative care interventions have been consistently associated with improved patient outcomes.^{34, 61}

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.⁶⁴ However, innovative financial models require quality metrics to ensure accountability for patients as well as payers and providers.^{25, 65} 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.⁶⁶ Palliative care quality measures would hold programs accountable for quality and would allow providers to demonstrate the value of

their services.⁶⁵ 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.^{65, 66}

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 played a key role in shaping 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.⁶⁷ 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).⁶⁸ MIPS assesses performance¹ 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.

¹ 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.

We identified several potential challenges related to implementation of the proposed measures. In focus groups, palliative care providers expressed concerns about attribution given patients see multiple providers, though this concern may be addressed by referencing a specific provider and team in 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 effects of survey mode 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 experience 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.⁶⁹ 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.²⁵ 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.⁷⁰ 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 communication training; encouraging providers to establish expectations with patients and set realistic goals; and root cause analysis to identify the sources of patient dissatisfaction, including external factors (i.e., experience in clinic or delays, long wait times to get an appointment).

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 made.

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.⁷¹⁻⁷⁵ In particular, there is a dearth of research on the cost of palliative care in ambulatory settings. The absence of these data makes calculating the additional costs to provide ambulatory palliative care services difficult.

Potential Unintended Consequences of the Measure (if any):

We anticipate few unintended adverse consequences from measuring the extent to which patients feel heard and understood by providers. In qualitative interviews with palliative care programs that participated in alpha and beta testing, providers were asked about potential unintended consequences of the heard and understood measure. Common concerns reported by providers were recall bias, social desirability bias, and repercussions of negative feedback. Comparison across palliative care programs may be challenging if patient populations have differences in disease trajectories that impact communication. In addition, there were concerns that some patients may have unrealistic expectations for palliative care, and patients whose expectations are not met may identify as not being heard and understood. Palliative care providers often have to deliver bad news to patients, which may negatively impact patient perceptions of the palliative care team.⁷⁶ Strategies recommended to prevent some of these unintended consequences included encouraging providers to establish expectations with patients up front and set realistic goals for palliative care. Providers also recommended framing the questions to help patients understand that the measures are useful for the program and ultimately for other patients.

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 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)
- 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 testing)

The target population for sampling includes all 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 is 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 12-month 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 following 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 rates will be determined following the beta test. 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 the 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 Feeling Heard and Understood* include:

- Improved patient experience and satisfaction with care;^{34, 61}
- Improved symptom management and quality of life.^{34, 61}

REFERENCES

1. Centers for Medicare & Medicaid Services Health Services Advisory Group. *CMS Quality Measure Development Plan Environmental Scan and Gap Analysis Report (MACRA, Section 102)*. 2017. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/MACRA-MIPS-and-APMs/MDP_EScan_GapAnalysis_Report.pdf
2. Institute of Medicine, Committee on Approaching Death Addressing Key End of Life Issues. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press; 2015.
3. Frosch DL, May SG, Rendle KA, Tietbohl C, Elwyn G. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Affairs*. 2012;31(5):1030-1038.
4. Norton SA, Tilden VP, Tolle SW, Nelson CA, Eggman ST. Life support withdrawal: communication and conflict. *American Journal of Critical Care*. 2003;12(6):548-555.
5. Gramling R, Stanek S, Ladwig S, et al. Feeling Heard and Understood: A Patient-Reported Quality Measure for the Inpatient Palliative Care Setting. *J Pain Symptom Manage*. 2016;51(2):150-154. doi:10.1016/j.jpainsymman.2015.10.018
6. Street RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient education and counseling*. 2009;74(3):295-301.
7. Medendorp N, Visser L, Hillen M, de Haes J, Smets E. How oncologists' communication improves (analogue) patients' recall of information. A randomized video-vignettes study. *Patient education and counseling*. 2017;100(7):1338-1344.
8. Murray CD, McDonald C, Atkin H. The communication experiences of patients with palliative care needs: A systematic review and meta-synthesis of qualitative findings. *Palliative & supportive care*. 2015;13(2):369-383.
9. Chochinov HM, McClement S, Hack T, Thompson G, Dufault B, Harlos M. Eliciting Personhood Within Clinical Practice: Effects on Patients, Families, and Health Care Providers. *J Pain Symptom Manage*. 2015;49(6):974-80.e2. doi:10.1016/j.jpainsymman.2014.11.291
10. Ingersoll LT, Saeed F, Ladwig S, et al. Feeling Heard & Understood in the Hospital Environment: Benchmarking Communication Quality Among Patients with Advanced Cancer Before and After Palliative Care Consultation. *J Pain Symptom Manage*. 2018;56(2):239-244. doi:10.1016/j.jpainsymman.2018.04.013
11. Welch LC, Teno JM, Mor V. End-of-life care in black and white: race matters for medical care of dying patients and their families. *J Am Geriatr Soc*. Jul 2005;53(7):1145-53. doi:10.1111/j.1532-5415.2005.53357.x

12. Smith AK, Davis RB, Krakauer EL. Differences in the quality of the patient-physician relationship among terminally ill African-American and white patients: impact on advance care planning and treatment preferences. *J Gen Intern Med*. Nov 2007;22(11):1579-82. doi:10.1007/s11606-007-0370-6
13. Coats H, Downey L, Sharma RK, Curtis JR, Engelberg RA. Quality of Communication and Trust in Patients With Serious Illness: An Exploratory Study of the Relationships of Race/Ethnicity, Socioeconomic Status, and Religiosity. *J Pain Symptom Manage*. Oct 2018;56(4):530-540.e6. doi:10.1016/j.jpainsymman.2018.07.005
14. Long AC, Engelberg RA, Downey L, et al. Race, income, and education: associations with patient and family ratings of end-of-life care and communication provided by physicians-in-training. *Journal of Palliative Medicine*. 2014;17(4):435-447. doi:10.1089/jpm.2013.0214
15. Siminoff LA, Graham GC, Gordon NH. Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns*. Sep 2006;62(3):355-60. doi:10.1016/j.pec.2006.06.011
16. Ahluwalia SC, Chen C, Raaen L, et al. A Systematic Review in Support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition. *J Pain Symptom Manage*. 2018;56(6):831-870. doi:10.1016/j.jpainsymman.2018.09.008
17. *National Consensus Project Clinical Practice Guidelines for Quality Palliative Care*. <https://www.nationalcoalitionhpc.org/ncp-guidelines-2018/>
18. Au SS, Couillard P, Roze des Ordons A, Fiest KM, Lorenzetti DL, Jette N. Outcomes of ethics consultations in adult ICUs: a systematic review and meta-analysis. *Critical care medicine*. 2018;46(5):799-808.
19. Kryworuchko J, Hill E, Murray MA, Stacey D, Fergusson DA. Interventions for Shared Decision-Making About Life Support in the Intensive Care Unit: A Systematic Review. *Worldviews on Evidence-Based Nursing*. 2013;10(1):3-16. doi:10.1111/j.1741-6787.2012.00247.x
20. Baidoobonso S. Patient care planning discussions for patients at the end of life: an evidence-based analysis. *Ontario health technology assessment series*. 2014;14(19):1-72.
21. Curtis JR, Downey L, Back AL, et al. Effect of a Patient and Clinician Communication-Priming Intervention on Patient-Reported Goals-of-Care Discussions Between Patients With Serious Illness and Clinicians: A Randomized Clinical Trial. *JAMA Intern Med*. 2018;178(7):930-940. doi:10.1001/jamainternmed.2018.2317
22. Bickel KE, Levy C, Macphee E, et al. An Integrative Framework of Appraisal and Adaptation in Serious Medical Illness. *J Pain Symptom Manage*. 2020;60(3):657-677.e6. doi:10.1016/j.jpainsymman.2020.05.018
23. American Academy of Hospice and Palliative Care Medicine. *Hospice and Palliative Care Medicine Core Competencies Version 2.3*. 2009.
24. National Quality Forum. *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*. 2006.

25. Anhang Price R, Stucky B, Parast L, et al. Development of Valid and Reliable Measures of Patient and Family Experiences of Hospice Care for Public Reporting. *J Palliat Med*. 2018;21(7):924-932. doi:10.1089/jpm.2017.0594
26. Dy SM, Shugarman LR, Lorenz KA, Mularski RA, Lynn J. A systematic review of satisfaction with care at the end of life. *J Am Geriatr Soc*. 2008;56(1):124-129. doi:10.1111/j.1532-5415.2007.01507.x
27. Smith AK, Walter LC, Miao Y, Boscardin WJ, Covinsky KE. Disability during the last two years of life. *JAMA Intern Med*. 2013;173(16):1506-1513. doi:10.1001/jamainternmed.2013.8738
28. Covinsky KE, Fuller JD, Yaffe K, et al. Communication and decision-making in seriously ill patients: findings of the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *J Am Geriatr Soc*. 2000;48(5 Suppl):S187-93.
29. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004;291(1):88-93. doi:10.1001/jama.291.1.88
30. Casarett D, Pickard A, Bailey FA, et al. A nationwide VA palliative care quality measure: the family assessment of treatment at the end of life. *J Palliat Med*. 2008;11(1):68-75. doi:10.1089/jpm.2007.0104
31. Teno JM, Lima JC, Lyons KD. Cancer patient assessment and reports of excellence: reliability and validity of advanced cancer patient perceptions of the quality of care. *J Clin Oncol*. 2009;27(10):1621-1626. doi:10.1200/jco.2008.16.6348
32. Teno JM, Freedman VA, Kasper JD, Gozalo P, Mor V. Is care for the dying improving in the United States? *Journal of palliative medicine*. 2015;18(8):662-666.
33. Khandelwal N, Curtis JR, Freedman VA, et al. How Often Is End-of-Life Care in the United States Inconsistent with Patients' Goals of Care? *Journal of palliative medicine*. 2017;20(12):1400-1404.
34. Rabow M, Kvale E, Barbour L, et al. Moving upstream: a review of the evidence of the impact of outpatient palliative care. *J Palliat Med*. Dec 2013;16(12):1540-9. doi:10.1089/jpm.2013.0153
35. Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc*. Jul 2007;55(7):993-1000. doi:10.1111/j.1532-5415.2007.01234.x
36. Gelfman LP, Meier DE, Morrison RS. Does Palliative Care Improve Quality? A Survey of Bereaved Family Members. *J Pain Symptom Manage*. 2008;36(1):22-28. doi:10.1016/j.jpainsymman.2007.09.008
37. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733-742. doi:10.1056/NEJMoa1000678
38. Ferrell B, Sun V, Hurria A, et al. Interdisciplinary Palliative Care for Patients With Lung Cancer. *J Pain Symptom Manage*. Dec 2015;50(6):758-67. doi:10.1016/j.jpainsymman.2015.07.005

39. Basch E, Deal AM, Kris MG, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *J Clin Oncol*. Feb 20 2016;34(6):557-65. doi:10.1200/jco.2015.63.0830
40. Nelson C, Chand P, Sortais J, Oloimooja J, Rembert G. Inpatient Palliative Care Consults and the Probability of Hospital Readmission. *The Permanente Journal*. 2011;15(2):48-51.
41. Morrison RS, Penrod JD, Cassel JB, et al. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168(16):1783-1790. doi:10.1001/archinte.168.16.1783
42. Center to Advance Palliative Care and the National Palliative Care Research Center. National Palliative Care Registry. Accessed May 7, 2019. <https://registry.capc.org/metrics-resources/state-reports/>
43. Borgsteede SD, Deliens L, Beentjes B, et al. Symptoms in patients receiving palliative care: a study on patient-physician encounters in general practice. *Palliat Med*. 2007;21(5):417-423. doi:10.1177/0269216307079821
44. Hui D, Elsayem A, De la Cruz M, et al. Availability and integration of palliative care at US cancer centers. *JAMA*. 2010;303(11):1054-1061. doi:10.1001/jama.2010.258
45. Anhang Price R, Elliott MN. Measuring Patient-Centeredness of Care for Seriously Ill Individuals: Challenges and Opportunities for Accountability Initiatives. *J Palliat Med*. 2018;21(Suppl 2):S-28-S-35. doi:10.1089/jpm.2017.0452
46. Rodriguez HP, von Glahn T, Elliott MN, Rogers WH, Safran DG. The effect of performance-based financial incentives on improving patient care experiences: a statewide evaluation. *J Gen Intern Med*. 2009;24(12):1281-1288. doi:10.1007/s11606-009-1122-6
47. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication Interventions Make A Difference in Conversations Between Physicians and Patients: A Systematic Review of the Evidence. *Med Care*. 2007;45(4)
48. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res*. Jun 11 2013;13:211. doi:10.1186/1472-6963-13-211
49. Howell D, Molloy S, Wilkinson K, et al. Patient-reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and implementation factors. *Ann Oncol*. Sep 2015;26(9):1846-1858. doi:10.1093/annonc/mdv181
50. Taenzer P, Bultz BD, Carlson LE, et al. Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients. *Psychooncology*. May-Jun 2000;9(3):203-13. doi:10.1002/1099-1611(200005/06)9:3<203::aid-pon453>3.0.co;2-y
51. Velikova G, Booth L, Smith AB, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol*. Feb 15 2004;22(4):714-24. doi:10.1200/jco.2004.06.078

52. Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA*. Dec 18 2002;288(23):3027-34. doi:10.1001/jama.288.23.3027
53. Takeuchi EE, Keding A, Awad N, et al. Impact of patient-reported outcomes in oncology: a longitudinal analysis of patient-physician communication. *J Clin Oncol*. Jul 20 2011;29(21):2910-7. doi:10.1200/jco.2010.32.2453
54. Berry DL, Blumenstein BA, Halpenny B, et al. Enhancing patient-provider communication with the electronic self-report assessment for cancer: a randomized trial. *J Clin Oncol*. Mar 10 2011;29(8):1029-35. doi:10.1200/jco.2010.30.3909
55. Velikova G, Keding A, Harley C, et al. Patients report improvements in continuity of care when quality of life assessments are used routinely in oncology practice: secondary outcomes of a randomised controlled trial. *Eur J Cancer*. Sep 2010;46(13):2381-8. doi:10.1016/j.ejca.2010.04.030
56. Champion FX, Larson LR, Kadlubek PJ, Earle CC, Neuss MN. Advancing performance measurement in oncology: quality oncology practice initiative participation and quality outcomes. *J Oncol Pract*. May 2011;7(3 Suppl):31s-5s. doi:10.1200/jop.2011.000313
57. Wunsch H, Angus DC, Harrison DA, et al. Variation in critical care services across North America and Western Europe. *Crit Care Med*. Oct 2008;36(10):2787-93, e1-9. doi:10.1097/CCM.0b013e318186aec8
58. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press 2015.
59. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC. Trends in the aggressiveness of cancer care near the end of life. *J Clin Oncol*. Jan 15 2004;22(2):315-21. doi:10.1200/jco.2004.08.136
60. Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. *Health Serv Res*. 2010;45(2):565-576. doi:10.1111/j.1475-6773.2010.01082.x
61. Kavalieratos D, Corbelli J, Zhang D, et al. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. *JAMA*. 2016;316(20):2104-2114. doi:10.1001/jama.2016.16840
62. Greer JA, Tramontano AC, McMahon PM, et al. Cost Analysis of a Randomized Trial of Early Palliative Care in Patients with Metastatic Nonsmall-Cell Lung Cancer. *J Palliat Med*. Aug 2016;19(8):842-8. doi:10.1089/jpm.2015.0476
63. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med*. Jan 12 2004;164(1):83-91. doi:10.1001/archinte.164.1.83
64. Center to Advance Palliative Care. *Payment Primer: What to Know about Payment for Palliative Care Delivery*. 2017.

65. California Health Care Foundation. *Lessons Learned from Payer-Provider Partnerships for Community-Based Palliative Care*. 2018.
66. Teno JM, Price RA, Makaroun LK. Challenges Of Measuring Quality Of Community-Based Programs For Seriously Ill Individuals And Their Families. *Health Affairs*. 2017;36(7):1227-1233. doi:10.1377/hlthaff.2017.0161
67. GovTrack.us. H.R. 2 - 114th Congress: Medicare Access and CHIP Reauthorization Act of 2015. 2019.
68. American Academy of Family Physicians. Frequently Asked Questions: Medicare Access and CHIP Reauthorization Act of 2015 (MACRA). Accessed March 21, 2019. <https://www.aafp.org/practice-management/payment/medicare-payment/macra-101/faq.html>
69. Parast L, Elliott MN, Hambarsoomian K, Teno J, Anhang Price R. Effects of Survey Mode on Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey Scores. *J Am Geriatr Soc*. 2018;66(3):546-552. doi:10.1111/jgs.15265
70. Kuchinad K, Sharma R, Isenberg SR, et al. Perceptions of Facilitators and Barriers to Measuring and Improving Quality in Palliative Care Programs. *Am J Hosp Palliat Care*. 2020;37(12):1022-1028. doi:10.1177/1049909120916702
71. Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med*. Feb 2014;28(2):130-50. doi:10.1177/0269216313493466
72. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage*. Feb 2003;25(2):150-68. doi:10.1016/s0885-3924(02)00599-7
73. Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care: a systematic review. *Jama*. Apr 9 2008;299(14):1698-709. doi:10.1001/jama.299.14.1698
74. Gomes B, Harding R, Foley KM, Higginson IJ. Optimal approaches to the health economics of palliative care: report of an international think tank. *J Pain Symptom Manage*. Jul 2009;38(1):4-10. doi:10.1016/j.jpainsymman.2009.04.008
75. Simoens S, Kutten B, Keirse E, et al. The costs of treating terminal patients. *J Pain Symptom Manage*. Sep 2010;40(3):436-48. doi:10.1016/j.jpainsymman.2009.12.022
76. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. Oct 25 2012;367(17):1616-25. doi:10.1056/NEJMoa1204410