

# Development of Palliative Care Quality Measures for Outpatients in a Clinic-Based Setting

## A Report on Information Gathering Activities

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## Preface

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Because of the rapid expansion of palliative care as a medical specialty, and the limited ability to measure the quality and experience of care delivered in this field, there has been a growing awareness of, and emphasis on, the importance of developing quality measures specific to palliative care. As palliative care services are increasingly offered earlier in the disease trajectory while patients may still be receiving curative care, key stakeholders including health care providers, payers, regulatory agencies, and patient advocates have called for a better understanding of the patient and caregiver experience of palliative care, particularly in the outpatient clinic-based setting.

This report presents the findings of information-gathering activities conducted by the RAND Health Care team in the first year of a project to develop two measures of palliative care quality for adult patients receiving such care in outpatient, clinic-based settings. In this report, we describe our findings, including the consensus that has developed for measurement priorities in the palliative care community, a summary of clinical practice guidelines, and the evidence base on palliative care. We also review current relevant regulations, existing measures of patient and caregiver experience, findings from a gap analysis on palliative care assessment, and findings from provider focus groups and interviews with patients and caregivers or family members.

This project is being conducted through a cooperative agreement with the American Academy of Hospice and Palliative Medicine (AAHPM). The Centers for Medicare & Medicaid Services provided funding to the AAHPM as part of the Medicare Access and CHIP Reauthorization Act of 2015 to develop patient-reported experience performance measures in the areas of pain and symptom management and communication for patients with serious illness (including those receiving palliative care). The cooperative agreement name is the “Palliative Care Measures Project.” The cooperative agreement number is 1V1CMS331639-01-00.

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## Summary

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Palliative care has expanded rapidly in recent years, and a consensus has been growing within the provider community regarding the need for measuring the quality of palliative care. Yet little is known about the quality of palliative care delivered, particularly among patients who receive their palliative care early in their disease trajectory in the outpatient setting. The patterns of palliative care received in outpatient clinics differ substantially from palliative care received in other settings. Outpatient palliative care often supplements a primary treating service such as oncology. Patients may have several visits with different members of the palliative care team, or they may only have a single visit. This variability in the patient experience of palliative care raises important measurement challenges. The Centers for Medicare & Medicaid Services (CMS) provided funding to the American Academy of Hospice and Palliative Medicine (AAHPM) as part of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) to develop patient-reported experience performance measures in the areas of pain and symptom management and communication for adult patients with serious illness, including those receiving palliative care. Between fall 2019 and summer 2021, AAHPM and their subcontractors—the RAND Corporation and the National Coalition for Hospice and Palliative Care—will develop, test, and implement two patient-reported experience measures for patients participating in outpatient, clinic-based, palliative care.

The two measures will need to be both broadly applicable to patients and families, and useful to clinicians and health systems in measuring and improving the quality of care that patients with serious illness receive. To meet these goals, this three-year project (October 2018–September 2021) includes a series of information-gathering, stakeholder engagement, and testing activities. The project is using an innovative approach to ensure broad stakeholder input; the Technical Expert Clinical User Patient Panel model elicits the perspectives of patients, caregivers, and family members, in addition to clinicians and researchers. Development of measures has been and will be informed by focus groups and interviews with providers, patients, and caregivers. Two stages of field testing will provide data on the feasibility and performance of the measures. After development and testing, the two measures will be submitted to the National Quality Forum for endorsement, with the ultimate goal of inclusion of the measures in CMS’s Quality Payment Program, including the Merit-Based Incentive Payment System (MIPS) and Alternative Payment Models (APMs).

This report describes information-gathering activities completed as of September 2019. The purpose of this report is to summarize important background information that demonstrates the importance of and need for development of quality measures based on patient-reported experience. Components of this report include a review of the literature and measure repositories to identify measures already in use, potential competition among existing instruments, and work

needed to facilitate harmonization among measures; a literature review to identify the most common symptoms experienced by patients with serious illness; a review of clinical practice guidelines to understand domains of clinical importance; a review of existing regulations to understand the parameters within which the proposed measures would be implemented; and patient or caregiver and provider interviews and focus groups to understand end-user perspectives, including what is most important to patients and what implementation of the proposed measures might look like in practice.

Our findings confirm that there is a need for quality measures focused on clinic-based palliative care, given the growth in demand for and provision of these services. Stakeholders previously convened consensus panels that included experts on serious illness care, researchers, payers, and patient advocates. These consensus panels generated **measurement priorities** that included the importance of assessing the quality of symptom management and communication, the areas of focus for measure development under this project. Core goals of high-quality palliative care are good communication, which can be measured by items that assess the extent to which a patient and/or caregiver felt heard and understood, and symptom management, which can be measured by items that assess the extent to which a patient's clinical needs have been met. In this work, we note the difference between measuring symptom management by level of symptoms reported (e.g., pain rated on a 1–10 scale), where higher levels of symptoms might be considered poor symptom management, and by asking patients the extent to which symptoms were managed adequately for their goals (e.g., getting as much help for pain as they wanted). Focusing on these two core areas—feeling heard and understood, and level of unmet needs for symptom management—will help assess the quality of clinical care delivery management of psychosocial needs, while accommodating the subjective experience of the patient.

To provide a broader context for the findings of our literature review and stakeholder engagement work, we also summarize pertinent clinical guidelines and regulations that influence palliative care quality measurement. **Clinical guidelines** for palliative care have been defined by the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care (NCP). The fourth revision of the NCP Guidelines, published in October 2018, set “expectations of excellence” across eight domains of care, ranging from structure and processes, cultural aspects, and legal aspects of care. It also includes a systematic review of the evidence base for palliative care. The levels of evidence—that is, the quality, validity, and applicability of the underlying studies—that inform care practices vary substantially, with low-quality evidence for several physical aspects of care, such as pharmacological interventions for common symptoms like pain, or for incorporating familial or cultural preferences into care delivery. Moderate quality evidence was found that a palliative care team can reduce symptom burden, and that care planning discussions can lead to preference-concordant care, yet the NCP notes little attention to patient goals or inclusion of the patient perspective in existing measures. Against this backdrop, we believe in developing quality measures that are based on patient-reported experience that is an



important next step in generating evidence on and ensuring that providers prioritize the perspective of patients receiving palliative care.

In recent years, **regulations** and policy priorities have focused on ways to ensure high-quality care by linking payment incentives to performance on quality measures. The Hospice Quality Report Program, created by the Affordable Care Act in 2010, established quality reporting requirements for hospices, which currently include the Hospice CAHPS (Consumer Assessment of Healthcare Providers and Systems) survey, a survey of bereaved family members of patients who die in hospice care. More recently, in 2015, the passage of MACRA changed payment calculation and quality reporting in the Medicare program and set the stage for a broader focus on high-value care that is enabled by more robust quality measurement and reporting. CMS expanded the types of providers eligible to participate in MIPS in 2019, all of whom will be able to use the quality measures developed and implemented through this project when they provide palliative care to patients. The measures that are being developed by this project are aligned with current CMS quality reporting priorities in that they will provide more options for providers to measure and report on the quality of care they are providing in order to meet the requirements of MIPS.

We identified over 300 **existing data elements** in 31 patient survey or interview instruments that assess communication and unmet needs with regard to symptom management in various contexts. These included the CAHPS suite of surveys, instruments that assess the experiences of bereaved family members, and instruments that assess patient experience and quality of end-of-life care, including within the Veterans Administration. The data elements we found will inform the selection and refinement of the quality measures we are developing for this project. We did not find many data elements targeted to the palliative care population in widespread use, and those that were in widespread use were not tailored to a seriously ill population. However, we did identify several themes across data elements for both areas of focus. For communication, data elements tended to assess how well providers listen to patients and their concerns, explain clinical information in an easy-to-understand manner, demonstrate caring and respect for the patient, and explain the dying process. Most data elements on symptom management and/or unmet need for symptom management tended to assess satisfaction with providers' management of overall symptoms (though some asked about specific symptoms, such as pain and trouble breathing), as well as the speed with which that care was delivered.

We also conducted a search of **symptoms** likely to be addressed by measures being developed in this project. Some studies on the prevalence of symptoms among end-of-life populations examined symptoms within specific care settings; others looked at symptoms within specific time frames such as the last year or weeks of life. Both types of studies found that pain, fatigue or sleeping problems, and eating or digestive symptoms are likely to be common problems among patients who receive palliative care. Other problems such as respiratory issues, low mood, and anxiety were reported by fewer studies or at lower rates but may also be important to assess.

Considering this information, we assessed gaps in existing quality measures to understand how the measures under development for this project will fit within the wider quality measurement landscape. Our scan identified 13 measures related to communication and symptom management. A central gap is that existing measures were not designed for use in, and have not been tested among, the population that this project focuses on: patients with serious illness receiving outpatient palliative care services. We concluded that current measures of communication and symptom management would need to be tailored for our focus population.

Findings from our **focus groups with providers and interviews with patients and caregivers** provided feedback on possible quality measure concepts and ways to assess key concepts through survey questions. Participants elaborated on the types of unmet symptom management experienced by patients with serious illness who receive palliative care from an outpatient clinic and provided feedback on ways to talk about symptoms and unmet needs that will be explored further in alpha and beta testing. Providers, patients, and families also discussed considerations for implementation of patient-reported outcome measures around unmet symptom needs and communication that we will take into consideration during measure development.

Results of the information-gathering activities to date have demonstrated the gap in measurement around the concepts and population of interest, those in outpatient palliative care. Information on data elements and quality measures from the research literature, and input on data elements and data collection approaches from providers and patients, will be used to inform data element development, alpha and beta testing, and the final specifications of the quality measures.

## Acknowledgments

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We wish to acknowledge the patients, caregivers, and family members who participated in interviews with our research team and thank them for their willingness to share their time and experiences.

## Abbreviations

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AAHPM	American Academy of Hospice and Palliative Medicine
ACP	advance care planning
APMs	Alternative Payment Models
BFS	Bereaved Family Survey
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CAHPS ECHO	CAHPS Experience of Care and Health Outcomes Survey
CANHELP	Canadian Health Care Evaluation Project
CAT	Communication Assessment Tool
CG-CAHPS	CAHPS Clinician and Group Survey
CI	confidence interval
CMS	Centers for Medicare & Medicaid Services
CQ-index PC	Consumer Quality Index Palliative Care
CSQ-8	Client Satisfaction Questionnaire-8
FATE	Family Assessment of Treatment at End of Life
FATE-S	Family Assessment of Treatment at End-of-Life Short Form Survey
FEHC	Family Evaluation of Hospice Care
FEPC	Family Evaluation of Palliative Care
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems Survey
HCBS CAHPS	Home and Community-Based Services CAHPS Survey
HHCAHPS	Home Health Care CAHPS Survey
HQRP	Hospice Quality Reporting Program
IDT	interdisciplinary team
MACRA	Medicare Access and CHIP Reauthorization Act of 2015
MIPS	Merit-Based Incentive Payment System

MMS	Measures Management System
MMS Blueprint	Blueprint for the CMS Measures Management System, Version 15.0
MSP	measure specification panel
NCP	National Consensus Project for Quality Palliative Care
NCP Guidelines	NCP's Clinical Practice Guidelines for Quality Palliative Care
NPAF	National Patient Advocate Foundation
NQF	National Quality Forum
PCFM	patient, caregiver, and/or family member
PROMISE	Performance Reporting and Outcomes Measurement to Improve the Standard of Care at End of Life
QCQ–EOL	Quality Care Questionnaire–End of Life
QEOLC	Quality of End-of-Life Care
QOC	Quality of Communication
QODD	Quality of Death and Dying
QPAC	Quality Indicators for Palliative Care
QPP	Quality Payment Program
SWC-EOLD	Satisfaction with Care at the End of Life in Dementia
TECUPP	Technical Expert Clinical User Patient Panel
VA	Veterans Administration



# Chapter 1. Project Background and Overview

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In recent years, the use of palliative care has grown substantially, and stakeholders in the palliative care community have demonstrated a need for quality measures of outpatient palliative care. The Centers for Medicare & Medicaid Services (CMS) provided funding to the American Academy of Hospice and Palliative Medicine (AAHPM) as part of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) to develop patient-reported experience performance measures in the areas of pain and symptom management and communication for patients with serious illness (including those receiving palliative care).

Under this MACRA cooperative agreement, AAHPM is working to advance clinical quality measure development for outpatient palliative care patients with serious illness through the engagement of stakeholders such as measure development technical experts, clinicians, clinical specialty societies, patient advocacy groups, patients/families/caregivers, health care systems, and other stakeholder groups. The objectives of this project are to

- develop, test, and implement two patient-reported experience measures for patients participating in outpatient, clinic-based, palliative care in a way that incorporates patient voice and patient preferences
- ensure that the proposed measures are broadly applicable to patients with serious illness—and their families—receiving palliative care services in a range of outpatient primary and specialty care settings
- convene a technical expert panel that incorporates patient, caregiver, and family input directly into the measure development, specification, testing, and implementation processes
- submit palliative care measures for endorsement by the National Quality Forum (NQF) and for inclusion into CMS’s Quality Payment Program (QPP), including the Merit-Based Incentive Payment System (MIPS) and Alternative Payment Models (APMs), so that clinicians can measure and improve the quality of care that patients with serious illness receive.

## Terminology Used in This Report

In this report, we use several terms to describe the components of quality measures. When we refer to individual items or questions on a survey, we use the term *data element*. We do this to be consistent with how CMS refers to items or questions on a survey within Measures Management System (MMS) materials. We reserve the word *measure* for use in the term *quality measure*, which is defined by the Blueprint for the CMS Measures Management System, version 15.0 (MMS Blueprint) as a “numeric quantification of healthcare quality for a designated accountable healthcare entity, such as hospital, health plan, nursing home, or clinician.”<sup>1</sup> We

note that survey instruments, which are composed of multiple data elements, may be associated with multiple quality measures.

When describing measure testing, we use the term *alpha test* to refer to small-scale pilot testing that is meant to establish feasibility and provide feedback on how to refine the data elements (e.g., question wording, response options). A *beta test* is the term used for large-scale field testing. Findings from a beta test can establish the reliability and other psychometric properties of data elements or measures, and help refine measure specifications. Because we are following the guidance of the MMS Blueprint, and because the MMS Blueprint uses the terms *alpha* and *beta* in lieu of *pilot* and *field* testing, respectively, we chose to use *alpha* and *beta* testing throughout this report.

## Project Components

The primary goal of this project is to develop quality measures for CMS's QPP that assess the experience of patients receiving outpatient palliative care services. This will be achieved through the project components outlined below. Project components are directed by AAHPM but supported by AAHPM's subcontractors: the RAND Corporation and the National Coalition for Hospice and Palliative Care. Project components are further supported by expertise provided by the National Patient Advocacy Foundation, the American Institutes for Research, and Swain Eng and Associates, L.L.C. Project staff and roles are listed in Appendix A.

Project components include a review of literature, existing instruments and measures, clinical guidelines, and regulations (completed as of September 2019); small-scale pilot testing of the proposed measures, or the alpha test (completed as of October 2019), national field testing, or the beta test (to be conducted between November 2019 and December 2020); and final reports and specifications of the final measures, which will be produced by summer 2021.

### *Review of Literature, Existing Instruments and Measures, Clinical Guidelines, and Regulations*

Project components, including a review of literature, existing instruments and measures, clinical guidelines, and regulations, were completed in the early stages of this project but will be continually updated during measure development and testing. Updates will ensure that the project team is aware of the most recent information relevant to the final measures. RAND, under the guidance of AAHPM, has systematically reviewed available information in these areas.

### *Stakeholder Input*

Stakeholder engagement activities will occur throughout the project. To meet the objective of incorporating patient voice and preference, stakeholders (patients, family members, caregivers, and/or their representatives) will be engaged iteratively throughout the development of the



measures. Project components that involve stakeholder input—including subject matter experts—are described below.

#### Technical Expert Clinical User Patient Panel and Measure Specification Panel

As part of its measure development process, AAHPM, along with its partners RAND and the National Coalition for Hospice and Palliative Care, has convened groups of stakeholders and experts who contribute in direction and thoughtful input during measure development and maintenance. To this end, a Technical Expert Clinical User Patient Panel (TECUPP) was convened in April 2019 and has provided and will continue to provide input on the development of the measures for patients with serious illness. The TECUPP includes individuals with expertise in measure development and testing methodologies who also serve on a measure specification panel (MSP), a subset of the TECUPP, that has and will continue to aid with the technical aspects of measure development and testing. Patients, families, and caregiver advocates also participate in the TECUPP, offering insights into the patient perspective on potential measures. The scope of the TECUPP is described in the TECUPP Charter (Appendix B). The TECUPP report can be downloaded from CMS's website at [https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/TEP-Current-Panels.html#Palliative\\_Care](https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/TEP-Current-Panels.html#Palliative_Care).

#### Provider Focus Groups

Because one goal of this project is to develop quality measures that can be used by palliative care providers as part of Medicare payment programs, it is important that the measure concepts and measure specifications align with providers' perceptions about high-quality palliative care. To better understand the perspectives of palliative care providers, the project team conducted four focus groups with 35 physicians, nurse practitioners, social workers, registered nurses, pharmacists, chaplains, physician's assistants, and administrators. Focus groups were conducted between January 29 and February 7, 2019 at locations in Los Angeles, California; Boston, Massachusetts; Atlanta, Georgia; and Chicago, Illinois. More information on the Provider Focus Groups is included in Chapter 8.

#### Patient and Caregiver Interviews

As another method of including the perspective of palliative care patients and their caregivers, the project team conducted 13 individual interviews with patients receiving hospice or palliative care, patients with advanced illness but not receiving hospice or palliative care, and caregivers of patients receiving hospice or palliative care. Interviews were conducted by phone between February and June 2019. More information on the Patient and Caregiver Interviews is included in Chapter 8.

## *Measure Testing*

Measure testing is being conducted in three phases: a cognitive testing phase that has been completed, a small feasibility pilot study (alpha test) phase that has been completed, and a large national field test (beta test) phase.

The cognitive testing phase was used to assess the comprehensibility and clarity of the data elements that may be included in the quality measures, which were identified and/or refined during our information gathering. Four rounds of cognitive testing—two conducted in English and two conducted in Spanish—were completed in September 2019, which allowed for iterative and rapid-cycle refinement of the data elements and survey instrument, based on participant feedback.

The pilot study was conducted in early fall 2019. This study assessed the data collection processes we will use in the beta test and identified challenges and necessary refinements to the testing plan. The results of the alpha test will help the team

- establish optimal site recruitment processes
- understand data capabilities across sites and tailor sample file requests accordingly
- establish average times from site recruitment to survey fielding to adjust the beta test timeline
- explore the feasibility of email/web-based survey fielding for the beta test
- clarify expected response rates and explore approaches to optimizing
- understand likely rates and reasons of caregiver (“proxy respondent”) response versus patient response
- identify those data elements with serious challenges to reliability (e.g., high rates of missing data or “ceiling effects”)
- develop scoring methodology.

The beta test will be conducted with a nationally representative sample in calendar year 2020 and will aim to establish the (1) psychometric properties of the data elements; (2) feasibility with regards to administration protocol, mode, and calculation of the quality measure; and (3) final measure technical specifications, rules regarding the numerator and denominator of the measure, and the reliability of the measure. Pending analysis of the alpha test data, the administration of the survey will be a mixed mode that utilizes a combination of mail with telephone follow-up and possibly a web survey (provided via patient email).

## **Purpose and Organization of This Report**

This report summarizes the results of information-gathering activities from the start of the project in fall 2018 through September 2019. These activities set the foundation and will inform all measure development and testing work throughout the remainder of the project period. The scope of this report is limited to reporting on information gathering; at this time, we cannot draw conclusions about how these findings will ultimately affect decisions related to measure

specifications, as those decisions also depend on the results of future testing, stakeholder engagement, and expert input.

In Chapter 2, we review measurement priorities in palliative care, drawing on both literature review and stakeholder input activities recently conducted by AAHPM. Next, we summarize clinical practice guidelines for palliative care (Chapter 3) and provide the regulatory context for our measure development work (Chapter 4) by describing MIPS, the component of the QPP that applies to many clinic-based palliative care providers. In Chapter 5, we review existing survey instruments that have been used to measure patient and caregiver experience of palliative care. We report on our review of symptom prevalence at end of life in Chapter 6. In Chapter 7, we review existing quality measures on similar and related topics. Finally, in Chapter 8, we summarize stakeholder input from palliative care providers and patients, caregivers, and/or family members that we collected via focus groups and interviews in 2019.

## Chapter 2. Measurement Priorities in Palliative Care

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In the last years of life, most persons face prolonged periods of functional impairment due to multiple comorbid illnesses.<sup>3</sup> In addition, many patients experience pain and other symptoms that are not adequately managed,<sup>4–10</sup> experience inadequate communication about prognosis and treatment options,<sup>11–15</sup> and receive care that is not consistent with their preferences.<sup>12, 15–17</sup> Palliative care has been shown to improve patient experience and satisfaction with care,<sup>18</sup> reduce caregiver burden,<sup>19</sup> and improve survival.<sup>20</sup> It has also been shown to reduce unnecessary hospital admissions and readmissions through effective care coordination and symptom management.<sup>21, 22</sup> Accordingly, an increasing number of physicians, nurse practitioners, and physician assistants have specialized in providing palliative care in inpatient, outpatient, and hospice settings.<sup>23</sup> For example, hospital-based palliative care teams now provide consultation in 67 percent of hospitals with at least 50 beds;<sup>23</sup> there are outpatient palliative care programs in over 1,200 counties;<sup>23</sup> and hundreds of cancer centers have associated outpatient palliative care programs.<sup>24, 25</sup>

Although palliative care is growing rapidly, there is little systematic information about the quality of care delivered by palliative care providers (and by other clinicians responsible for seriously ill patients), particularly in outpatient settings. As a result, stakeholders—including patients and their advocates, as well as providers and health systems—lack actionable measures to guide improvement efforts, as noted by NQF and the CMS Measures Application Partnership, as well as the 2017 CMS Environmental Scan and Gap Analysis Report.<sup>26</sup> Measures of palliative care quality are also underrepresented in the CMS QPP, with current measures addressing small populations that are often limited to patients with cancer or hospice patients. Furthermore, palliative care quality assessment that incorporates patient preferences (i.e., patient “voice”) is noticeably absent despite the patient-centered nature of palliative care.<sup>27–30</sup> Patient-centered measures, and especially patient-reported measures, are an important complement to clinician-reported data. Apart from risk of bias when providers are asked to rate their effectiveness or their patients’ status, research has found that the act of reporting on processes of care is likely to affect adherence to those care processes.<sup>31</sup> Asking patients to report on their own experience circumvents these threats to validity of quality measures.

It is important to note when assessing palliative care that patients are seriously ill and death is not always a negative outcome, though the quality of that death is important. Accordingly, palliative care requires measures that examine whether patients are receiving care that aligns with their goals, rather than meeting clinical outcomes that may be more appropriate to other conditions, such as mortality.

## Review of Measurement Priorities Identified by Stakeholders

To identify key measurement priorities for palliative care, the project team reviewed the results from several consensus panels held in recent years with experts, patient advocates, researchers, payers, and other stakeholders.<sup>2, 32-37</sup> We summarize highlights from those panels and guideline committees below.

- In 2017, the Moore Foundation convened a panel of 45 serious illness care experts and stakeholders to identify a path for building an accountability system for high-quality, community-based serious illness care programs.<sup>34</sup> Panelists included palliative care physicians, patient advocates, researchers, quality and policy experts, government leaders, and health plan representatives. Among the proposed “starter” measures were the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey (which panelists recommended modifying for the serious illness population) and a potential Serious Illness Experience of Care Survey module for the Medicare Advantage and Accountable Care Organization populations. Both surveys were recommended as a starting point for developing measures of effective communication that could be used to promote treatments that are concordant with patient goals.
- From July 2017 to May 2018, the project team worked in partnership with affiliates and internal experts from the National Coalition for Hospice and Palliative Care and AAHPM to identify high priority palliative care items for CMS’s QPP. The Coalition’s Quality Workgroup selected pain and symptom management and effective communication, with caregiver involvement and support related to pain management and patient communication as subtopics.
- The National Consensus Project for Quality Palliative Care (NCP) developed Clinical Practice Guidelines (NCP Guidelines) for quality palliative care, with a 4th edition completed in October 2018 that has been endorsed by over 80 national organizations.<sup>32</sup> The guidelines establish the foundation for gold-standard palliative care for all people living with serious illness, regardless of their diagnosis, prognosis, age, or setting. Other medical professional societies have also developed guidelines for the care of individuals with serious illness (e.g., American Society of Clinical Oncology,<sup>33</sup> Society of Critical Care Medicine<sup>36</sup>). Each guideline recommends appropriate attention to communication among seriously ill patients and to symptom management, with a focus on the patients’ and family members’ experience of care.

The findings of these prior efforts emphasized the areas of communication and symptom management, but also highlighted patient centeredness and the patient and caregiver experience, which led us to focus on the measure concepts of feeling heard and understood, and unmet need for symptom management. We note that these focus areas align with two key CMS Quality Priority areas: Patient and Caregiver Experience (communication, including feeling heard and understood) and Clinical Care (management of symptoms in patients with serious illness).

### *Additional Rationale for the Focus on Unmet Need for Symptom Management*

As noted above, managing patient symptoms and psychosocial needs is a key goal of palliative care. The most serious and prevalent symptoms among the seriously ill include pain,<sup>38-44</sup>

dyspnea,<sup>45 51</sup> nausea/vomiting,<sup>52</sup> constipation,<sup>53</sup> and depression or anxiety.<sup>24</sup> Many existing quality measures assess standardized clinical outcomes and processes of care, and some of them rely on patient-reported data (e.g., pain reduced to a comfortable level within 48 hours, as reported by patient during clinical assessment [NQF 0209]). The use of patient-reported data is important, but we assert again that questions and response options about symptom management must be asked relative to the patient's particular wishes and perceptions. We believe that the subjective experience of symptoms does not lend itself to a "one size fits all" evaluation approach. Patients with serious illness often make important trade-offs (e.g., patients may prefer experiencing moderate pain in exchange for remaining alert or avoiding treatment side effects) and have 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. For this reason, in this work we distinguish between measuring symptom management by level of symptoms reported (e.g., pain rated on a 1–10 scale), where higher levels of symptoms might be considered poor symptom management, and by asking patients the extent to which their symptoms were managed adequately for their goals (e.g., getting as much help for pain as they wanted; level of unmet needs).

#### *Additional Rationale for the Focus on Feeling Heard and Understood*

Seriously ill persons often report feeling silenced, ignored, and misunderstood in medical institutions.<sup>54 56</sup> 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.<sup>57</sup> 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.<sup>58</sup> These elements directly shape patient experience and, when done well, help patients feel known, informed, in control, and satisfied, thus improving the well-being and quality of life.<sup>58 60</sup> Assessing the extent to which the patient felt heard and understood has demonstrated implications for communicating prognosis and treatment options and assuring adherence to the treatment plan.<sup>57, 61</sup>

## Chapter 3. Summary of Clinical Practice Guidelines

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To understand the broader context for the quality measures that we are developing, we reviewed clinical practice guidelines for palliative care. Alignment between best practices for palliative care, as set out in the clinical practice guidelines, and our measure focus areas would provide support for the importance of these measures in assessing the core features of palliative care.

### Overview

The National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care (NCP Guidelines) set standards for high-quality palliative care practice. First published in 2004, they play a critical role in providing guidance to providers and advancing palliative care practice. The overarching goal of the Guidelines is to “promote access to quality palliative care, foster consistent standards and criteria, and encourage continuity of palliative care across settings.”<sup>62</sup> The NCP Guidelines informed the 2006 NQF-endorsed framework for palliative care and hospice, including 38 preferred practices across the following eight domains of care:

- structures and processes of care
- physical aspects of care
- psychological and psychiatric aspects of care
- social aspects of care
- spiritual, religious, and existential aspects of care
- cultural aspects of care
- care of the imminently dying patient
- ethical and legal aspects of care.

The NCP Guidelines, 4th edition, was published by the National Coalition for Hospice and Palliative Care in 2018. This version expands on the guidance provided in the 3rd edition, from 2013, with a focus on the following two key concepts:

- Palliative care is inclusive of all people with serious illness regardless of setting, diagnosis, prognosis, or age.
- Timely provision of palliative care is the responsibility of all clinicians who care for seriously ill individuals, including primary care providers as well as specialists (palliative care and others, such as oncologists and neurologists).

The 4th edition of the NCP Guidelines also updates the 2013 NCP Guidelines to address best practices in palliative care for both specialists and all clinicians who care for people with serious illness. This expansion reflects a growing move in the field to provide palliative care services earlier in the disease trajectory, alongside standard disease management. This shift underscores

the growing availability of palliative services in outpatient, clinic-based settings. The expectation conveyed in the 4th edition NCP Guidelines is that all clinicians caring for seriously ill patients will incorporate and adhere to core palliative care competencies following the guidance provided in the guidelines.

Another key addition to the 4th edition NCP Guidelines is the inclusion of a systematic review of current evidence in palliative care to support recommendations;<sup>63</sup> prior editions have been solely expert consensus based. The NCP Guidelines provide important support for the work proposed in the current measure development project. Below, we describe the evidence and major recommendations of the Guidelines and summarize how the Guidelines provide a rationale for the proposed work.

## Summary of Major National Consensus Project for Quality Palliative Care Recommendations

The NCP Guidelines set “expectations for excellence” across eight domains of palliative care among clinicians caring for patients with serious illness. They do not provide explicit recommendations for clinical practice, nor do they identify professional or clinical competencies. The following is a summary of the core expectations and principles described in the NCP Guidelines.

### *Domain 1: Structure and Processes of Care*

Palliative care is provided by an interdisciplinary team (IDT) of physicians, advanced practice registered nurses, physician assistants, nurses, social workers, chaplains, and others based on need. Team members have the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Palliative care begins with a comprehensive assessment of needs and, throughout its delivery, emphasizes patient and family engagement, communication, care coordination, and continuity of care across health care settings. In the 4th edition of the NCP Guidelines, care coordination is emphasized as a critical element of quality palliative care, particularly when patients receive community-based services.

### *Domain 2: Physical Aspects of Care*

Management of physical aspects of care begins with the IDT understanding the patient’s goals and focuses on optimizing functional status and quality of life and relieving the symptom experience within the context of those goals. Management of physical symptoms includes pharmacological, nonpharmacological, interventional, behavioral, and complementary treatments. In the 4th edition of the NCP Guidelines, the importance of using validated tools to assess, track, and manage pain and other symptoms is emphasized.



### *Domain 3: Psychological and Psychiatric Aspects of Care*

The IDT conducts a comprehensive developmentally appropriate and culturally sensitive screening of seriously ill patients and consistently communicates to the patient and family the implications of psychological and psychiatric aspects of care in developing a care plan. The IDT addresses family conflict, assesses and provides grief support, and provides relevant resources or referrals from diagnosis onward. In the 4th edition of the NCP Guidelines, the roles and responsibilities of the social worker in terms of mental health assessment and treatment are highlighted. In addition, the IDT's responsibilities to patients and families are highlighted, given the limited availability of specialist psychologist and/or psychiatric care. The provision of adequate grief assessment and support is highlighted within this domain; bereavement is included as a distinct and important expectation of palliative care practice in Domain 7.

### *Domain 4: Social Aspects of Care*

Palliative care includes an assessment of the environmental and social factors (i.e., social determinants of health) that affect optimal functioning and quality of life. The IDT, including a social worker, works with the patient and family to address areas of social need. The 4th edition of the NCP Guidelines emphasizes the importance of assessing social supports, relationships, practical resources, and the safety or appropriateness of the care environment for each seriously ill patient.

### *Domain 5: Spiritual, Religious, and Existential Aspects of Care*

Spirituality is noted as a fundamental aspect of patient- and family-centered palliative care. The IDT serves each patient and family in a way that respects their spiritual beliefs and practices, including allowing space for patients and families to decline spiritual support. Palliative care professionals acknowledge their own spirituality as part of their providing role. The 4th edition of the Guidelines also emphasizes the need for training for spiritual care providers.

### *Domain 6: Cultural Aspects of Care*

Assessing and respecting values, beliefs, and traditions related to health, illness, roles/responsibilities, and decisionmaking are central to culturally sensitive care. A comprehensive care plan incorporates culturally sensitive resources and strategies to meet patient and family needs. The conscious practice of cultural humility is emphasized. This includes IDT members' awareness of their own perceptions and biases regarding race, ethnicity, gender identity, sexual orientation, immigration status, social class, and other characteristics.

### *Domain 7: Care of the Patient Nearing the End of Life*

The importance of attending to the rapidly changing needs of patients and families in the final weeks and days of life (including the days after the death of the patient) is emphasized, as is

the responsibility of all clinicians caring for seriously ill patients to ensure adequate bereavement support is offered. This includes comprehensive management or assessment of pain and other physical symptoms and of social, spiritual, psychological, and cultural needs as the patient nears death. Palliative care professionals provide developmentally appropriate education to the patient, family, and other caregivers about what to expect near and following death.

### *Domain 8: Ethical and Legal Aspects of Care*

The IDT applies ethical principles to the care of seriously ill patients, including honoring patient preferences and decisions made by legal proxy decisionmakers. Emphasis is placed on the surrogates' obligation to represent the patient's preferences, goals, and best interests, not their own. Palliative care professionals have familiarity with state and local laws relevant to advance care planning (ACP) and life-sustaining treatment decisionmaking.

## **Level of Evidence**

The systematic review undergirding the 4th edition NCP Guidelines, which identified 139 systematic reviews published since the 3rd edition, addresses key research questions across the eight palliative care domains. The review makes it clear that much of the evidence for palliative care remains low quality, due to inconsistency in study findings, the lack of precise effect estimates to support the effectiveness of interventions, and large variation in study designs, with few randomized controlled trials that allow strong evidence statements contributing to the evidence base.<sup>63</sup> Below, we describe the evidence found in the domains most relevant to the current quality measure work: Physical Aspects of Care (relevant to pain and symptom management), Cultural Aspects of Care, and Ethical and Legal Aspects of Care (relevant to communication, personhood, acknowledgement). A more detailed description of the level of evidence can be found in the publication describing the systematic review.<sup>63</sup>

### *Level of Evidence: Physical Aspects of Care*

Forty-eight reviews were identified that evaluated the effect of palliative care on symptom management, but much of the evidence is of low quality due to inconsistent findings regarding the effect of interventions on symptoms. In particular, evidence on pharmacological interventions for common symptoms like pain, dyspnea, nausea/vomiting, and constipation was of low to very low quality due to inconsistent findings across studies and a lack of pooled effect estimates.<sup>64-77</sup> Although there was moderate quality evidence supporting the use of alternative interventions, such as music and art therapy,<sup>78-80</sup> symptom reduction was the primary outcome typically measured, with little attention to the patient's goals for management. In addition, there was moderate-quality evidence that a comprehensive palliative care team can achieve sustainable reductions in symptom burden, though it remains unclear what aspects of the team-based intervention is responsible for these improvements. The absence of attention to patient goals and

values in the current evidence regarding palliative symptom interventions, combined with poor evidence regarding the more commonly used 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.

#### *Level of Evidence: Ethical and Legal Aspects of Care; Cultural Aspects of Care*

Thirty-six reviews were identified that evaluated the effect of ACP on substitute decisionmaking. Several reviews addressed communication interventions; for example, moderate-quality evidence suggests that ethics consultations improve consensus around clinical decisions and that care planning discussions lead to preference-concordant care, patient-family agreement regarding treatment decisions, and ACP documentation.<sup>81-83</sup> While this evidence supports the role and importance of clear patient-provider communication in the delivery of palliative care, existing studies rarely incorporate the patient's perspective in the delivery of the communication intervention. Studied outcomes tend to address what is needed by the care team, for example, ACP documentation or consensus regarding decisions, but do not address the patient's experience of and satisfaction with the communication in the context of whether their needs were met and whether they felt adequately acknowledged.

There is also very low-quality evidence from only three systematic reviews that culturally sensitive care leads to positive communication outcomes.<sup>84-86</sup> While the evidence base remains limited, these findings point to the potential effect of incorporating patient and family cultural perspectives and needs in the delivery of palliative care. Measuring the extent to which patients feel heard, understood, acknowledged, and seen as a whole person, and feel that their individual needs are being attended to, may help to encourage greater attention to the unique cultural perspectives that individuals bring to their care near the end of life.

## **Conclusion**

From our review of the NCP Guidelines, we conclude that communication and symptom management are core competencies for palliative care providers, and measuring quality of care based on the patient's experience in these two domains would be expected to capture overall quality of care, given how central these two factors are.

Regarding the evidence base that informs current palliative care practices, the review included in the NCP Guidelines found many areas where further research is needed and highlighted the need for patient perspectives and a focus on patients' goals and preferences. We interpret this call for more research that includes the patient voice as support for the development of quality measures that focus on patient experience of care.

## Chapter 4. Review of Federal Programs

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As part of our information gathering, we identified two major regulations that have influenced the landscape of quality measurement for patients with serious illness.

### Hospice Quality Reporting Program

The Hospice Quality Reporting Program (HQRP) was created as part of the Affordable Care Act in 2010 and directed the Secretary of Health and Human Services to establish quality reporting requirements for hospice programs. These reporting requirements are currently met by hospices through submission of the Hospice Item Set and the Hospice CAHPS survey, a survey of bereaved family members of patients who die in hospice care. Quality measures for hospices—calculated from the Hospice CAHPS as well as other sources—are reported to the public through the Hospice Compare website.

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 acknowledge the palliative rather than curative nature of hospice care, which is currently a requirement of Medicare’s hospice benefit. In contrast, the targets of the quality measures we are developing may be receiving palliative care without any limitations on efforts to cure or treat the underlying serious illness. 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.

### Programs Enacted by Medicare Access and CHIP Reauthorization Act of 2015

The second regulation that is directly related to the current quality measure development project is MACRA. In contrast to the relatively narrow HQRP, MACRA affects many aspects of payment and quality reporting for health care providers.

MACRA<sup>87</sup> 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 MIPS.<sup>88</sup>

Medicare providers now choose one of two payment tracks—APMs and MIPS—which offer different combinations of incentives and requirements to encourage high-quality, low-cost care.<sup>89</sup>

MIPS assesses performance<sup>\*</sup> 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 ensure 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.

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<sup>\*</sup> Beginning in performance year 2019, MIPS-eligible providers include physicians, osteopathic practitioners, chiropractors, physician 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.

## Chapter 5. Existing Data Elements and Instruments That Assess Dimensions of Patient Experience Relevant to Palliative Care

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As part of our literature review to support the development and refinement of the measure concepts related to unmet symptom needs and communication, we sought to identify potentially relevant data elements, surveys, and other instruments that could be used to help refine the proposed data elements for use in a palliative care population (e.g., to refine question wording or response options, mode of administration, and patient eligibility). Below we describe the methods and findings of this component of our literature review.

### Methods

We used a two-pronged approach to identifying data elements and survey instruments relevant to the measure concepts. One component of our literature search focused on identifying survey instruments used in palliative care populations and other patients with serious illness. We used a purposive “snowball” approach to identifying relevant studies, first identifying key studies, then reviewing citations to identify findings in related papers. The other component of our literature search was to review CAHPS surveys to identify potential data elements that may be relevant to the seriously ill population.<sup>90</sup>

In the first component of our search, we identified 19 key studies conducted in seriously ill populations and related to the project’s measure concepts by soliciting input from internal experts and reviewing documentation (e.g., measure descriptions) for related measures known to the project team.<sup>2, 11, 13–15, 27–29, 57, 91–100</sup> We then used forward and reverse citation mining (i.e., reviews of article citations and citations of the articles) to find relevant studies, as well as the “find similar articles” and “related articles” tools from PubMed and Google Scholar, respectively. We included studies describing a relevant patient-reported measure and/or the psychometric testing or performance of relevant patient-reported measures and studies addressing implementation and usage of the measure published in English during 2008–2018 (10-year time frame selected for feasibility and relevance). We also included specific references identified by project advisers as important or relevant, regardless of publication date. We excluded studies conducted in pediatric populations because our measure development process focused on the adult population, studies of measures that were not patient-reported, non-English studies, and studies where the original instrument used to collect the measure data was not available.

We identified 28 instruments with development or validation studies published in the peer-reviewed literature. We identified an additional three instruments for which we were not able to find studies describing development or validity, for a total of 31 instruments. For the data

elements (i.e., questions or survey items) or survey instruments described in these papers, we focused on data elements that pertained to the measure concepts of symptom management experience and communication or patient-provider relational experience, as well as overall patient experience. For these data elements, we extracted the following information into a tracking spreadsheet: data element, response options, name of survey instrument, use in quality measurement programs, clinical setting, survey mode, respondent type, feasibility, validity, reliability, potential implementation issues.

The second component of our search focused on CAHPS surveys. A subset of CAHPS surveys was identified based on discussions within our team and with our internal advisers. Members of the project team reviewed these surveys and related studies and abstracted contents into the tracking spreadsheet described above.

### *Approach to Summarizing Findings*

Across the full set of data elements identified through the two prongs of the search, we identified data elements that are comparable or related to the “heard and understood” and “unmet symptom needs” measure concepts. We list candidate data elements within the relevant survey instruments below, along with information that could be used to help refine our measure concepts for use in a palliative care population, such as wording or response options, mode of administration, and patient eligibility criteria. We also extracted data elements that related to a single overall rating of quality of care.

## **Results**

We identified 304 data elements in 31 survey instruments relevant to the measure concept areas. To summarize the results, and because many of the survey instruments were related to or derived from others, we present the results in the following groups:

- CAHPS instruments relevant to one or both measure concepts
- bereaved family member instruments addressing one or both measure concepts
- instruments and their derivatives primarily assessing patients’ experience of end-of-life care within the Veterans Administration (VA)
- quality of life at the end-of-life assessment instruments
- satisfaction with end-of-life care instruments
- other instruments not related to any of the above.

The abstraction spreadsheet in Appendix C provides greater detail on each instrument.

### *Relevant CAHPS Survey Instruments*

CAHPS surveys are commonly used by payors to assess quality, by providers and practices to inform quality improvement initiatives, and by consumers and patients to assist in selecting among providers and health plans.<sup>101</sup> They are typically administered using mixed modes (e.g.,

mail with telephone follow-up). Despite concerns regarding length, burden, relevance for accountability purposes, and response rates, the surveys remain the most widely used method for collecting and understanding patient experience.<sup>102</sup> While the various instruments assess patient experience in different care settings and across multiple domains as relevant to each setting, several surveys include (1) multiple data elements across composite areas such as How Well Providers Communicate with Patients and Helpful, Courteous, and Respectful Office Staff, as well as (2) multiple data elements measuring unmet need. The identified CAHPS instruments are described below and summarized in Table 5.1.

**Table 5.1. Overview of CAHPS Survey Instruments and Data Elements**

<b>Instrument</b>	<b>Setting; Population</b>	<b>No. of Communication Data Elements</b>	<b>No. of Symptom Management Data Elements</b>	<b>No. of Overall Rating Data Elements</b>
CAHPS Cancer Care Survey	Oncology; patients	14	—	2
CG-CAHPS Survey	Outpatient clinic settings; patients	9	—	1
CAHPS ECHO Survey	Behavioral health; patients	4	—	2
CAHPS Hospice Survey	Hospice; reported after death by the bereaved family member (or other important informal caregiver)	7	11	2
CAHPS Nursing Home Family Member Survey	Nursing home; family members of patients	3	—	2
HCBS CAHPS Survey	Long-term services and supports through HCBS; patients	6	—	2
HHCAHPS Survey	Home health; patients	6	—	2
HCAHPS Survey	Inpatient setting; patients	7	2	2

### CAHPS Cancer Care Survey

The CAHPS Cancer Care Survey<sup>103, 104</sup> assesses the care experiences of oncology patients. We identified 14 relevant communication data elements from the CAHPS Cancer Care Survey. The data elements assess general types of communication, such as how often the cancer surgery team explained things clearly or listened well, and more trust-building aspects of communications, such as whether the cancer surgery team was respectful or spent enough time with the patient. Finally, the CAHPS Cancer Care Survey also fields survey data elements about the level and quality of provider communication around symptom management (e.g., “Patient and cancer care team talked about changes in patient’s energy levels”). Survey data elements are measured on



three scales, including: Yes, definitely/Yes, somewhat/No; Never/Sometimes/Usually/Always; and Yes/No.

#### CAHPS Clinician and Group Survey

The CAHPS Clinician and Group (CG-CAHPS) Survey<sup>105</sup> assesses experience of care of patients who use outpatient services. CG-CAHPS is NQF endorsed (NQF 0005) and is used in Physician Compare and within the MIPS program. We identified nine data elements on communication. The majority of the relevant communication items were included in the composite measure areas of How Well Providers Communicate with Patients and Helpful, Courteous, and Respectful Office Staff. These data elements included Provider Explained Things in a Way That Was Easy to Understand, Provider Listened Carefully to Patient, Provider Showed Respect for What Patient Had to Say, Provider Spent Enough Time with Patient, Clerks and Receptionists Were Helpful, Clerks and Receptionists Were Courteous and Respectful, and Provider Knew Important Information About Patient's Medical History. All items used a scale of Never/Sometimes/Usually/Always. In a study by Dyer and colleagues that evaluated factor structure and reliability of the CG-CAHPS Survey, both composite measures demonstrated reliability of 0.7 or above, using Cronbach's alpha.<sup>106</sup>

#### CAHPS Experience of Care and Health Outcomes Survey

The CAHPS Experience of Care and Health Outcomes (ECHO) Survey<sup>107</sup> assesses access to care, medication and symptom management, and patient rights among patients receiving behavioral health care. We identified four data elements from CAHPS ECHO addressing communication. These data elements asked patients to focus on their experiences in counseling and treatment, focusing on how often the care teams listened carefully, explained things well, spent enough time with the patient, or were respectful. All items used a scale of Never/Sometimes/Usually/Always. We were unable to find published performance data on these data elements, though the composite measure for communication has well-established validity and reliability, as demonstrated in other CAHPS settings.<sup>106</sup>

#### CAHPS Hospice Survey

The CAHPS Hospice Survey<sup>108</sup> assesses the patient's experience of hospice care as reported after death by the bereaved family member or other significant informal caregiver. The CAHPS Hospice Survey is NQF endorsed (NQF 2651) and used in the HQR. We identified seven communication data elements of interest and 11 symptom management data elements of interest. However, four of the 11 symptom management data elements were "screening questions" asking about the presence of symptoms only. The data elements came from several composite areas within CAHPS Hospice, including Hospice Team Communication, Treating Family Member with Respect, Getting Help for Symptoms, Getting Hospice Care Training, and Getting Timely

Care. In developmental research on this survey by Price and colleagues, the various composite areas showed reliability in the range of alpha of 0.61 to 0.85.<sup>28</sup>

#### CAHPS Nursing Home Family Member Survey

The CAHPS Nursing Home Family Member Survey<sup>109</sup> is a multimodal (mail and telephone) survey fielded to family members of nursing home patients. We identified three relevant communication survey data elements from the survey. The data elements pertained to the perception of staff courtesy, respect, and caring. All data elements used a scale of Never/Sometimes/Usually/Always. Survey development research demonstrated a high overall response rate of 63 percent.<sup>110</sup> Reliability for the three items ranged from 0.77 to 0.82, and the intraclass coefficient ranged from 0.06 to 0.08.

#### Home and Community-Based Services CAHPS

The Home and Community-Based Services (HCBS) CAHPS survey<sup>111, 112</sup> is an NQF-endorsed survey (NQF 2967) that assesses experiences of beneficiaries who receive home- and community-based services, a form of long-term services and support delivered to community-dwelling patients. Although it largely targets services provided by non-MIPS eligible clinicians (e.g., personal care workers, home aides), the data element concepts and wording are structured similarly to other CAHPS surveys and may have relevance to outpatient-based palliative care services. We identified six communication data elements and two overall data elements.

#### Home Health CAHPS

The Home Health Care CAHPS (HCAHPS)<sup>113, 114</sup> is an NQF-endorsed survey (NQF 0517) that measures home health patients' experience of care received from home health care agencies. Survey findings are used in public reporting on the Home Health Compare website. We found six communication data elements included in the Communication Between Providers and Patients composite measure. Internal consistency of these scales was good, with an alpha of 0.75 for Care of Patients, 0.73 for Communication between Providers and Patients, and 0.84 for Specific Care Issues, indicating that the items in these composites are related to each other. When testing for discriminant validity of the three scales, items within each scale correlated more highly with their own scale than with other scales.

#### Hospital CAHPS Survey

Hospital CAHPS (HCAHPS)<sup>115, 116</sup> is an NQF-endorsed survey (NQF 0166) for use in hospital populations. It is used in Hospital Compare, the Hospital Inpatient Quality Reporting program, the Hospital Value-Based Purchasing program, and the Prospective Payment System-Exempt Cancer Hospital Quality Reporting program. We identified seven data elements addressing communication and two items addressing unmet symptom need in the HCAHPS survey. The communication items assess the patient's perception of doctors' ability to listen well and explain things clearly, and whether the patient felt respected during their care. The unmet

symptom needs items to assess if patients perceive that hospital staff did everything possible to help with their pain and if they felt that their pain was well controlled. (A recent version of HCAHPS under NQF review includes modified symptom management [pain] data elements that focus on communication about symptoms.) All data elements use a scale of Never/Sometimes/Usually/Always. HCAHPS performance data has been reported more consistently at the composite measure level, but findings indicate good to excellent validity.<sup>117</sup>

### *Surveys Derived from Bereaved Family Member Instruments*

We identified several related inventories and citations of instruments assessing the experience of end-of-life care as perceived by bereaved family member proxy respondents including primarily the After-Death Bereaved Family Member Interview (all versions),<sup>118, 119</sup> as well as Family Perspectives on End-of-Life Care,<sup>12</sup> Advanced Cancer Patient Perceptions of the Quality of Care,<sup>15</sup> Family Evaluation of Hospice Care (FEHC),<sup>120</sup> and the Family Evaluation of Palliative Care (FEPC).<sup>120</sup> This group, listed in Table 5.2, primarily includes surveys on the perception of family and informal caregivers on multiple areas of care for the seriously ill, including hospice care, nursing care, and palliative care. In addition, we included the Advanced Cancer Patient Perceptions of the Quality of Care survey that aims to obtain patient perceptions, but was based on the FEHC survey. The work described in this group has been tested using a variety of modes: in-person interviews, telephone surveys, and mailed survey administration. Some common measurement themes were receiving the desired amount of information, receiving any contradictory information, receiving the “right amount” of symptom management, and an overall rating of symptom management. The FEHC/FEPC instrument informed the development

**Table 5.2. Overview of Bereaved Family Member Instruments and Data Elements**

<b>Instrument</b>	<b>Setting; Population</b>	<b>No. of Communication Data Elements</b>	<b>No. of Symptom Management Data Elements</b>	<b>No. of Overall Rating Data Elements</b>
Advanced Cancer Patient Perceptions of the Quality of Care	Oncology; family member	10	—	—
After-Death Bereaved Family Member Interview	Multiple settings; bereaved family members (telephone)	1	11	—
After-Death Bereaved Family Member Interview (CARE/Nursing Home)	Nursing home; bereaved family members (in-person or telephone)	15	8	1
FEHC and FEPC	Hospice, palliative care; bereaved family members	5	11	1
Family Perspectives on End-of-Life Care	Multiple settings; family member or other close individuals of patients	10	7	—

of the CAHPS Hospice Survey, which is described above. The After-Death Bereaved Family Member Interview also formed the basis for the VA Performance Reporting and Outcomes Measurement to Improve the Standard of Care at End of Life (PROMISE) work, which is described in the next section.

#### Advanced Cancer Patient Perceptions of the Quality of Care

This instrument<sup>15</sup> consists of two surveys administered to patients diagnosed with cancer at an advanced stage (one administered at diagnosis, the other at initial treatment). Our review identified ten communication data elements. Data elements used two response scales: Yes/No or Never/Sometimes/Usually/Always. Several data elements asked about communication around diagnosis/prognosis: how much information they received, if the information was explained in a comprehensible fashion, if the information was presented with sensitivity, and how much emotional support was received. Other data elements assessed communication regarding testing results and treatment plans: if test results were presented clearly, whether patients wanted additional information about their test results, how much providers listen to patient concerns about the treatment plan, the clarity of provider communication about the treatment plan, if providers communicate well with family and friends about the treatment plan, and if providers provide sufficient emotional support to family and friends. Development research indicates that the “preliminary validation provides evidence of reliability and validity that warrants further testing to develop measures that capture patients’ views on quality of care.”<sup>15</sup> Reliability was good for Communication at the Time of Diagnosis (Cronbach’s alpha = 0.84) and fair for Communication at the Time of Treatment Decisionmaking (Cronbach’s alpha = 0.78).

#### After-Death Bereaved Family Member Interview

The After-Death Bereaved Family Member Interview<sup>118, 119</sup> is a retrospective telephone-based survey with bereaved family members focusing on care in multiple settings (e.g., outpatient hospice, nursing home, inpatient). Our assessment identified one communication data element of interest and 11 symptom management data elements of interest. The communication data element assessed perceptions about doctors listening to patients’ concerns. The item response scale was Yes/No/Had no concerns. Four of the 11 symptom management data elements were “screener questions” asking about the presence of symptoms (e.g., pain, trouble breathing). The other data elements assessed if patients got the help they needed, and if they got the “right amount” of help. This scale included a data element on help with personal care needs. Response scales varied by data element type, including Yes/No/Don’t know for symptom screeners, Yes/No for getting help, and Less than was needed/Right amount for the amount of help. A study examined the reliability of the survey tool by calculating “problem scores,” which captured the opportunity to improve quality by summing negative responses to questions for each domain (i.e., a high score indicates more opportunities to improve). For the overall instrument, Cronbach’s alpha scores varied from 0.58 to 0.87, with two problem scores (each

of which had only three survey data elements) having a low alpha of 0.58. The mean item-total correlation—a measure of the reliability of a multi-item scale—of all eight problem scores ranged from 0.36 to 0.69. The authors noted that these properties were satisfactory, although some were in the lower ranges because of other factors present in the testing, such as a low rate of observed problems for some scales and the ability of the scales to differentiate between hospital care and hospice services.

#### After-Death Bereaved Family Member Interview (CARE/Nursing Home)

The After-Death Bereaved Family Member Interview (CARE/Nursing Home) survey<sup>119</sup> is a version of the After-Death Bereaved Family Member Interview tailored for family members of nursing home patients. It may be administered as an in-person or telephone survey. We identified 15 relevant communication data elements and eight relevant symptom management data elements. Data elements used a variety of response scales, including No/Yes/(Don't Know, No Treatments), Always/Usually/Sometimes/Rarely/Never, Less than was wanted/Right amount/(variation: too much or too little), or a 0–10 scale. The communication data elements assessed the quality of doctors' communication with the patient, including the quality of information transfer. They also assessed whether the respondents had spoken with the doctors themselves, if respondents ever had trouble understanding what the doctors were trying to communicate about patient treatment, whether respondents felt that the doctors listened to their concerns, if the care team provided treatment that was consistent with patient wishes, and how often the patient was treated kindly. The data elements also assessed the information provided if the care team provided the right amount of information about the patient's condition, how often any doctor gave contradictory information about the patient's condition, if the family received information about medication management (and, if so, if they would have wanted more), if the family received information about the dying process (and, if so, if they would have wanted more), if the family received information about what to do after the patient's death (and, if so, if they would have wanted more). The symptom management data elements assessed whether the patient was on medicine for the treatment of pain, if the care team discussed the treatment of pain in a comprehensible fashion, and if the patient received the "right amount" of medication for pain management. A similar set of these data elements were assessed for trouble with breathing and feelings of anxiety or sadness. Finally, one data element rated both communication and symptom management by asking for a 0–10 rating of the overall quality of care team in making sure that patient symptoms were controlled. According to developmental research,<sup>119</sup> reliability was fair for Informing and Making Decisions scales (Cronbach's alpha = 0.77), poor for the Family Emotional Support scale (Cronbach's alpha = 0.58), and good for "Patient Focused, Family Centered" Problem Score (Cronbach's alpha = 0.87).

#### Family Evaluation of Hospice Care and Family Evaluation of Palliative Care

The FEHC<sup>121</sup> and FEPC<sup>122</sup> are questionnaires sent to bereaved family members.<sup>120</sup> We describe these instruments together because they were developed together and share many data

elements. We identified five relevant communication data elements and 11 relevant data elements on symptom management. Data elements used a variety of response scales, including No/Yes/(Don't Know, No Treatments), Always/Usually/Sometimes/Rarely/Never, Less than was wanted/Just the right amount/More help or attention to these [symptoms], and 0–10 (worst care to best care). The communication data elements focus on whether the care team treated the patient with respect, explained the care plan in a comprehensible way, and communicated sufficiently about the illness and likely outcomes of care. The data elements also assess if the care team gave confusing or contradictory medical information, or if the care team appeared insufficiently knowledgeable to provide the best possible care. The symptom management data elements contain a cluster of data elements related to the management of pain that assessed the following: if the patient had pain or took medication for pain, if the patient received the “right amount” of medicine for the pain, whether the patient or their family received information about pain management, and if they had wanted additional information than the amount they received. A subset of these data elements ask about difficulty breathing and anxiety or sadness. Finally, one data element asks respondents to rate the care team on their overall ability to control symptoms for the patient. The FEHC and FEPC are derived from the After-Death Bereaved Family Member Interview, which contains information on the performance of the data elements.

#### Family Perspectives on End-of-Life Care

The Family Perspectives on End-of-Life Care<sup>12</sup> is a telephone survey administered in end-of-life care settings to patients' family members or other close individuals. We identified ten data elements that were relevant for communication and seven data elements relevant for symptom management. A small number of these were identified as “screener questions.” Response scales varied, including Yes/No/NA, Less than the right amount of . . . /More than the right amount of . . . /Just the right amount of . . . , and Always/Usually/Sometimes/Never/NA. In assessing communication, one set of data elements assesses information flow: if there were problems understanding what the doctor was communicating about treatment expectations, if the doctors listened, whether the patient received the “right amount” of information, and if the patient received contradictory information. One data element assesses how often the patient perceived being treated with respect. A final set of communication data elements assesses the information received about the treatment plan: whether information was received about symptom management and whether the patient and the family received sufficient information about expectations for the dying process. The symptom management data elements assess symptom management for pain, difficulty breathing, and feelings of anxiety or sadness. The data elements assess the presence of symptoms (as a screener), whether the patient received help with the management of those symptoms, and if they received the “right amount” of help for each symptom, respectively. These data elements were derived from the After-Death Bereaved Family Member Interview, which contains performance information.

## VA/PROMISE Group

This group of instruments was developed based on the After-Death Bereaved Family Member Interview (see above). This work focuses on patients seeking care with the VA and is included with the PROMISE quality program (<https://www.hsrd.research.va.gov/impacts/promise.cfm>) that originally centered on the development of the Family Assessment of Treatment at End of Life (FATE) Survey. The Bereaved Family Survey (BFS) is a modified version of the FATE, while the QUAL-E (FAM) assesses family perspectives and is viewed as a complement to the FATE. The QUAL-E (FAM) was also tested both within and outside of the VA setting. The instruments within this group are summarized in Table 5.3.

**Table 5.3. Overview of VA/PROMISE Instruments and Data Elements**

<b>Instrument</b>	<b>Setting; Population</b>	<b>No. of Communication Data Elements</b>	<b>No. of Symptom Management Data Elements</b>	<b>No. of Overall Rating Data Elements</b>
BFS	VA facilities; next of kin (mailed; phone option)	7	6	—
FATE-S	VA Medical Center; family member (telephone)	5	6	—
QUAL-E (Fam)	Inpatient terminally/seriously ill; family members	6	4	—

### Bereaved Family Survey

The BFS is a mailed survey (with phone option) of bereaved next of kin for patients in VA facilities. We identified seven data elements on communication and six data elements on symptom management. Most data elements used a response scale of Always/Usually/Sometimes/Never/Unsure. Two screener data elements used a Yes/No/Unsure scale. One data element added a response option related to the presence of postcombat stress. The communication data elements assess if providers took time to listen to patients, listened to patients' concerns, were perceived as caring and respectful, kept family members informed, and whether the family was alerted about impending death. The symptom management data elements assess how often patients received help with personal care needs, if patients had pain or stress stemming from combat, and how often the pain or stress made them uncomfortable. The data elements assess if patients received medication for pain and how often they received the medication and treatment they wanted. Developmental research<sup>123, 124</sup> found the instrument to be valid and reliable. Reliability was good for the overall survey and for communication (Cronbach's alphas = 0.81 and 0.84, respectively) and fair for emotional support (Cronbach's alpha = 0.71).

## FATE-S

The Family Assessment of Treatment at End of Life (Short Form) Survey (FATE-S) is a telephone-based survey of family members of VA Medical Center patients. Our review identified five relevant data elements for communication and six relevant data elements for symptom management. The communication data elements assess if providers listened well, communicated clearly, were respectful and caring, kept patients informed, and adequately explained the dying process. The majority of data elements use a scale of Never/Sometimes/Usually/Always/Did not speak to staff. The symptom management data elements assess how often the following occurred: patients received unwanted care, the providers attended to personal care, patients experienced pain, and patients experienced pain that made them uncomfortable. Finally, the survey addresses whether patients received sufficient emotional support. The majority of the data elements use a scale of Always/Usually/Sometimes/Never/Unsure (some including variants of “did not have symptom” or “did not want support”). Developmental research found that this instrument had strong psychometric properties.<sup>13, 125</sup> The Respect for Treatment Preferences domain was shown to have high correlation with global preferences. Discriminant validity for the communication and information domains was strong (Spearman  $\rho = 0.67$ ) and reliability was good (Cronbach’s alpha = 0.83). Reliability of a composite scale of data elements related to Well-Being and Dignity was fair (Cronbach’s alpha = 0.78).

## QUAL-E (Fam)

The QUAL-E (Fam) is an interviewer-administered survey of family members of terminally ill or seriously ill patients in the inpatient setting.<sup>126</sup> We identified six relevant data elements of communication and four data elements relevant for symptom management. Many data elements use a scale of Always/Usually/Sometimes/Rarely/Never, while a smaller number (primarily in symptom management) use Very Severe/Severe/Moderate/Mild/Not at all, or Great Deal/Good bit/Somewhat/Only a little/Not at all. The communication data elements address how much the care team told the family what to expect about the course of illness and how often the care team involved the family in decisionmaking, kept the family informed, communicated unclearly, or provided confusing information or provides conflicting information. The symptom management data elements assess how often the patient has experienced a given symptom recently, how severe that symptom has been, how much that symptom has interfered with the patient’s life, and, overall, how much the patient is perceived to be suffering. Developmental research, conducted within the VA,<sup>126</sup> showed that the health care provider and symptom scales were distinct constructs, with good test-retest reliability.

## *Quality of Life at End-of-Life Group*

We identified three related surveys in our review: the Quality of Communication (QOC) Questionnaire, the Quality of End-of-Life Care (QEOLC) Questionnaire for family members, and the Quality of Death and Dying (QODD) Questionnaire. The QOC asks about a broad set of



provider communication skills for end-of-life care including some specific communication skills, such as making eye contact. The QEOLC asks about a smaller set of communication experiences, such as if the provider spoke in an open and straightforward way. The QEOLC includes dimensions of symptom management that are not included within the QOC. The QODD is a family member or informal caregiver survey, focused on family perceptions of comfort and quality of the patient's end-of-life care. Relevant data elements from the QODD pertain to symptom management. The instruments within this group are summarized in Table 5.4 below.

**Table 5.4. Overview of Quality of Life in End-of-Life Instruments and Data Elements**

<b>Instrument</b>	<b>Setting; Population</b>	<b>No. of Communication Data Elements</b>	<b>No. of Symptom Management Data Elements</b>	<b>No. of Overall Rating Data Elements</b>
QOC Questionnaire	Inpatient and outpatient hospice; patients	7	—	—
QODD Questionnaire for family members	Funeral homes; bereaved informal caregivers (in-person interview)	—	2	—
QEOLC Questionnaire	Patients with life-threatening illnesses, and their families (mailed)	3	6	—

#### Quality of Communication Questionnaire

The QOC Questionnaire is an in-person interview of patients focusing on inpatient and outpatient hospice care. We identified seven relevant communication data elements from the QOC. All data elements use a 0–10 response scale. The data elements ask patients to think about patient-provider communication in the context of “important issues.” Data elements include basic communication, such as using clear language and making eye contact. Data elements also assess meaningful participation, such as including loved ones in decision, answering all questions, and listening well. Finally, data elements assess overall attentiveness, care about the patient as a person, and giving the patient full attention. Development research found evidence of convergent and discriminant construct validity. Reliability for the communication scale was excellent (Cronbach's alpha >0.90).<sup>127</sup>

#### Quality of Dying and Death Questionnaire for Family Members

The QODD Questionnaire is an in-person interview of bereaved informal caregivers at funeral homes. We identified two relevant data elements of symptom management. Both data elements used a response scale that provided a rating of 0–6. One data element assesses if the patient's (“loved one's”) pain had appeared to be under control. The second data element assesses if the patient had appeared to breathe comfortably. Developmental research<sup>128</sup> found the QODD to be valid; higher scores were associated with the types of outcomes associated with high quality of life at end of life, such as death in the location the patient desired, lower

symptom burden, and higher ratings of symptom treatment. Reliability was also good (Cronbach's alpha = 0.89).

#### Quality of End-of-Life Care Questionnaire

The QEOLC Questionnaire is a mailed survey assessing end-of-life care for patients with life-threatening illnesses and their families. We identified three relevant communication data elements and six data elements relevant for symptom management. All data elements use a 1–5 (“poor” to “excellent”) rating scale, with an option of “does not apply.” The communication data elements assess if the provider was accessible, communicated in a way that is honest and straightforward, and communicated openly with the patient’s family. Some of the symptom management data elements assess the care the patient received: if the provider was knowledgeable about care needed during the dying process and if the provider knew when to stop treatments that were no longer helpful. The other data elements assess treatment in the context of the individual: if the provider accounted for patient wishes in managing symptoms, if the provider was responsive to emotional needs, if the provider treated the “whole person,” and if the provider factored social considerations into the treatment plan. A validation study found evidence for construct validity by association between factors with QEOLC and patients’ and families’ ratings of quality of care, levels of symptom distress, and providers’ palliative care knowledge.<sup>129</sup>

#### Satisfaction with End-of-Life Care Group

The following two surveys, the FAMCARE-2 and FAMCARE-P, were developed by the Edmonton Zone Palliative Care Program in Canada.<sup>130</sup> The surveys assess patient satisfaction in palliative oncology care. FAMCARE-2 focuses on family satisfaction, and FAMCARE-P is a version that is modified for the patient perspective. The individual scores, when taken together, are meant to yield a composite satisfaction score (within each respective survey). The surveys address concepts both of patient-provider communication as well as symptom management. The instruments within this cluster are summarized in Table 5.5.

**Table 5.5. Overview of FAMCARE Satisfaction Instruments and Data Elements**

Instrument	Setting; Population	No. of Communication Data Elements	No. of Symptom Management Data Elements	No. of Overall Rating Data Elements
FAMCARE-P	Outpatient palliative care; patients with advanced cancer	5	4	—
FAMCARE-2	Inpatient and community-based palliative care; family members	—	3	—

## FAMCARE-P

FAMCARE-P is a written questionnaire sent to patients with advanced cancer being seen in an outpatient palliative care setting. We identified five relevant data elements of communication and four relevant data elements of symptom management. All data elements use a response scale of Very satisfied to Very dissatisfied. The data elements on communication assess patient satisfaction with provider (doctor/nurse) availability to respond to questions, information received about prognosis, answers from health professionals, and the inclusion of family in care decisions. The data elements on symptom management assess patient satisfaction with provider attention to patient's symptom description and the thoroughness of the provider assessment, the speed of symptom treatment, and pain relief. The FAMCARE-P is based on a prior tool (FAMCARE).<sup>131</sup> Preliminary assessment found construct validity and excellent reliability across the tool (Cronbach's alpha >0.90).

## FAMCARE-2

The FAMCARE-2 scale is a survey of patients' family members focusing on palliative care services in the inpatient and community setting. We identified three relevant data elements of symptom management. All data elements used a response scale of Very satisfied to Very dissatisfied. The symptom management data elements assess family members' satisfaction with patient's comfort, the ways patient's comfort needs were met, and providers' attention to the patient's symptoms. Developmental research found, through factor analysis, that the three data elements loaded onto a single factor that was described as "management of physical symptoms and comfort."<sup>132</sup> The overall Cronbach's alpha for the survey exceeded 0.90.

## *Other Instruments*

We identified ten additional survey instruments (see Table 5.6) in the literature review.

### Canadian Health Care Evaluation Project

The Canadian Health Care Evaluation Project (CANHELP) is a questionnaire administered in-person to patients with advanced life-limiting illness and their family caregivers in inpatient and outpatient facilities and affiliated home care programs. Our review identified 12 relevant communication data elements and two data elements relevant to symptom management. All data elements used a response scale of Not at all satisfied to Completely satisfied. The communication data elements assess satisfaction with the provider's ability to listen to the patient and communicate in a way that is honest and straightforward, and if the provider communicated in a comprehensible fashion and listened to what patients and families had to say. The data elements also assess satisfaction with providers giving timely updates, discussions about the progression or worsening of disease, and the use of life-saving technology. Families report satisfaction on whether they received consistent information, had discussions around wishes for future care, and whether care was consistent with patient preferences or wishes. The symptom management data

**Table 5.6. Additional Surveys Identified in the Literature Review**

<b>Instrument</b>	<b>Setting; Population</b>	<b>No. of Communication Data Elements</b>	<b>No. of Symptom Management Data Elements</b>	<b>No. of Overall Rating Data Elements</b>
CANHELP	Inpatient and outpatient facilities (and affiliated home care programs); patients with advanced life-limiting illness and their family caregivers	12	2	—
CSQ-8	Inpatient and outpatient care for behavioral health and substance abuse; patients	—	1	—
CollaboRATE	Outpatient; patients	3	—	—
CAT	Inpatient or outpatient; physicians and patients or caregivers (phone or internet)	15	—	—
CQ-index PC	Palliative care; patients (in-person or mail)	7	11	—
Dartmouth COOP "Feelings" chart (modified)	Palliative care; clinicians and other providers and adult patients (or health care proxies) with metastatic cancer (interview)	—	2	—
QCQ-EOL	Conventional care facilities and hospices; terminally ill patients	—	2	—
QPAC	Palliative care; patient	9	1	—
SWC-EOLD	Nursing home; residents or proxies	1	4	—
VOICES: Postal Questionnaire	Hospice and inpatient; bereaved caregivers (mail)	—	6	—

elements assess satisfaction with adequacy of control for physical and emotional symptoms, respectively. Developmental research reported good construct validity for general patient and caregiver questionnaires; correlations between the survey's satisfaction score and rating of satisfaction with care were 0.49 for patient and 0.63 for family (correlation coefficients) for patient and family.<sup>133</sup> Reliability between patient and caregiver responses ranged from poor to excellent (Cronbach's alphas 0.69 to 0.94) across items, but were good for symptom management (Cronbach's alphas 0.88 to 0.89).

#### The Client Satisfaction Questionnaire

The Client Satisfaction Questionnaire-8 (CSQ-8) is a point-of-care questionnaire for patients assessing behavioral health and substance abuse care in the inpatient and outpatient care

settings.<sup>134</sup> We identified one relevant data element of symptom management within this survey. The data element asks patients how satisfied they were with the amount of help they received and used a scale of Quite dissatisfied/Indifferent or mildly dissatisfied/Mostly satisfied/Very satisfied. Research has found CSQ-8 to have excellent internal consistency (Cronbach's alpha = 0.92) and has been validated against other patient perception questionnaires.<sup>134, 135</sup>

#### CollaboRATE

CollaboRATE is a patient survey for outpatient care, focusing on shared decisionmaking. We identified three relevant communication data elements. All data elements used a response scale with a 0–10 rating. The communication data elements focus on provider-patient communication, such as the level of the provider's effort to help the patient understand health issues, the extent to which the provider focused on the things that mattered most to the patient about their health issues, and how much effort was made to include those important issues into health decisions. A study on the performance of CollaboRATE found mixed evidence on the validity of the instrument, but inter-rater reliability was good, at 0.86.<sup>136</sup>

#### Communication Assessment Tool

The Communication Assessment Tool (CAT) is a telephone or internet-based survey of physicians and patients or caregivers in the inpatient or outpatient setting. Our review focused on the patient perspective. We identified 15 relevant data elements related to communication. All data elements use a response scale of 1–5 ("poor" to "excellent"). The communication data elements assess a broad set of communication skills. These include the patient perspective on the extent to which the provider performed the following: provided a suitable greeting, treated the patient with respect, showed care and concern, spent adequate time, paid adequate attention, and showed interest in the patient's health. The data elements also assess to what extent the patient thought the provider understood the major health concerns, let the patient speak uninterrupted, gave the desired amount of information, and spoke clearly and comprehensibly. The data elements assess to what extent the patient thought the provider encouraged questions and involvement in decisionmaking and discussed next steps. Finally, one data element assesses if the patient felt the staff treated him or her with respect. In developmental research, the authors describe the tool as both valid and reliable, reporting very high reliability (overall scale reliability: Cronbach's alpha = 0.96).<sup>137</sup>

#### Consumer Quality Index Palliative Care

The Consumer Quality Index Palliative Care (CQ-index PC) is an in-person or mailed survey for palliative care patients.<sup>138</sup> We identified seven relevant data elements related to communication and 11 relevant data elements related to symptom management. All of the data elements used a response scale of Never/Sometimes/Usually/Always. Two of the communication data elements address basic communication: how often did the provider (or "caregivers," which was the term used in this Dutch study to refer to clinical staff) listen carefully or explain things in a

comprehensible fashion. The other communication data elements address aspects of the provider-patient relationship: perceptions of how often the providers were polite or took the patient seriously, were “warm,” or showed interest in the patient’s personal situation. For symptom management, a set of data elements assesses how often the patient felt he or she received support for pain, feeling tired, shortness of breath, constipation, anxiety, and depression, respectively. A data element assesses perspective on provider expertise. One data element asks about receiving medical supports soon enough, while another assesses if the patient got care in general soon enough when needed. The final data element asks about receiving timely care for acute situations. This instrument has not been subject to testing to determine psychometric validity of the patient-reported items, but family-member items have been found to be reliable.<sup>139</sup>

#### Dartmouth COOP “Feelings” Chart (Modified)

The Dartmouth COOP Charts are an interviewer-administered functional status measure originally designed for use in primary care,<sup>140</sup> but which have been subsequently used in other settings and populations.<sup>141</sup> Gramling and colleagues<sup>142</sup> adapted several items from the Dartmouth COOP instrument for use with patients with metastatic cancer in the palliative care setting and their family members or proxies. We identified two relevant data elements of symptom management from the adapted items. Both data elements use a response scale of Not at all/ Slightly/Moderately/Quite a bit/Extremely. The identified data elements ask patients or proxies how much they have been bothered by physical symptoms, such as pain, upset stomach, or difficulty breathing; and how much they have been bothered by emotional problems, such as feeling anxious, depressed, irritable, or downhearted and blue. The Dartmouth COOP instrument exhibited strong psychometric properties when tested in the original form, in a primary care population.<sup>143</sup> However, testing on the items adapted for use in a palliative care population has not been performed.

#### Quality Care Questionnaire–End of Life

The Quality Care Questionnaire–End of Life (QCQ–EOL) is a survey developed for use with terminally ill patients in conventional care facilities and hospices. We identified two relevant data elements of symptom management. Both data elements use a response scale of Not at all/ A little/Quite a bit/Very much. One data element assesses if the patient perceives that their pain and other physical symptoms have been “fairly well” controlled. A second data element assesses the same thing (i.e., symptom control) for psychological symptoms, such as depression or anxiety. Development research found high internal consistency among subscales and total scores (Cronbach’s alphas = 0.73 to 0.89).<sup>144</sup> We note that testing was conducted in South Korea, but it is unclear if or how that would affect reports of symptom management.

#### Quality Indicators for Palliative Care

Leemans and colleagues<sup>145, 146</sup> aimed to develop a minimal set of quality indicators for palliative care and included data elements for patient reporting in the palliative care setting. We

identified nine relevant communication and one relevant symptom management data elements. The identified data elements used four response scales: Less than necessary/Just the right amount/More than enough, None of them do/Some of them do/Most of them do/All of them do, Never/Sometimes/Usually/Always, and Yes/No. Some of the communication data elements assess information flow: if patients felt they got enough information about diagnosis as well as the course of disease; and if they received information about end-of-life care. Some data elements assess if patients have had things explained to them clearly, and if they received conflicting information. Other data elements assess if patients felt that they are co-deciding their care plan, had the freedom to plan their day, if providers took their wishes into account, and if providers checked on how they are feeling. The symptom management data element assesses if patients felt the treatment has adequately addressed their care needs. The data elements are still undergoing development, and psychometric testing is unavailable currently.

#### Satisfaction with Care at the End of Life in Dementia

The Satisfaction with Care at the End of Life in Dementia (SWC-EOLD) is a point-of-care questionnaire for nursing home residents or their proxies. We identified one relevant communication data element and four relevant symptom management data elements. The identified data elements use the response scale Strongly disagree/Disagree/Agree/Strongly agree. The communication data element assesses if the health care team was sensitive to the patient's (care recipient's) needs and feelings. The symptom management data elements assess if all measures were taken to keep the care recipient comfortable, if the care recipient received all needed assistance, if the care recipient received all treatments or interventions of benefit, and if the care recipient needed better medical care at the end of life. The SWC-EOLD is an extension of other work developing a set of EOLD scales. A psychometric study found evidence of good to excellent internal consistency (Cronbach's alphas 0.83 to 0.90) and convergent validity with instruments measuring similar constructs.<sup>147</sup> That study's authors note that the study sample was primarily White, and it is not clear whether the reliability and validity of the scales generalize to people of other racial or ethnic backgrounds.

#### VOICES: Postal Questionnaire

The VOICES: Postal Questionnaire is a mailed follow-up questionnaire for bereaved caregivers of patients who were cared for in the hospice and inpatient setting. We identified six relevant data elements of symptom management. The data elements use a variety of response scales, including Yes/No/Don't Know; Yes, we got as much supported as we wanted/Yes, we got some support but not as much as we wanted/No, although we tried to get more help/No, but we did not ask for more help/We did not need any help; Completely all of the time/Completely some of the time/Partially/Not at all/Don't know; and Yes, definitely/Yes, to some extent/No/[S/he] did not need any help with [need]/Don't know. A few of the symptom management data elements assess if the patient had pain, received treatment for pain, and whether the treatment relieved the pain. One identified data element assesses if the informal caregiver had confidence

and trust in the care institution (e.g., hospital). The remaining data elements focus on whether the informal caregivers felt they got as much help and support as they needed: from health and social services during the time they were caring for the patient and to meet the personal care needs of the patient (i.e., bathing, eating, dressing, etc.). Survey developers<sup>148</sup> did not conduct psychometric testing, but asserted the validity of the instrument by describing sound survey development processes, including cognitive and pilot testing of new questions. However, survey developers did evaluate differences in mode of administration and found that mailed survey versus interview administration did not significantly affect response rate or respondent characteristics.<sup>148</sup> In-person interviews appeared to be subject to social desirability bias for service satisfaction and symptom control data elements.

## Summary of Findings

The literature review for competing or related instruments identified many surveys and survey data elements related to the proposed measure concepts. Most related data elements came from existing CAHPS surveys, surveys based on the Toolkit After-Death Bereaved Family Member Interview, and surveys based on the FATE-S within the VA/PROMISE program.

### *Communication*

For the proposed measure concept related to communication, we identified some common themes across data elements in use in various surveys, as well as themes that we believe have specific relevance to patients with serious illness receiving outpatient palliative care. These include

- listening carefully to patients and listening to patient concerns
- explaining things in a way that was easy to understand, explaining things clearly, not providing confusing and/or contradictory information
- being kind, caring, and respectful; showing respect for what patients had to say
- spending enough time with the patient
- explaining the dying process
- providing emotional support around prognosis
- provider ability to communicate in an honest and straightforward way
- provider ability to convey a “warm” attitude
- providers demonstrating interest in patient’s personal situation and demonstrating sensitivity to patient’s needs and feelings.

### *Symptom Management/Unmet Need*

For the proposed measure concept related to symptom management, most data elements that we identified focused on satisfaction with overall symptom management or the speed with which symptoms were treated. If surveys asked about specific symptoms, nearly all asked about pain management. Support for trouble breathing and emotional support (sometimes expressed as



anxiety and sadness) were the next most likely symptoms to be named specifically, with a few surveys asking about other symptoms such as constipation or personal care needs. Less frequently, symptom management data elements asked about getting help during nonstandard hours, if care was consistent with patient wishes, and satisfaction with providers (e.g., in their attention and responsiveness to patient's symptoms).

The approach to assessing symptom management varied. Many of the CAHPS surveys used a "how often" approach to assess providers' symptom management (with a response scale of Never/Sometimes/Usually/Always), while other surveys, such as those based on the Toolkit After-Death Bereaved Family Member Interview, focused on whether the patient received the "right amount" of help for symptoms. Other surveys asked for a rating on the provider's quality, and so on. The wording of the symptom management data elements also varied based on whether the question was asking the patient about his or her own experience or asking a caregiver to answer based on their perception of the patient's experience.

## Chapter 6. Symptom Prevalence

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To determine a list of symptoms for which our proposed measure could assess adequacy of management, we first needed to understand symptom prevalence and importance in the palliative or end-of-life population. Our objective was to create a short list of symptoms that should be assessed in order to fully understand patients' experience of care—that is, to capture the extent to which their symptoms were addressed, according to their needs and wishes. We used a targeted approach to identifying key studies that could guide our decisions regarding symptoms. From an initial list of 14 key studies identified by advisers,<sup>10, 12, 18, 39, 40, 47, 49, 50, 149, 152</sup> we used a snowball approach to identify an additional seven studies related to symptom prevalence.<sup>24, 153, 158</sup> This chapter contains a narrative summary of these studies.

### Setting-Specific Symptom Prevalence

Several studies examined symptom prevalence or importance within specific care settings. In one large study of inpatient care among patients who qualified for palliative care (N = 185), tiredness (34.6 percent), pain (31.1 percent), and weakness (28.8 percent) were among the most important or bothersome physical symptoms reported by patients; “low mood” (19.9 percent) and anxiety (16.1 percent) were reported as the most important or bothersome psychological symptoms.<sup>155</sup> In another study of patients in hospice and palliative care units, the most common complaints at admission were respiratory problems (22 percent), pain (11 percent), and mental status changes (10 percent).<sup>157</sup> Finally, Potter and colleagues<sup>158</sup> assessed symptoms among patients referred to palliative care services in the hospice, hospital, and outpatient settings and found that the most prevalent symptoms (collapsed across setting type) were pain (64 percent), anorexia (34 percent), constipation (32 percent), weakness (32 percent), and dyspnea (31 percent). Among patients referred to outpatient palliative care, these symptoms were still prevalent but at different rates—higher for pain but lower for other symptoms. For patients receiving outpatient palliative care, the prevalence of pain was 75 percent, anorexia was 17 percent, constipation was 17 percent, weakness was 10 percent, and dyspnea was 13 percent.

### Symptom Prevalence Near the End of Life

Other studies assessed symptoms more generally across the last year or weeks of life, agnostic to care setting. A recent study<sup>150</sup> assessing symptom trends in the last year of life using decedent data from the Health and Retirement Survey found that in 2010, the prevalence of anorexia was 65.4 percent, severe fatigue was 63.7 percent, any pain was 60.8 percent (moderate or severe pain prevalence was 52.4 percent), depression was 57.0 percent, dyspnea was 54.8 percent, periodic confusion was 53.9 percent, incontinence was 48.1 percent, and frequent vomiting was

11.2 percent. Between 1998 and 2010, proxy reports of periodic confusion increased for all decedents by 31.3 percent (95 percent confidence interval [CI] 18.6 percent, 45.1 percent), prevalence of depression increased for all decedents by 26.6 percent (CI 14.5 percent, 40.1 percent), and the prevalence of any pain (mild, moderate, or severe) increased for all decedents by 11.9 percent (CI 3.1 percent, 21.4 percent). A 2015 study looked at the prevalence of symptoms in early- to late-stage lung and colorectal cancer patients.<sup>151</sup> Over 90 percent had at least one symptom in early stage, with over 50 percent reporting symptoms that were moderate to severe. By late stage, the most prevalent lung cancer symptom was cough (84.1 percent) while the most prevalent colorectal cancer was depression (79 percent). In a 2013 prospective cohort study focused on “restrictive symptoms”—those that impeded life-functioning—fatigue, musculoskeletal pain, dizziness or unsteadiness, and shortness of breath were the most common symptoms throughout the study period, increasing significantly compared with other symptoms in the five months prior to death.<sup>156</sup> In a 2007 study of symptoms in the last three months of life among patients still under the care of a primary care provider, 92 percent of patients had at least one symptom, and the average number of symptoms reported was ten.<sup>24</sup> Digestive symptoms were the most prevalent (59 percent), mainly problems with eating and drinking (29 percent) and nausea or vomiting (25 percent). Pain was reported at 56 percent. A number of prevalent psychological symptoms were also reported: restlessness (25 percent), sleeping problems (17 percent), and anxiety (13 percent). Older studies have reported that anorexia is a common symptom at the very end of life, as are dry mouth and asthenia. For example, Conill and colleagues<sup>39</sup> found that the most frequently reported (>50 percent prevalence) symptoms at the end of life were anorexia, asthenia, dry mouth, confusion, and constipation. Similarly, Hockley and colleagues<sup>50</sup> described the most commonly reported symptoms at the end of life as anorexia, insomnia, immobility, malaise, sore mouth, and cough. While evidence indicates that pain is often the primary symptom at the time of referral to palliative or supportive care services, 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.<sup>49</sup>

## Summary

Despite considerable heterogeneity in study designs, time frames, and symptoms examined, studies suggest that pain, fatigue/tiredness including insomnia or other sleeping problems, and eating or digestive symptoms (e.g., anorexia, nausea or vomiting, constipation) are common and bothersome problems for patients in palliative care. Some studies also identified additional symptoms that appear to be prevalent but less frequently reported on, such as dyspnea or respiratory problems, depression or low mood, and anxiety. In using this information to guide the refinement of quality measures around unmet symptom need, it will also be critical that we evaluate the extent to which these symptoms can be effectively addressed by palliative care and the extent to which they may co-occur (e.g., effective management of pain may result in symptoms of constipation).

## Chapter 7. Review of Existing Quality Measures and Gap Analysis Summary

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In order to understand where the proposed measures might fit within the broader quality measurement landscape and facilitate measure harmonization, we identified existing quality measures related to the concepts of interest. While the data elements described in Chapter 5 were individual questions or survey items that were developed to quantify patient experience (e.g., of symptoms, of quality of communication with their provider), the quality measures described in this chapter have been tested and specified to be used in CMS's quality reporting programs. Many of these quality measures have also been endorsed by NQF. A fully specified quality measure includes instructions for how to collect data and calculate the measure (e.g., numerator, denominator, exclusions) so that values are comparable across patient groups or practices. In addition, many quality measures are composites, derived from a set of data elements rather than an individual item, which provides stability and helps capture a higher-level construct that is possible with a single survey item.

### Methods

We conducted a scan of three measure repositories and data banks to identify potentially relevant quality measures related to end-of-life and palliative care in adult patients: the CMS Measures Inventory Tool (N = 2,179 measures),<sup>159</sup> the PCPI Foundation (N = 211 measures),<sup>160</sup> and the Assessing Care of Vulnerable Elders-3 project (N = 21 measures).<sup>161, 162</sup> We did not systematically search the NQF list of measures because the CMS Measures Inventory Tool included relevant NQF-endorsed measures.

After compiling 2,411 measures from these three sources, two researchers independently reviewed measures to determine if each measure was related to the two primary measure concepts (i.e., captured same or similar construct as the proposed measure concepts). We also included overall rating measures associated with patient experience measures, given that the primary measure concepts require testing alongside such measures. We excluded measures that were not patient reported, such as process-of-care measures and outcome measures derived from administrative data. We also excluded measures that would not apply to or could not be adapted for seriously ill populations (e.g., measures of functional status after surgery) and measures that would only apply to very narrow seriously ill populations (e.g., measures specific to the care of individuals with advanced Parkinson's disease). Any measure assessed as relevant by at least one researcher was referred for further screening by a clinician researcher with expertise in palliative care. Results are described and compiled in Tables 7.1 and 7.2 below.

## Results

Through our review, we identified 13 measures related to the two proposed measure concept areas, listed separately below as communication measures (Table 7.1) and symptom management measures (Table 7.2). None of the measures were directly tested among outpatient palliative care populations or in outpatient seriously ill populations, and each involves measure concepts that differ from the proposed measure concepts.

In the communication domain, we identified seven quality measures based on data elements collected in five CAHPS surveys: the CAHPS Hospice, CG-CAHPS, HCBS CAHPS, HHCAHPS, and HCAHPS. Measure names and the data elements that contribute to the measures are shown in Table 7.1. Some data elements within these measures ask respondents about various aspects of communication. We have selected data elements that are most pertinent to the proposed measure concepts to be included in our testing, alongside the proposed measure concepts.

**Table 7.1. Related Communication Measures and Constituent Data Elements**

Measure Name	Data Elements That Contribute to Measure	Instrument
Hospice team communications	<p>How often did the hospice team keep you informed about when they would arrive to care for your family member?</p> <p>How often did the hospice team explain things in a way that was easy to understand?</p> <p>How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?</p> <p>How often did the hospice team keep you informed about your family member's condition?</p> <p>How often did the hospice team listen carefully to you?</p> <p>How often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?</p>	CAHPS Hospice Survey
Treating family member with respect	<p>While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?</p> <p>While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?</p>	CAHPS Hospice Survey
How well your providers communicate	<p>In the last 6 months, how often did this provider explain things in a way that was easy to understand?</p> <p>In the last 6 months, how often did this provider listen carefully to you?</p> <p>In the last 6 months, how often did this provider show respect for what you had to say?</p> <p>In the last 6 months, how often did this provider spend enough time with you?</p>	CG-CAHPS
Communication with doctors	<p>During this hospital stay, how often did doctors treat you with courtesy and respect?</p> <p>During this hospital stay, how often did doctors listen carefully to you?</p> <p>During this hospital stay, how often did doctors explain things in a way you could understand?</p>	HCAHPS

Measure Name	Data Elements That Contribute to Measure	Instrument
Communication with nurses	<p>During this hospital stay, how often did nurses treat you with courtesy and respect?</p> <p>During this hospital stay, how often did nurses listen carefully to you?</p> <p>During this hospital stay, how often did nurses explain things in a way you could understand?</p> <p>During the hospital stay, after you pressed the call button, how often did you get help as soon as you wanted it?</p>	HCAHPS
Staff listen and communicate well	<p>In the last 3 months, how often did [personal assistance/behavioral health staff] treat you with courtesy and respect?</p> <p>In the last 3 months, how often were the explanations [personal assistance/behavioral health staff] gave you hard to understand because of an accent or the way [personal assistance/behavioral health staff] spoke English?</p> <p>In the last 3 months, how often did [personal assistance/behavioral health staff] treat you the way you wanted them to?</p> <p>In the last 3 months, how often did [personal assistance/behavioral health staff] explain things in a way that was easy to understand?</p> <p>In the last 3 months, how often did [personal assistance/behavioral health staff] listen carefully to you?</p> <p>In the last 3 months, did you feel [personal assistance/behavioral health staff] knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?</p> <p>In the last 3 months, how often did [homemakers] treat you with courtesy and respect?</p> <p>In the last 3 months, how often were the explanations [homemakers] gave you hard to understand because of an accent or the way the [homemakers] spoke English?</p> <p>In the last 3 months, how often did [homemakers] treat you the way you wanted them to?</p> <p>In the last 3 months, how often did [homemakers] listen carefully to you?</p> <p>In the last 3 months, did you feel [homemakers] knew what kind of help you needed?</p>	HCBS CAHPS
Communication between providers and patients	<p>When you first started getting home health care from this agency, did someone from the agency tell you what care and services you would get?</p> <p>In the last 2 months of care, how often did home health providers from this agency keep you informed about when they would arrive at your home?</p> <p>In the last 2 months of care, how often did home health providers from this agency explain things in a way that was easy to understand?</p> <p>In the last 2 months of care, how often did home health providers from this agency listen carefully to you?</p> <p>In the last 2 months of care, when you contacted this agency's office did you get the help or advice you needed?</p> <p>When you contacted this agency's office, how long did it take for you to get the help or advice you needed?</p>	HHCAHPS

In the symptom management domain, we identified multiple measures that address symptom management in the CAHPS Hospice and HCAHPS surveys. In the CAHPS Hospice survey, for instance, family members are asked whether patients got as much help as needed for pain, trouble breathing, constipation, and feelings of anxiety or sadness. The HCAHPS survey also asks about pain management and control during the hospital stay and whether hospital staff did everything they could to help with pain, though new data elements are being tested that focus on how often hospital staff talked with the patient about pain levels and how to treat the pain.

In addition, we identified in CMS's Measures Inventory Tool two patient-reported measures of symptom management not based on the CAHPS surveys. These measures address pain control within 48 hours for patients receiving hospice care and palliative care, respectively, and are currently used in CMS quality report programs.<sup>163, 164</sup> Data are collected through patient interview during the clinical assessment.

**Table 7.2. Related Symptom Management Measures and Constituent Data Elements**

Measure Name	Data Elements That Contribute to Measure	Instrument
Getting emotional and spiritual support	While your family member was in hospice care, how much emotional support did you get from the hospice team? In the weeks after your family member died, how much emotional support did you get from the hospice team: Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?	CAHPS Hospice Survey
Getting help for symptoms	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?	CAHPS Hospice Survey
Communication about pain during the hospital stay <sup>a</sup>	During this hospital stay, did you have any pain? During this hospital stay, how often did hospital staff talk with you about how much pain you had? During this hospital stay, how often did hospital staff talk with you about how to treat your pain?	HCAHPS
Communication about treating pain postdischarge <sup>a</sup>	Before you left the hospital, did someone talk with you about how to treat pain after you got home? Before you left the hospital, did hospital staff give you a prescription for medicine to treat pain? Before giving you the prescription for pain medicine, did hospital staff describe possible side effects in a way you could understand?	HCAHPS

Measure Name	Data Elements That Contribute to Measure	Instrument
Comfortable dying: pain brought to a comfortable level within 48 hours of initial assessment	[Yes/no question about if patient is uncomfortable because of pain at the initial assessment compared with answer to same question 48 hours later]	Patient interview during clinical assessment
Pain brought under control within 48 hours	[Patients aged 18 and older who report being uncomfortable because of pain at the initial assessment (after admission to palliative care services) who report pain was brought to a comfortable level within 48 hours]	Patient interview during clinical assessment

NOTE: <sup>a</sup> Beginning with patients discharged in January 2018, the three original Pain Management items were removed from the HCAHPS Survey and replaced by three new items that will comprise the new Communication about Pain measure. The original Pain Management measure will be publicly reported on the Hospital Compare Web site until December 2018. The new Communication about Pain measure will be publicly reported beginning in October 2020.

### *Summary of Measures Scan*

The measures scan identified 13 quality measures related to communication and symptom management. Understanding quality measures currently available will facilitate measure harmonization and ensure that measures developed within this project fit within the broader quality measurement landscape.

### **Gap Analysis Summary**

The proposed measure concepts would fill gaps in the measures identified in this scan. We will be testing both proposed measure concepts in populations in which existing measures have not been tested—that is, patients with serious illness receiving outpatient palliative care services. In addition, the proposed “heard and understood” concept addresses a different topic than is currently available in existing communication measures. Unlike existing measures, the “unmet need” measure concept is directly tailored to address whether patients are receiving care in accord with their wishes.



## Chapter 8. Stakeholder Input

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As part of our information-gathering process, we sought to obtain the perspectives of stakeholders directly involved in palliative care (that is, palliative care providers, patients, and caregivers or family members) on measuring the quality of palliative care received by adult patients in outpatient clinic-based settings and specifically on the proposed measure concepts of communication and unmet symptom need. To accomplish this goal, we conducted four focus groups with palliative care providers and interviews with 13 total patients, caregivers, and/or family members (PCFMs). In the focus groups and interviews, we sought to elicit information on the relevance and importance of the measure concepts, the feasibility of collecting patient-reported data on communication and unmet symptom need in outpatient palliative care, and the potential barriers and facilitators to implementing the proposed quality measures in practice, including the use of a mailed survey. We also asked about alternative approaches to measure communication and unmet symptom need.

The following sections describe recruitment strategies, participant characteristics, and data collection procedures first for the provider focus groups and then for the PCFM interviews. Because transcripts from all data collection activities were analyzed together, the description of the data collection is followed by a single results section that discusses what we found across both the provider and PCFM participants. We highlight notable differences in resulting themes based on respondent type.

### Palliative Care Providers

We conducted four in-person focus groups for palliative care providers in metropolitan areas across the United States (Los Angeles, California; Boston, Massachusetts; Atlanta, Georgia; and Chicago, Illinois).

#### *Provider Recruitment*

We recruited providers with direct experience providing palliative care services, with a preference for individuals who were currently practicing in outpatient clinic-based or home-based palliative care (i.e., not inpatient palliative care or hospice care). We intentionally sought participants from a variety of disciplines to increase the diversity of perspectives included in the groups. Participants included physicians (medical doctors or doctors of osteopathy), advanced practice registered nurses, physician assistants, registered nurses, social workers, chaplains, and pharmacists. We targeted clinicians directly involved in patient care activities,

rather than academic experts or administrators, to better understand the value and feasibility of implementing the proposed quality measures, from their perspectives.

To begin recruitment, AAHPM distributed information about the research activities to the AAHPM Research Committee, Quality Committee, QI Workgroup, Research Special Interest Group, and Outpatient Palliative Care Special Interest Group and requested that they suggest individuals who might be suitable participants. A standard nomination form that collected basic information, such as name, discipline, and affiliation was requested from each nominee. AAHPM also compiled a list of all its members in the potential focus group locations and sent information and the nomination form to the members on this list. Additional recruiting was supported by the National Coalition for Hospice and Palliative Care, which reached out to the Coalition Board, the presidents/chief executive officers of all member organizations, and Quality Workgroup representatives from the ten Coalition member organizations. A project team member with a dual clinical-research appointment at University of California, Los Angeles also disseminated nomination materials in the Los Angeles area.

AAHPM and the National Coalition for Hospice and Palliative Care's outreach was targeted to Los Angeles, California; Boston, Massachusetts; Washington, DC; Chicago, Illinois; Atlanta, Georgia; and St. Louis, Missouri. We selected these cities due to the presence of the RAND Corporation offices in Los Angeles, Boston, and Washington, DC, and AAHPM's office in Chicago, which could provide a meeting space. Atlanta and St. Louis were also selected to gain perspective from the midwestern and southern regions of the United States, because of regional differences in health care delivery patterns as well as racial and ethnic variation. We received the least number of nominations from Washington, DC, and St. Louis and thus proceeded with focus groups in the remaining four cities.

We scheduled meetings for each of the four focus groups in consultation with all the nominees; we selected the date and time for which the most nominees representing a range of palliative care disciplines were available. We required that each focus group include at least two MIPS-eligible clinicians—that is, providers that meet CMS eligibility criteria to participate in the MACRA QPP.<sup>165</sup> At the time of our recruitment, these providers that met the criteria (which has since been updated by CMS QPP) included physicians, physician assistants, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists.\*

Participants were given a \$300 honorarium at the conclusion of the focus group.

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\* Recent revisions to the MACRA QPP have expanded this list for the 2021 adjustment year to also include physical/occupational therapists, speech-language pathologists, audiologists, nurse midwives, clinical psychologists, dietitians/nutritional professionals.

## *Participants*

The three-hour, in-person focus groups were held on January 29, and February 1, 6, and 7, 2019, in Los Angeles, California; Boston, Massachusetts; Atlanta, Georgia; and Chicago, Illinois, respectively. There was a total of 35 participants across the four locations. They consisted of

- eight physicians (including two CMOs and one medical director)
- six nurse practitioners
- six social workers
- three registered nurses
- three pharmacists
- five chaplains
- two physician assistants
- two administrators.

The above participants included at least five senior officers (“C-suite”) and seven director-level positions. The providers were employed or primarily affiliated with a total of 27 organizations, which included outpatient clinics; hospitals; health systems; universities; palliative care, hospice, or home health providers; and professional associations.

## *Data Collection*

The focus groups protocol covered the following topics: patient assessment process, symptom management and unmet needs, communication (including being heard and understood), and implementation challenges when collecting patient experience information. Appendix C contains all the questions we developed for the provider focus group protocol. All focus groups were recorded and later transcribed by a transcription servicing company.

## **Patients, Caregivers, and Family Members**

Although we initially planned to convene in-person patient, caregiver, and/or family member focus groups, input from the National Patient Advocacy Foundation (NPAF) (one of several partnered organizations for this quality measure development effort) highlighted the challenges palliative care patients would face in participating in a focus group. This feedback led us to revise our approach and to instead schedule one-on-one telephone interviews with PCFMs at the participant’s convenience.

## *Patient, Caregiver, and Family Member Recruitment*

For the PCFM interviews, we sought patients who were currently receiving palliative care and/or hospice or who had received such services in the past, patients with advanced illness who were not currently receiving hospice and/or palliative care services, informal caregivers of patients receiving hospice and/or palliative care services, and patient advocates.

The Coalition sent outreach emails with information on this research to partners at the NPAF, American Cancer Society, Family Caregiver Alliance, and National Alliance for Caregiving, and solicited nomination forms. NPAF also identified and provided the contact information of individual PCFMs, whom RAND directly contacted via phone.

The interviews were scheduled based on PCFM availability. The interviews were conducted by phone and were 30–60 minutes long. A \$100 honorarium was sent by mail to the participants after the interview.

### *Participants*

The 13 PCFM interviews were held between February and June 2019. Interview participants consisted of

- four patients with advanced illness, not receiving and with no past use of hospice and/or palliative care (one of whom was joined by his wife during the interview)
- eight patients currently receiving palliative care or who had received palliative care in the past
- one caregiver.\*

### *Data Collection*

The interview protocols included the following topics: what it is like to receive palliative care, what information sharing between patients and providers would look like in an ideal situation, unmet symptom need and communication, and preferences for responding to mail versus in-person surveys. Appendix E contains the PCFM interview protocol. All interviews were recorded and later transcribed by a transcription servicing company.

### *Analysis*

We developed a coding structure based on the interview protocol themes and study aims. One senior researcher then reviewed one focus group transcript for content pertaining to each theme, grouped the information from transcripts according to themes, and created additional themes as needed; all information was captured in a findings document. A second researcher then reviewed the same transcript and themes and examined the information in the findings

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\* Due to recruitment challenges, we were able to conduct only one interview with a caregiver. Understandably, most informal caregivers are already overburdened by their caregiving responsibilities, which they perform in addition to paid work, parenting, and other roles. We hope to gather the perspective of additional caregivers in qualitative data collection related to the alpha and beta tests. Recruitment challenges also influenced our ability to recruit family members separately; as a result, the wife who joined the interview and the caregiver provide representation for the family member role.

document. Both researchers were in agreement about the application of the thematic structure to the transcript. The senior researcher then applied the same thematic structure to the remaining focus group and interview transcripts. The second researcher also reviewed these remaining transcripts to ensure that all relevant information was included in the findings document.

## Results

Data from the provider focus groups and PCFM interviews were combined for analysis. Below we describe the themes we identified. We present these themes within the following topics: unmet symptom needs, emotional support, communication, and considerations for implementation. Where relevant, we note where providers and PCFMs offered different perspectives.

### *Unmet Symptom Needs*

Providers and PCFMs discussed types of symptoms relevant to unmet needs and barriers and facilitators to addressing unmet needs, and gave feedback on example unmet need data elements that we presented to them.

#### Understanding and Experience of Unmet Symptom Need

PCFMs did not always understand the word *symptom* and at times needed to be given examples of symptoms prior to providing their own examples. This suggests that the word *symptom* may be confusing for the general public.

Providers and patients most frequently mentioned pain as an example of a symptom. Several issues were highlighted by providers and PCFMs concerning the measurement of pain. First, providers noted that it is important to consider multiple types of pain that patients experience beyond physical, such as emotional, existential, psychological, social, and spiritual. Relatedly, 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 affect their experience of pain. Complicating the issue 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.” A third issue with addressing patient pain concerns patients’ expectations about pain control. Providers from three focus groups 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 over which providers might not have complete control in terms of meeting 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). One participant said,

If you didn't tell the provider that you expected that your pain was going to go from a seven to a zero after swallowing the tablet, then you're frustrated because your pain is not managed. But the provider thinks it's managed cause it went from a seven to a three. So the provider feels good, and the patient says, "I thought I was going to be feeling like I felt before this illness came on." I think that's a frequent patient perspective that doesn't get clarified. The patient thinks that they're going to feel like they felt before they had the illness sometimes, and . . . you have to talk through that, cause that's not the way it's going to be.

In addition, providers questioned whether it was fair to be held accountable or rated based on patient symptoms over which they might have little impact.

Providers and PCFMs mentioned both specific symptoms and more global concepts related to symptoms, such as quality of life or overall functional status. Participants in multiple focus groups mentioned additional specific symptoms and global concepts (Table 8.1). Importantly, all providers and PCFMs identified multiple areas where unmet need could be improved and addressed; comments were not limited to only pain or functional status.

**Table 8.1. Specific Symptoms and Global Concepts Mentioned by Providers and PCFMs**

Theme	Provider Focus Group	PCFM Interviews
<i>Specific Symptom or Concern</i>		
Pain	All groups	All interviews
Depression, anxiety, or other mental health	All groups	All interviews
Constipation	>1	
Fatigue	>1	
Nausea	>1	
Shortness of breath	>1	
Sleeping	1	>1
Side effects to medication	1	>1
Consciousness to interact with others	1	1
Essential needs (food, transportation)	1	
Vomiting	1	
Cognitive function		1
<i>Global Concepts</i>		
Quality of life	All groups	All interviews
Full understanding of care	1	>1
Patient goals	1	>1
Functioning despite symptoms	1	
Meaning and purpose in life	1	

PCFMs mentioned significant external challenges that likely contribute to unmet need for symptom management. When interviewing PCFMs, we noted that PCFMs actively wanted to discuss additional issues that had not been addressed. For example, multiple patients mentioned being caught between the provider's recommendations and the insurance company's allowances. When one patient was prescribed a medication, the insurance company refused to cover it, and the patient noted needing to pay over \$10,000 for the medication. This example illustrates a second-order effect in that the patient might have an unmet need for pain because the patient cannot afford the prescribed medication and therefore cannot take it. Providers also noted that they have patients for whom they prescribed an opioid for pain control, but the patient was unable to obtain the medication because of barriers beyond the provider's control. One barrier cited was patients not having a pharmacy within driving distance that stocked the medication. Another barrier was pharmacists behaving in a way that stigmatized patients, either by commenting or counseling the patient that he or she should not take the prescribed medication, or by requiring additional documentation or information on the patient's need for the medication, beyond what is required for a prescription. These barriers contributed to patients having an unmet need despite providers' actions. This example suggests that the behavior(s) being assessed by the data elements on unmet needs must be within the purview of the providers under assessment.

#### Feedback on Example Data Elements Measuring Unmet Need

We showed providers example data elements to prompt discussion regarding the relative strengths and weaknesses of these data elements, and to elicit ideas regarding item wording. Example data elements included "During the last four weeks, did you get the help you wanted from your doctor for your [symptom]?" and "During the last four weeks, did you get as much help with pain as you needed?" Comments were grouped into several themes, described below.

Providers discussed how the item wording or specifics of example data elements would affect the data collected. For example, providers questioned the appropriateness of a 4-week assessment time frame, given that some patients in outpatient palliative care are only seen once every 6 months.

**Referent.** Providers asked whether the data elements should reference a doctor, provider, staff, or team, particularly given the interdisciplinary nature of teams in palliative care settings.

**Focus on "support" and "experience."** Providers preferred the word *support* more than *help* because, for example, providers can provide support to address pain symptoms, but they might not be able to help the patient completely alleviate these symptoms. One issue to consider is whether all support is viewed as assisting unmet needs or whether some types of support—emotional support for symptoms, for example—would not be the right type of support given that unmet need data elements will likely need to focus on support to better manage symptoms. Similarly, focusing on whether patients were satisfied with their experience with their providers as opposed to eliminating suffering was perceived by providers as more within provider control.

**Interference.** Providers from one focus group thought that asking whether pain interfered with the ability to socialize with others was valuable because this also tapped into the “psychosocial component” that patients and providers must address. Interestingly, two focus groups had diametrically opposite perspectives on interference data elements, with the data elements resonating with one group, and the second group feeling that questions focused on interference with daily living were not specific enough.

**What is important to patients?** Providers suggested data elements that ask PCFMs to identify issues of importance to them; for example, “What is the most important thing to you right now?” and “What is the most important thing for us to know about you to provide the best care for you?” so that they can better understand patient needs.

**Global concepts.** Providers mentioned the possibility of focusing questions on more global concepts such as patient goals (“During this clinic visit, did we help you move toward your health goal?”), functional status (eating, walking, being more independent), and quality of life (“Did this clinic visit help to improve your quality-of-life goals?”).

### *Emotional Support*

During PCFM interviews, the theme of emotional support emerged as PCFMs expressed the stress and anxiety of living with their illness, and the need and importance of receiving emotional support from their providers. Though not within the scope of the project’s information-gathering and measure development effort, the prominence of these issues for PCFMs suggested the need for inclusion in this report. We summarize key points below.

#### Understanding and Experience of Emotional Support

In discussing emotional support from their providers, PCFMs described (1) why patients need emotional support, (2) the term *emotional support*, (3) what emotional support consists of, and (4) the importance of palliative providers giving emotional support.

**Why patients need emotional support.** Stress and anxiety were symptoms that were volunteered at all four focus groups and among most PCFMs. Patients expressed their fear of dying and need to communicate to someone about it. Some PCFMs resided alone or away from family members in order to stay with their providers or be able to receive treatment that was only possible within specific states, and thus they did not have a support system. PCFMs described the numerous health-related issues and other associated challenges they faced that added to their stress such as trouble breathing, memory loss, or no longer being able to drive. Not being able to work also resulted in financial hardships that added to daily stresses. One patient noted her loss of confidence, as she once had been a singer and now dealt with lung issues that distorted her voice and made it difficult to project her voice. For these reasons and more, PCFMs emphasized their need for emotional support.

**The term *emotional support*.** PCFMs agreed that emotional support was an appropriate and understandable term for what they were seeking.



**What does emotional support consist of?** When asked what emotional support they wanted to receive, PCFMs reported something as simple as a pat on the back to having someone with whom to communicate about being afraid of death. Patients wanted someone to relieve their fears and treat anxiety, which for some meant being given a prescription. PCFMs sought consolation from their providers when faced with news of prognosis and/or having to begin new treatment plans. PCFMs also emphasized the providers' role in communicating with and supporting families, beyond focus on the patient. They noted that although the patient is often the focus, family caregivers are dealing with a lot of stress in addition to the prospect of losing their loved one. One patient also noted she had a 14-year-old son and how she communicated with her provider about the struggles of raising children while ill.

**Importance of giving emotional support.** PCFMs agreed that they would expect palliative care providers, of all providers, to give emotional support and help them navigate their illnesses. One patient noted the absence of a peer support group in the area by explaining that peers would be dying and constantly turning over, and that a professional would be most valuable to talk to. She elaborated that her care team did not have a social worker or other provider to give this specialized service, but that she received some emotional support from her nurse practitioner.

### *Communication*

We asked focus group and interview participants two primary questions related to communication, and we summarize key findings from those discussions below.

#### **What Does Good Communication Mean to You, and What Does It Look Like?**

Providers and PCFMs described how the approach to communication, content, and tone were key components of good communication between providers or teams and palliative care patients. Participants acknowledged that some surveys, such as some CAHPS surveys, already assess whether patients feel heard and understood. However, participants felt that directly assessing whether PCFMs feel heard and understood is "very, very important" and thought that there was room for improvement in the way this topic is asked about in surveys.

**Approach to communication.** Providers described various positive communication practices related to the concept of feeling heard and understood, including (1) using an active listening approach, where providers iteratively listen and reflect back what was heard from the patient "because that really helps to validate that we've heard them," (2) ending conversations with PCFM by asking, "What other questions do you have?" (3) employing the teach-back method to make sure that the patient understands what he or she needs to do after a visit, (4) establishing the expectation that communication is important between PCFMs and providers, (5) encouraging PCFMs to share their stories or journeys, (6) providing undivided attention during conversations with PCFMs, and (7) following through on promises so that when patients are told that "we're going to call you in two days, [we] call in two days and that makes someone feel like their needs are important." PCFMs mentioned that good communication occurs when

providers listened to the PCFMs even if unrelated to the primary symptoms for which the patient is being treated.

**Communication content.** Providers believed that good communication requires that providers communicate certain key messages to their patients, including (1) explaining to PCFMs the specific roles that providers have; (2) making sure that providers and patients are using terms in the same way so that there is a shared understanding (i.e., do both agree on what constitutes effective pain management?); and (3) focusing on the patient's, not provider's, goal and helping patient try to achieve that goal. PCFMs noted that good communication occurred when they received the needed information (i.e., test results) from a doctor and when the provider "explained all the steps."

**Communication tone.** Providers also mentioned that patients' feelings are influenced by provider-patient communications, which would be reflected by (1) PCFMs viewing the provider as taking his or her concerns seriously, (2) PCFMs feeling respected based on interactions with the provider, (3) providers demonstrating empathy in discussions with PCFMs, and (4) providers being willing to take the time to get to know and develop a relationship with PCFMs to establish a comfort level when it comes time to discuss the more challenging topics such as prognosis or surgery. PCFMs remarked that they appreciated communication from a provider that was positive and where the provider did not act superior to the patient.

Providers also noted barriers that affect good communication, such as not having enough time to talk with PCFMs and cultural barriers where a patient's culture might influence his or her comfort with certain providers (i.e., someone might be more comfortable talking with a nurse as opposed to a social worker). Other barriers to good communication that were raised include mixed messages from the different members of the palliative care interdisciplinary team and across providing teams (e.g., cardiology and palliative care), poor communication within providing teams, and differing understanding across providers and PCFMs of what palliative care encompasses. PCFMs also mentioned dealing with providers who have assumptions about who the patient is or what the patient would want (e.g., an oncologist incorrectly assuming the patient wanted to have chemotherapy). Many providers do not receive formalized training about how to communicate with patients, and this is exacerbated by the lack of protocols and standardization in palliative care.

PCFMs also discussed the value of measuring heard and understood as a concept. Some PCFMs commented that the concept of feeling heard and understood makes sense to measure after a visit. One patient highlighted the importance of the "heard and understood" concept in the patient-provider relationship:

Heard and understood. . . . What does it mean to me? It means everything. If you're not heard, if you're not understood, you might as well walk away and find another doctor, because then . . . you have nothing. That's the basis of . . . the relationship. What's the point [otherwise]? Just so that he can tell you, "Oh, the test was okay." [or] "The test wasn't okay." Well, I need more than that from a doctor.

## What Are PCFM and Provider Reactions to Example Data Elements Measuring Feeling Heard and Understood?

We asked providers to share their thoughts about the strengths and weaknesses of example data elements. Example data elements included “Over the past four weeks, how much have you felt heard and understood by your palliative care team?” and “During the past four weeks, how often did doctors treat you with courtesy and respect?” “During the past four weeks, how often did doctors listen carefully to you?” Providers commented on the following aspects of the data elements:

**Referent.** Similar to the unmet need example data elements, providers questioned whether data elements should reference a doctor, provider, staff, or team. Providers in one focus group said, “Our palliative patients never meet the doctor,” and PCFMs similarly noted that provider or team or staff all make sense when thinking about answering these data elements.

**Time frame.** Providers also questioned whether the 4-week time period is the correct time frame, with suggestions including having no time frame in the question and asking patients when they want to be surveyed.

**Double-barreled nature of the item.** Providers commented on the idea that asking about two constructs—heard and understood—in one question was inherently double barreled. They recommended splitting the data elements out into multiple questions that address the two concepts separately (i.e., “Did you feel listened to?” and “Did you feel understood?”). An additional comment was that a third question was needed about support because that is the “crux” of the issue (i.e., “Did you actually feel supported?”).

**Response choices.** One provider focus group suggested avoiding yes/no types of questions because they are too limited and will miss potential nuances in answers. Conversely, a different provider focus group recommended changing “how much” to “enough” in one of the example data elements so that it reads, “Did you feel heard and understood enough?”

Suggestions for other types of data elements that should be considered to measure heard and understood are located in Appendix F.

### *Implementation Considerations*

In addition to discussing patient-provider communication and unmet needs, both the focus groups and interviews raised important implementation considerations related to assessing patients with serious illness, providing palliative care that meets patient needs, and methods for assessing quality in outpatient palliative care. We categorize our findings into general barriers and facilitators to meeting patient needs and considerations when using a patient-reported survey instrument for quality measurement.

### **Barriers and Facilitators to Meeting Patient Needs**

In general, providers thought that measuring unmet need was important and that such information needs to come directly from a patient. To the latter point, a provider mentioned the

importance of obtaining patient input about unmet needs given that “only the patient can tell us what the unmet need is.” Another provider noted that “providers can be biased about what an unmet need is even though a patient might not perceive it as an unmet need (i.e., living alone).” Both comments illustrate the importance of framing questions in such a way that patients can identify the unmet needs they perceive.

**Barriers.** Providers noted that their patients do not always have access to specific treatments or approaches that might help them (e.g., lack of access to needed medications, alternative therapies, or pain clinics). One area of tension concerns the amount of time that providers can spend with patients given that “if you really want to approach people in that holistic sense in depth, you do need to have low caseloads.” Lack of resources in outpatient clinics makes it difficult to “deliver the palliative care needs without” the team approach that is fundamentally important to palliative care and can be realized in other settings. Other barriers may include different providers conceptualizing unmet need differently, providers trying to address all needs by giving patients an overwhelming amount of information, patient symptoms being dismissed by providers (e.g., patient claims he or she is out of breath and internal medicine provider says oxygenation is sufficient), or a patient disagreeing with the treatment approach and indicating that disagreement on a survey via a negative rating about the experience with the provider.

**Facilitators.** Providers identified several facilitators that allowed them to meet patient needs. First, they noted that having a goals-of-care conversation with patients and sharing the information with the care team allowed multiple providers to develop a comprehensive understanding of the patient and his or her goals. Second, providers with an in-depth understanding of palliative care are able “to look at the disease trajectory . . . really assess and be proactive in managing the patient’s symptoms.” Finally, some providers are accustomed to conducting “very thorough initial assessments” by using a comprehensive assessment approach and/or an interdisciplinary team approach. Relatedly, a participant who was a chaplain mentioned using a “spiritual assessment tool just looking at the spiritual needs of the patients, whether that be family dynamics, whether that’d be legacy issues or . . . end of life . . . or existential crisis.” Thorough assessments can also include understanding important topics not typically covered in some health care situations, such as discussions about dental issues or domestic violence concerns.

### Implementation Considerations

Providers and PCFMs noted three key considerations when assessing quality and experience using patient-reported surveys: mode of administration, accuracy of survey results, and use of proxy respondents. Each of these are discussed below.

**Mode of administration.** Providers and PCFMs shared similar views about the trade-offs between mailing a survey to a patient to complete later versus asking the patient to complete a survey immediately after a clinic visit. Both groups mentioned that email and mail surveys sent to a patient after a visit might result in the patient returning the survey, though low response rates among currently used patient surveys were also mentioned by both groups as a concern. One

suggestion was to provide the patient with a survey in a self-addressed stamped envelope before leaving the clinic so that the patient could complete and mail it back at his or her convenience. Some patients claimed they would want to provide negative feedback immediately and would likely want a day or two prior to providing positive feedback. These patients would not want to provide immediate feedback via a survey in the clinic because of concerns about anonymity and fear of retribution in the care they would receive in the future. Providers were also concerned that patients might feel pressured to provide positive responses if asked to complete a survey before leaving the clinic.

**Accuracy of survey results.** Providers questioned the potential accuracy of survey results, positing that extraneous information (e.g., patient not liking food in an inpatient setting, for example) might affect patients' perceptions about their visit. Providers also thought that patients might see a lot of providers, and this might cause patients to not know which provider to think about when completing a survey. Alternatively, some providers think that patients might rate using a halo effect, where their perception of their main provider is the perception they have about all their providers. There were several patient-focused issues that providers mentioned, such as the health literacy of patients, patients who have dementia, language or culture barriers between provider and patient, and patients with unrealistic expectations about care who might never be satisfied with the care received. Convincing patients to return surveys was raised as a concern, given that providers anticipated low response rates. Providers and patients also mentioned the fear of retribution that patients have, meaning that any critique or negative feedback patients provide might result in worse care they receive from providers. Finally, some providers believed that non-English-speaking patients are less likely to complete surveys, even if they are translated.

**Use of proxy respondents.** We obtained input about issues to consider if administering the survey to family members. One specific wording recommendation was to use the phrase "loved one" instead of "family member" in data elements because the former seems more appropriate. Reaction to surveying family members was mixed, with some providers citing "real value in knowing their [family member] perspective" while others raised concerns about the accuracy of estimates of specific symptoms. For example, in the case of a patient's pain, providers in the focus group suggested that proxy respondents may tend to overestimate a patient's level of pain, and therefore provide worse ratings of providers. Providers also questioned how the correct family member would actually receive the survey to complete. To the latter issue, patients who had a family caregiver largely felt it was appropriate for their caregivers to respond to surveys on their behalf, as these family members go through everything with the patients and understand how to care for them.

## Summary

Focus groups and interviews provided valuable information about both of the measure concepts we sought to understand as well as issues to consider when using surveys. We heard from a wide range of palliative care providers, both in terms of disciplinary background and geographic region. Although we identified a number of crosscutting themes in the focus groups and interviews, PCFM contributions to these themes are based on a relatively small number of respondents. We plan to conduct more qualitative data collection with PCFMs as part of the alpha and beta testing. Below we provide a summary of our findings and discuss related practical implications.

**Unmet symptom needs.** Providers and patients most frequently mentioned pain as an example of a symptom. Providers expressed concern that patients may have difficulty having their needs met for a variety of personal reasons, as well as unrealistic expectations about pain relief. Providers and PCFMs also mentioned other specific symptoms, such as fatigue and cognitive dysfunction. However, because there are fewer effective treatment options for providers to offer patients, these may not be suitable for identifying unmet needs.

Providers encouraged focusing on overall satisfaction with the provider (or team) from the patient perspective or having PCFMs identify the most important issue. It is worth noting that PCFMs (including those with substantial experience with health care providers) did not always understand the word *symptom*, and that PCFMs mentioned nonsymptom issues, such as complex financial needs. Providers also acknowledged other concerns, such as overwhelming patients with too much information as well as patients disagreeing with a treatment approach.

**Emotional support.** PCFM interviewees discussed the need for emotional support from providers to help manage the stress and anxiety of their conditions. Participants agreed that they expected providers—especially palliative care providers—to be able to offer emotional support and help navigating their illness.

**Communication (i.e., heard and understood).** In the focus groups and the interviews, both PCFMs and providers noted that the “heard and understood” concept was valuable as a question to ask and as an outcome in itself. Both providers and PCFMs noted the importance of content, tone, and approach, although patients emphasized content to a greater extent than providers. Neither providers nor patients had clear criteria for appropriate time frames (for eligibility or for PCFM recall), though both groups noted that it would be important to explain the role of each provider, and that communication between the entire team and the patient was important to assess.

**Considerations for implementation.** Providers expressed concern that sending surveys to family members might introduce bias, particularly if family member perceptions were not aligned with patient perceptions (e.g., thinking that pain was undertreated). Providers also expressed concern about attribution given that patients see multiple providers, though this concern may be addressed in testing by including questions that reference an individual