

## **Cancer Care Quality Measures: Symptoms and End-of-Life Care**

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The information in this report is intended to help clinicians, employers, policymakers, and others make informed decisions about the provision of health care services. This report is intended as a reference and not as a substitute for clinical judgment.

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## Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-Based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. This report was requested and funded by the Centers for Disease Control and Prevention (CDC), the Centers for Medicare & Medicaid Services (CMS), and the National Cancer Institute (NCI). The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

To bring the broadest range of experts into the development of evidence reports and health technology assessments, AHRQ encourages the EPCs to form partnerships and enter into collaborations with other medical and research organizations. The EPCs work with these partner organizations to ensure that the evidence reports and technology assessments they produce will become building blocks for health care quality improvement projects throughout the Nation. The reports undergo peer review prior to their release.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

We welcome comments on this evidence report. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by e-mail to [epc@ahrq.gov](mailto:epc@ahrq.gov).

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# Structured Abstract

**Objectives.** To systematically identify quality measures and the evidence for them— to support quality assessment and improvement in the palliative care of patients with cancer in the areas of pain, dyspnea, depression, and advance care planning (ACP), and to identify important gaps in related research.

**Data Sources.** MEDLINE<sup>®</sup>, CINAHL<sup>®</sup>, and PsycINFO<sup>®</sup> in English 1995-2005. We also conducted an extensive Internet search of professional organizations seeking guidelines and other grey literature (i.e., not published in peer-reviewed journals) using similar terms and attempted to contact all measure developers.

**Review Methods.** We searched using terms for each domain for patients (adults and children) with a cancer diagnosis throughout the continuum of care (e.g., diagnosis to death). Pain and depression searches were limited to cancer, but we searched broadly for dyspnea and ACP, because the evidence base for dyspnea is more limited and experts advised that ACP measures would be generalizable to cancer. Measures were included if they expressed a normative relationship to quality and included a measurable numerator and denominator. Citations and articles were each reviewed/abstracted by two of six palliative care researcher/clinicians who described populations, testing, and attributes for each measure.

**Results.** The literature search identified 5,187 titles, of which 4,650 were excluded at abstract review. Of 537 articles, only 25 contained measures: 21 on ACP, 4 on depression, 2 on dyspnea, and 12 on pain. Ten relevant measure sets were identified: ACOVE, QA Tools, Cancer Care Ontario, Cancer Care Nova Scotia, Dana-Farber, Georgia Cancer Coalition, University Health Consortium, NHPCO, VHA, and ASCO. We identified a total of 40 operationalized and 19 non-operationalized measures. The most measures were available for pain (12) and ACP (21), compared with only 4 for depression and 2 for dyspnea. Few of the measures were published, and few had been specifically tested in a cancer population.

**Conclusions.** A large number of measures are available for addressing palliative cancer care, but testing them in relevant populations is urgently needed. No measures or indicators were available to evaluate the quality of supportive pediatric cancer care. Basic research is urgently needed to address measurement in populations with impaired self-report. Funding field testing of highest quality measures should be an urgent patient and family-centered priority to meet the needs of patients with cancer.



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# Executive Summary

## Overview

Cancer is a common, costly problem that affects many Americans and their families. Approximately 9.6 million Americans who were alive in January 2000 were estimated to be living with a previous diagnosis of cancer, and approximately 1.4 million cases of cancer were diagnosed in 2004. Direct medical expenditures on cancer exceeded \$180 billion in 2000. The most common malignancies include lung, breast, colorectal, and prostate, for which 2003 estimates of 5-year survival rates varied from 15% (lung) to 99% (prostate).

Cancer imposes its burdens from diagnosis to death, and even survivors live with substantial impairments; therefore, supportive care is an important consideration of all phases of management. Supportive care addresses the direct and treatment-related impacts of cancer including, pain, and symptom management; the psychosocial context, including spirituality; and caregiving. Supportive approaches focus on assisting patients and caregivers to maximize well-being and can ameliorate many of the debilitating consequences of living with a cancer diagnosis, regardless of cancer stage. As early diagnosis and more effective treatment extend the experience of living with cancer, seamless integration of supportive principles and approaches becomes even more imperative.

In spite of the prevalence of cancer and its enormous costs, little effort has been made to systematize the assessment of the quality of palliative cancer care. AHRQ and a collaborative of Federal Partners, including the Centers for Disease Control and Prevention (CDC), the Centers for Medicare & Medicaid Services (CMS), and the National Cancer Institute (NCI), requested a systematic review of quality measures for supportive cancer care. This report, prepared by the Southern California Evidence-Based Practice Center, is intended to assist the National Quality Forum (NQF) by describing quality measures in the areas of pain, dyspnea, depression, and advance care planning (ACP) and to identify priorities for a quality measurement research agenda.

## Reporting the Evidence

This report addressed the following questions:

- 1. What quality-of-care measures are available and what evidence supports those measures to assess pain, depression, dyspnea, and advance care planning for patients with cancer, including:**
  - a. Patient assessment,**
  - b. Intervention and appropriate management, and**
  - c. Timeliness and effectiveness of intervention.**
  
- 2. What gaps in knowledge about quality measurement are evident from the currently available literature, including absence of measures or measures lacking evidence of their scientific soundness, whether for the population of cancer patients as a whole or for specific subpopulations?**

## **Methodology**

In consultation with the AHRQ Task Order Officer (TOO) and the NQF, we created a Technical Expert Panel (TEP) of leading scientists and clinicians with expertise in oncology and palliative medicine and a broad knowledge of research and policy issues in the field of oncology and palliative care in the United States to guide the evidence report. Project staff worked closely with AHRQ, NQF, and the TEP to refine the research questions and focus on the relevant outcomes. Drs. Karl Lorenz and Joanne Lynn met with the NQF and members of their Steering Committee in December 2004 to discuss the task order question and plans for the systematic review.

Originally, Question 1 specified focusing on “measures to assess pain, depression, distress, and advance care planning.” However, the Committee indicated that distress had been incorporated in order to address broad psychosocial and spiritual concerns. However, the group expressed concerns relative to the feasibility of conducting a systematic review of distress. They also agreed that the broader spiritual and psychosocial concerns could be taken into account in conducting the literature review of depression measures. Because dyspnea is an important symptom among cancer patients and a recent systematic review found promising evidence related to its treatment, the Committee recommended that RAND should add dyspnea as a topic. After consulting with the AHRQ Task Order Officer, the review team agreed to focus on pain, depression, dyspnea, and advance care planning.

The first of a series of calls was held on February 9, 2005 with our TOO and the TEP. An important issue that arose for discussion during our initial conference call with the TOO and TEP in February 2005 was the extent to which searches should be restricted to cancer. Limiting the search logic to cancer provided an extremely limited number of references, particularly for ACP and dyspnea quality measures. Our TEP advised that measures that were applied to the care of symptoms and advance planning in other disease states would also be relevant to cancer; thus, for those two topics, we broadened the search to include conditions other than cancer. However, because our initial searches indicated that the literature on pain and depression was extensive, we restricted our review of these citations to cancer only.

### **Literature Search and Review**

We searched MEDLINE<sup>®</sup>, CINAHL<sup>®</sup>, and PsycINFO<sup>®</sup> for English language literature (January 1995 - February 2005) using terms for pain, dyspnea, depression, and ACP combined with terms for cancer, quality assessment or improvement, and palliative care. Because our previous experience identified limitations in the indexing of quality measures in scientific databases, we used pre-specified terms to search the Internet for evidence-based standards or quality measures that had been developed by healthcare organizations or specialty societies. (February to March 2005). We directly contacted developers of all measures or measure sets we identified and sought additional information using a ‘contact form.’

### **Study Selection and Abstraction**

Six reviewers, with clinical backgrounds in internal medicine and nursing, and research careers in palliative care, organized into four teams by domain, each reviewed documents

independently, resolving disagreement by consensus. We applied the following inclusion and exclusion criteria at both the title/abstract and article screening phases. Study reports or other documents were accepted only if they contained either indicators or measures. An *indicator* was defined as “a descriptive statement with a normative relationship to quality that includes a numerator and denominator and that is expressed as a measurable standard.” A *measure* is an indicator fully specified for measurement, including data elements, the data collection approach, data sources, analysis, and presentation.

Documents were excluded if they:

- Were non-Western (i.e., not United States, Canada, Australia, New Zealand, Great Britain, or European),
- Were published in a non-English language,
- Focused exclusively on a disease other than cancer UNLESS they were on the topic of pain or depression, or
- Focused on cancer but considered only a topic other than ACP, depression, dyspnea, or pain,
- Addressed only specific types of cancer and/or processes of care that were not generalizable across the most common cancer conditions (e.g., particular pain syndromes for tumor subtypes),
- Guidelines were excluded if they did not contain any description of their methods or how they were developed.

For the domains of pain and depression, if a measure or indicator was developed for populations (e.g., hospice) that generally include cancer patients, but the development or field testing for the indicator did not explicitly include cancer patients, we did not exclude the document or citation.

Articles accepted at the screening stage were subjected to full abstraction using standardized forms. Some studies or documents described only indicator or measure development, whereas others described testing or use in an actual population. Detailed information on the attributes of these tools was abstracted.

## The Report

In general, the review was organized around fundamental domains of symptom management—assessment, treatment, and follow-up. Assessment includes all activities related to evaluating the presence of a symptom. Treatment includes all activities subsequent to identification related to mitigating the symptom. Follow-up includes re-assessment and/or re-treatment of the symptom. For consistency, ACP was also organized around these domains since they are reasonably analogous, although for ACP, the task of ‘assessment’ is to evaluate goals

and preferences, ‘treatment’ is the application of advance care plans, and ‘follow-up’ refers to actual implementation.

## **Peer Review**

We received comments from eight peer reviewers and eleven TEP members who reviewed our draft report. We compiled the comments and made appropriate changes to the report.

# **Findings**

## **Literature Review**

The literature search identified 4,580 titles. We identified an additional 389 articles from the database we had assembled for a systematic review of research on *End-of-Life Care and Outcomes*. Our web search identified 105 guidelines. An additional 109 articles were suggested from by the project members. Four additional articles were suggested by our TEP upon review of the draft version of this evidence report. In total, the RAND reviewers examined 5,187 titles.

Of the 5,187 possibly relevant titles, 4,599 were excluded at abstract review, leaving 588. Repeat review by one principal investigator (KL) excluded an additional 51 titles, leaving 537 reports and guidelines.

Of the 537 articles ordered, we retrieved 536 prior to the cut-off date (June 10, 2005). Screening resulted in the exclusion of 485 articles: 347 included no indicator; 113 had no domain of interest; 8 considered a disease other than cancer; 5 were guidelines with no methods; 6 originated in a non-Western location; 2 presented duplicate data; 2 were duplicate articles; and 2 were useful for background only.

Of the remaining 51 articles, 25 that contained measures and/or indicators and described their methods were reviewed in detail. Potential indicators were identified by each team based on their working knowledge of research literature and prioritized based on each team’s opinion of the most important gaps in measurement. The remaining 26 articles contained only potential indicators. As one article can report on multiple topics and may include multiple measures and/or indicators/potential indicators the numbers in the domain boxes in Figure 1 represent the numbers of measures, indicators or potential indicators that were abstracted into the Evidence Tables and not the actual number of articles.

## **Pain - Measures and Indicators**

This category addressed the general conceptual areas of pain assessment (five measures, two indicators) with numeric or nonspecific scales; treatment (two measures, two indicators), including timely intervention; side effect/constipation prophylaxis; radiotherapy; and follow-up (four measures, one indicator) including timely relief, satisfaction, and degree of relief (Table 2). Assessment measures and indicators specifically focused on cancer addressed routine pain assessment using numeric or non-specific scales in inpatient, intensive care, outpatient, and unspecified settings.

## **Dyspnea - Measures and Indicators**

Dyspnea measures and indicators addressed the general conceptual areas of routine assessment (one measure) with a numeric scale; treatment (three indicators), which included any treatment, terminal treatment, and addressing hypoxia; and follow-up (one measure), addressing timely relief.

## **Depression - Measures and Indicators**

Depression measures and indicators addressed the general conceptual areas of assessment (one measure, one indicator), including psychosocial, spiritual assessment, treatment (two measures) including regular assessment or treatment.

## **ACP - Measures and Indicators**

ACP measures and indicators addressed the general conceptual areas of assessment (1 measures, 4 indicators), including surrogate identification, preference evaluation, patient/family participation, and timely planning; ACP application (2 measures), addressing documentation across venues and evaluation of specific life sustaining preferences; and ACP follow-up (10 measures, 1 indicators), which addressed preference-treatment consistency, hospice admission, late life utilization of hospital or intensive care settings, emergency care, and chemotherapy.

## **Recommendations for Future Research**

We identified priorities for future research in a number of important areas:

### **Field Testing in Relevant Populations**

Many of the measures may be useful now for local quality assessment and improvement, but most measures lack even basic published evidence of reliability and validity. Before these measures are deployed at higher levels of the health care system, information about their ability to discriminate quality performance and responsiveness to change will be required. Furthermore, health care systems must consider the cost and feasibility of data collection and must be assured that measures are at low risk for perverse incentives and that they can provide timely feedback.

### **The Need for Measures To Address Impaired Self-Report**

None of the indicators address how to evaluate symptoms among individuals with impaired self-report, which can be due to either temporary (e.g., delirium) or durable factors (e.g., dementia, brain metastasis). There is no doubt that delirium is common among cancer patients, although its incidence and prevalence are not well studied. Some recent reports noted a prevalence of 18-50% among patients with cancer in general, and observed rates are even higher in certain treatment settings such as the intensive care unit or the nursing home, where almost 60% of the population is also living with dementia.

## **The Lack of Pediatric Measures**

We noted the complete absence of pediatric measures or indicators. Cancer represents the second leading cause of death among children ages 5 to 15 in the United States, and serious deficiencies in the care of pediatric cancer cases have been noted. It is insufficient to propose that adult measures or indicators could simply be adopted for pediatric care, as the kinds of disease, challenges of symptom reporting and intervention, and basic approach to care differ so significantly between pediatric and adult oncology care.

## **Defining the “End-of-Life”**

The lack of consensus on definitions of “end-of-life” presents what has been called the “denominator” problem. Many of the indicators define end-of-life retrospectively (e.g., last six months of life). This definition does not provide guidance on important clinical service, and retrospective analyses may introduce a number of biases, since the timing of death is often not predictable. Prospective indicators would account for patient preferences but will require methodological work to define which cancer patients (those with certain types that are usually fatal, those at advanced stage) should be in the denominator.

## **The Publication Gap for Quality Measurement**

An important finding of our report was that much of the evidence on the measures that we identified was unpublished. Additional information that might be available to inform the evidence base for these measures was likely collected by non-academic organizations and is probably unpublished. Much of the actual experience with measures and measurement has probably been reported in an anecdotal rather than an archival form. Those who conduct future systematic reviews should be aware of this important issue and make an explicit effort to capture this unpublished information. Methods for systematically compiling and analyzing this type of data might help to improve the evidence base for quality measurement.

## **Strengthening Quality Measurement of Depression in Cancer**

Given the recognized prevalence of depression among cancer patients, surprisingly few indicators have been evaluated depression in cancer. Indicators developed for other settings may be appropriate but have not been tested in this population. For late-stage disease, more fundamental clinical research is needed, for example to assess the optimal approach to screening and the usefulness of short term treatment.

## **Building an Evidence Base To Compare Population Subgroups**

We found insufficient evidence to comment on population differences. An important priority for future research is evaluating measures in important sub-populations (e.g., those that differ by race/ethnicity, language, or gender). It is also important to define subgroups of cancer by stage of illness and to understand the performance of indicators among major subgroups, including

disease type and settings of care. Fewer indicators are available for outpatient than for inpatient care evaluation, even though the majority of patient care over time occurs in the outpatient setting.





# **EVIDENCE REPORT**



# Chapter 1. Introduction

Cancer is a common and costly problem that affects many Americans, their families, and their caregivers, since many are affected by a cancer diagnosis. Approximately 9.6 million Americans who were alive in January 2000 were living with a diagnosis of cancer, and approximately 1.4 million new cases of cancer were diagnosed in 2004.<sup>1</sup> The most recent estimate of lifetime risk suggests that males have an approximately one in two risk and women a one in three risk of developing cancer.<sup>1</sup> Direct medical expenditures on cancer exceeded \$180 billion in 2000. The costs of care are concentrated in the time just following diagnosis and the last few months before death, with about one-third of expenditures in the final year.<sup>2</sup> The most common malignancies include lung, breast, colorectal, and prostate, for which 2003 estimates of 5-year survival rates varied from 15% (lung) to 99% (prostate).<sup>3</sup>

In spite of the prevalence of cancer and its enormous personal and societal costs, little effort has been made to systematize the assessment of the quality of palliative cancer care. In 2004, the Agency for Healthcare Research and Quality requested a systematic review of quality measures for supportive cancer care in the areas of pain, dyspnea, depression, and advance care planning (ACP). AHRQ and a collaborative of Federal Partners, including the Centers for Disease Control and Prevention (CDC), the Centers for Medicare & Medicaid Services (CMS), and the National Cancer Institute (NCI), sponsored the report in order to assist the National Quality Forum (NQF) by identifying and describing quality measures for supportive cancer care including the evidence that they are ready or nearly ready for incorporation into routine clinical practice. An additional purpose of this report was to identify gaps in measurement that could be the basis for a quality measurement research agenda, including areas in which no measures exist, or in which measures exist but for which additional evidence is needed.

## Supportive Care and the Cancer Continuum

Cancer imposes its burdens on patients and caregivers from diagnosis to death, and even long-term survivors often live with substantial impairments. Supportive care addresses the direct and treatment-related impacts of cancer, pain and symptom management and the psychosocial context, including spirituality and the challenges of caregiving; it is important in all phases of cancer care. Symptoms may prompt (e.g., dyspnea) or be precipitated by (e.g., depression) the diagnosis of cancer, and treatment and progressive illness typically impose substantial symptomatic burdens. Some common cancers are diagnosed at a late stage: Only 16% of lung cancer cases are localized at the time of diagnosis.<sup>1</sup> Supportive approaches focus on assisting patients and caregivers to maximize well-being and can ameliorate many of the debilitating consequences of living with a cancer diagnosis, regardless of cancer stage.<sup>4-6</sup> As early diagnosis and more effective treatment extend the experience of living with cancer, seamless integration of supportive principles and approaches becomes even more imperative.

Pain is one of the most common symptoms in patients with cancer and is often inadequately treated when measured by patient or staff perceptions, particularly in vulnerable subgroups.<sup>7-9</sup> Cancer pain can result from direct primary or metastatic tumor involvement, including bone and neurologic pain; from diagnostic interventions; and as a side effect of chemotherapy or radiation therapy.<sup>7</sup> One-third to one-half of patients in active treatment, and three quarters of patients with advanced cancer experience pain.<sup>10</sup> Chronic pain also may be a component of cancer

survivorship, and many patients with cancer also have pain due to unrelated causes. Many studies have documented that pain is often inadequately treated, and the quality of treatment varies widely among centers.<sup>8</sup> Racial and ethnic disparities in pain assessment and management have been described.<sup>11</sup>

Dyspnea is an unpleasant, distressing, and common experience among cancer patients: over half of cancer patients experience significant shortness of breath.<sup>12-18</sup> In the final months and days of life with cancer, rates of dyspnea range from 60% to 90%, with the symptom especially prominent in those with lung cancer.<sup>13-16,19</sup> For example, 87% of 673 patients with stage III or IV non-small cell lung cancer reported dyspnea.<sup>19</sup> Numerous etiologies for dyspnea exist in cancer, including pulmonary or pleural metastasis, anemia, and muscular weakness. Despite the prevalence of dyspnea among cancer patients, the majority of dyspnea research has been conducted in patients with chronic pulmonary conditions.<sup>13,20,21</sup> However, a promising evidence base supports assessment and interventions to improve the experience of cancer patients with dyspnea.<sup>21</sup>

Depression has received increasing attention as a cause of distress or suffering in patients living with cancer.<sup>10</sup> Studies suggest that around one quarter of cancer patients experience depression during the course of their care.<sup>10</sup> Depressive symptoms often accompany the diagnosis of cancer,<sup>22</sup> and depression is strongly associated with other symptoms—such as pain—that may fluctuate in severity over the course of cancer treatment.<sup>10</sup> Depressive symptoms accompany patient and caregiver experiences throughout all stages of cancer care, including wrestling with treatment disappointments, the complications of therapy and of cancer itself, and progressive illness. Evidence has demonstrated an important relationship between depression and spiritual or existential well-being, especially related to how patients and caregivers maintain hope along the trajectory of the cancer experience.<sup>23-26</sup>

Another important area of consideration regarding cancer care is ACP. Early on, the emphasis in ACP was on legal initiatives, “living wills,” and other similar documentation; however, over time, the concept has broadened to emphasize a process of effective communication and planning ahead to shape an appropriate course of care.<sup>27</sup> Now, high quality practice includes ACP for a number of reasons: to allow patients to shape care to their preferences, to avoid imposition of unwanted treatment in urgent situations, to relieve patient and family anxiety, and to ensure availability of the specific practical arrangements that will allow the patient to have optimal care, on his or her own terms. Cancer treatment commonly requires potentially difficult interventions such as chemotherapy or surgery. The utilization of high intensity care such as hospitalization, particularly in an ICU, varies significantly among elderly cancer patients, without a clear relationship to patient-centered outcomes.<sup>28-30</sup> Because of the emphasis on documentation of choices among a narrow set of treatment preferences, research on this topic emphasizes outcomes related to health care utilization generally or the actual use of particular services.<sup>21</sup> However, informed consent and self-determination are cardinal ethical principles, and self-determination is endorsed by both patients and caregivers as an important value in late life care.<sup>31</sup> Furthermore, planning ahead allows deliberate forgoing of undesired care.

## Summary

Supportive care emphasizes treatment to minimize symptoms and enhance patient and caregiver well-being and is relevant across the trajectory of cancer care, from diagnosis and initial treatment to chronic progressive illness and the end-of-life. Palliative care is a term that is sometimes used interchangeably with the term supportive care, except that palliative care generally refers to a focus on care for patients in more-advanced stages of illness. Pain, dyspnea, depression, and ACP are common, high impact concerns to be considered as targets for quality assessment and improvement. All of these areas represent problems that affect many patients receiving care for common malignancies, although the importance of particular symptoms varies among major cancers and throughout the illness trajectory. Pain, dyspnea, and depression, and ACP represent areas in which substantial initial research has begun to define the scope of the challenges and effective interventions for patients with cancer. ACP is relevant to all phases of cancer, as potentially difficult treatments may be employed, and effective communication is always important to cancer patients and their caregivers.



# Chapter 2. Methods

## Final Task Order Questions

The Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), and the National Cancer Institute (NCI) requested this systematic review. They also requested that the review be available in time for review by the National Quality Forum's (NQF) Steering Committee in September 2005. The following key questions were addressed in the response to the Request for Task Order (RFTO):

- 1. What quality-of-care measures are available and what evidence supports those measures to assess pain, dyspnea, depression, and advanced care planning for patients with cancer, including:**
  - a. Patient assessment,**
  - b. Intervention and appropriate management, and**
  - c. Timeliness and effectiveness of intervention.**
  
- 2. What gaps in knowledge about quality measurement are evident from the currently available literature, including absence of measures or measures lacking evidence of their scientific soundness whether for the population of cancer patients as a whole or for specific subpopulations?**

## Overview

In order to accomplish the tasks as directed, we assembled a team of clinical and methodological experts and staff who worked closely with the directors and staff of the Southern California Evidence Based Practice Center (SCEPC). Dr. Karl Lorenz led the day-to-day work of the review and writing teams with the close assistance and regular involvement of Drs. Joanne Lynn, Paul Shekelle, and Sally Morton. Our team included six literature reviewers (with Dr. Lorenz) with experience and expertise in palliative care and with diverse clinical training and experience, including an oncology nurse, one intensivist, and two general internist/palliative care physicians. The reviewers were trained and experienced in the critical analysis of scientific literature and had conducted a systematic review of palliative care in December 2004.<sup>21</sup>

The entire team met weekly to review and refine the methodology of the task order. Meetings and teleconferences of the SCEPC staff with the TEP helped specify issues central to this report within the framework of the key questions. The SCEPC conducted a comprehensive search of the medical literature to identify studies that addressed the key questions. Staff conducted an extensive search for grey (unpublished) literature, including a Web search; reviewed relevant articles; contacted quality-of-care measure developers; compiled tables of measures; appraised the methodological validity of studies and measures; and summarized the results.



## Technical Expert Panel and Approach to the Report

In consultation with the AHRQ Task Order Officer (TOO) and the NQF, we created a Technical Expert Panel (TEP) to guide the evidence report. We invited a multidisciplinary group of leading scientists and clinicians with expertise in oncology and palliative medicine and a broad knowledge of research and policy issues in the field of oncology and palliative care in the United States to participate. The list of potential technical experts and their curriculum vitae were submitted to the Task Order Officer for approval, and the final list of members is included in Appendix A\*.

Project staff worked closely with AHRQ, NQF, and the TEP to refine the research questions and focus on the relevant outcomes in the topic areas. Drs. Karl Lorenz and Joanne Lynn met with the NQF and members of the NQF Steering in December 2004 to discuss the task order question and plans for the systematic review. At that initial meeting, the specific domains that were the focus of the task order and the task order questions were discussed at length and finalized.

The first of a series of teleconferences was held on February 9, 2005 with our TOO and the TEP. In preparation for the call, we conducted a series of exploratory MESH-based literature searches for each of the domains. We also conducted an initial Web-based search for grey literature, including important guidelines and recommendations of major specialty societies. We solicited the TEP's knowledge about the relative strengths and weaknesses of the evidence base for quality measures in the domains of interest and asked them to complete a worksheet listing existing measures and important sources, as well as priorities for improving quality measurement (Appendix B\*).

An important issue that arose for discussion with our TEP was the extent to which our searches should be restricted to cancer. Although the purpose of the systematic review was to provide measures for improving palliative cancer care, restricting the search logic to cancer would severely limit the number of pertinent references, particularly for ACP and dyspnea quality measures. Furthermore, our TEP advised that measures of the care of symptoms and advance planning in other disease states would also be applicable to patients with cancer and should be considered in the systematic review, as they would likely be useful to the NQF Committee.

During the call, we reviewed terms, logic, and results of our initial searches. We finalized our formal literature (Appendix C\*) and Web searches and finalized the list of organizations from which we would attempt to retrieve guidelines and other relevant information. Because our initial searches indicated that the literature on pain and depression was relatively extensive, we restricted our review of these citations to cancer only, because of resource limitations. However, for the topics of dyspnea and ACP, we followed our TEP's advice and in consultation with our TOO, broadened the search to include conditions other than cancer. We limited our search to the past decade because our experience with this topic suggested that most of the relevant research would be relatively recent based on typical progress in medical knowledge.<sup>21</sup> Although the task order specified limiting the review to US measures only, we decided to include all English-language sources in the systematic review and to highlight the origin of particular measures in our report.

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>

## Analytic Framework

According to the model of Donabedian, the evaluation of quality of care includes structure, process, and outcomes.<sup>32</sup> Structural measures focus on the capacity of the health care delivery system and depend upon demonstrating a relationship between structure and the health outcomes of interest, which is often difficult to establish. Process-of-care measures evaluate whether providers deliver the appropriate service for the patient's presenting condition. Outcome measures directly assess relevant effects of care on the patient (or possibly, in the case of palliative care, the caregiver). Focusing on either processes or outcomes alone has both advantages and disadvantages.

Compared with outcomes, processes are more numerous (thus providing more measurement options), they are more directly attributable to the health care system rather than the patient, and the performance of some processes can be measured in routine health care records or data. When processes are selected for quality monitoring, they should exhibit a strong relationship to outcomes. Even when outcomes are satisfactory, inadequate processes of care can reflect problems with health care provision.

In contrast, outcomes provide direct insight into relevant effects of care, but they can be difficult to measure, especially in frail or very sick patients, they may not be routinely measured in health care encounters, and they are affected by the individual patient's health status and comorbidities. Thus, outcomes must typically be risk-adjusted, but adjusting for patient characteristics can be difficult. In addition, the low frequency of serious adverse events requires large sample sizes. The task order directed us to focus our attention on process measures, because they would be most relevant to NQF's concerns. Thus, our review and discussion emphasize process measures; however, for the sake of completeness, our report also includes outcome measures.

### **Processes Relevant to Symptom Care and Advance Care Planning Quality Measurement**

We organized the review in general around three domains of care that are fundamental to symptom management – assessment, treatment, and follow-up (Table 1). Assessment includes all activities related to measuring or evaluating the presence of a symptom in a patient. Treatment includes all activities (including distinct concurrent or stepwise activities such as medication and counseling) subsequent to identification that are related to mitigating the symptom. Follow-up includes re-assessment and/or re-treatment of the initial symptom. We organized our review of ACP around these same domains for clarity since they are reasonably analogous, although “assessment” becomes evaluation of goals and preferences, “treatment” is the application of advance care plans, and “follow-up” refers to actual implementation.

Both symptom management and ACP fundamentally begin with the patient's own symptom description. Thus, assessing self-report ability is a fundamental process to be considered for quality measurement and has important implications for denominator determinations in these domains. Patients who are impaired in this regard may need to “opt-out” of measures, or providers may need to seek alternative measures that are appropriate for them. Symptoms are “subjective evidence of disease,”<sup>33</sup> and ACP requires eliciting the patient's values and care preferences. Our review included both adults and children, and self-reports may be impossible

for very sick or very young individuals. Pediatric assessment must be developmentally appropriate.<sup>34</sup> Adults may experience a variety of sensory or expressive impairments, most commonly dementia in the elderly, that interfere with self-expression. Surrogate reporting is essential for symptom assessment in young children and adults with impairments; and designation of a surrogate for decision-making and care planning are critical for ACP.

Symptom management begins with addressing the presence of the symptom, as well as frequency, severity, and bother or functional impact.<sup>35,36</sup> Specific historical, physical examination, and technical diagnostic tests are employed in searching for specific etiologies.<sup>37</sup> Treatment must consider targeting specific etiologies as well as relieving symptoms alone. Pursuing specific symptom etiologies involves tradeoffs in the burden for patients, even when those etiologies are identified. Therefore, measuring the quality of symptom care may need to include patients' right to "opt-out" among care preferences as well as considering the contraindications for certain supportive care diagnostic or treatment algorithms.<sup>38</sup> Some treatments for dyspnea such as supplemental oxygen, may be relatively easy to arrange and tolerate, but others such as pulmonary stenting are more challenging. For that reason, the phase of illness and preferences may moderate decisions about appropriate diagnostic testing or the specific etiologic treatment.<sup>39</sup>

Differences in the time course of symptom occurrence and treatment, as well as the side effect profile of therapies, offer considerations for quality measurement. Some symptoms fluctuate over brief intervals, and the reliability and validity of measurement vary with patients' cognitive ability and the length of the retrospective lookback.<sup>40</sup> Chronologic considerations also affect appropriate follow-up intervals. For example, pain and dyspnea may fluctuate over short periods; whereas, depression is typically a more durable symptom. However, depression also varies with other physical symptoms (e.g., pain), and transient mood states are common in cancer.<sup>7,41</sup> The frequency with which these effects influence measurement varies with the treatment setting. Although follow-up of the symptom depends on both chronological variability in the symptom and expected timing of responses to treatment, the side effects of treatment may be experienced before the benefits. High quality care includes prophylaxis for some side effects (e.g., constipation with opioids); whereas, other effects (e.g., sedation with opioids) require timely monitoring and supportive care until they abate.

Measures of ACP as a component of quality care may reflect a variety of processes or steps that are necessary in focusing on the most crucial medical decisions that are likely to confront the patient and the process of considering alternative care approaches. Measurement may need to account for the patient's changing clinical status, because preferences about treatments fluctuate over time.<sup>42, 43</sup> An important consideration for culturally sensitive care is whether or not care planning begins with an assessment of informational preferences and how others should participate in decisions. Elements of care planning include prediction of the clinical situation or prognostication, awareness of alternative treatment plans, eliciting preferences through clear communication, including key decisionmakers, and synthesizing preferences and alternatives. Advance care plans must be available to medical providers when patients need them and through important transitions in care. Ultimately, care plans should be reflected in the actual medical treatment a patient receives.

**Table 1: Processes potentially relevant to symptom care and advance care planning**

	<b>Symptom Management</b>	<b>Advance Care Planning</b>
<b>Assessment</b>		
	Evaluation of self-report capacity; determination of severity, frequency, bother/functional impact; history, physical examination, and diagnostic testing; preferences for evaluation and treatment including desired level of relief; consideration of specific etiologies.	Evaluation of self-report capacity; evaluation of information preferences and caregiver(s) involvement.
<b>Treatment (or “Application” of Advance Care Planning)</b>		
	Specific etiologic treatment(s); symptom-guided treatment; patient education including information about side effects; prophylaxis of side effects.	Clear communication; prognostication of patient’s clinical situation and potential clinical scenarios; provision of information about alternative choices; elicitation of patient and/or surrogate values and preferences; appropriate documentation.
<b>Follow-up</b>		
	Timely follow-up of symptom changes and side effect manifestations; treatment adjustment; appropriate care for complications of therapy.	Availability of preferences to other providers, and across settings; implementation of preferences to actual care delivered; re-assessment with notable changes in clinical context.

## **Evidence Sources and Searches**

### **Literature Searches**

Sources for our review included MEDLINE<sup>®</sup>, the Cumulative Index to Nursing & Allied Health Literature (CINAHL<sup>®</sup>) database, and PsycINFO.<sup>®</sup> The RAND Library staff performed the searches. Members of the project team worked closely with the TEP and the librarians to refine the search strategy. We limited the searches to articles published in the English language, appearing in journals between the years 1995 and 2005, involving human subjects, and excluding

individual case reports. We limited our search to the past decade because our prior experience demonstrated that most of the progress in the science of supportive or palliative care was limited to that period.

The main search strategy included an extensive list of terms intended to identify all research publications associated with all of the following:

- Each of the domains of interest (pain, dyspnea, depression, and advance care planning)
- Quality assessment or improvement
- Quality measurement

As described above, searches for pain and depression were limited with terms related to cancer. Searches for dyspnea and ACP were not limited with cancer-specific terms. We searched both the adult and pediatric cancer literature. We also searched “related articles” (e.g., using similar articles linked by MEDLINE<sup>®</sup>) for citations that described using measures within the Assessing Care of the Vulnerable Elders (ACOVE) measure set that were likely to meet our criteria. All of these searches were conducted during February 2005. The search strategies can be found in Appendix C\*.

## **Grey Literature - Internet Search**

Because of limitations in the indexing of quality measures in traditional scientific databases, we employed a number of additional search strategies. We sought to identify guidelines that would point to recommended evidence-based standards of practice or specific quality measures that had been developed by health care organizations or specialty societies. Most of these searches involved the Internet. First, we used the National Guideline Clearinghouse ([www.guidelines.gov](http://www.guidelines.gov)) and the National Quality Measures Clearinghouse (<http://www.qualitymeasures.ahrq.gov/>) to identify guidelines and indicators that fit our criteria. In addition, we accessed the websites of specific professional societies, disease societies, medical organizations, medical associations, and patient advocacy groups to search for any relevant guidelines or measures, as follows:

- ASCO (American Society of Clinical Oncology) - [www.asco.org](http://www.asco.org)
- European Society for Medical Oncology - [www.esmo.org](http://www.esmo.org)
- Canadian Cancer Society - [http://www.cancer.ca/ccs/internet/frontdoor/0,,3172\\_\\_\\_langId-en,00.html](http://www.cancer.ca/ccs/internet/frontdoor/0,,3172___langId-en,00.html)
- Canadian Association of Psychosocial Oncology - <http://www.capo.ca/eng/index.asp>
- ONS (Oncology Nursing Society) - [www.ons.org/evidence](http://www.ons.org/evidence)

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>

- Canadian Association of Nurses in Oncology - <http://www.cos.ca/cano/web/en/index.html>
- American Cancer Society - <http://www.cancer.org/docroot/home/index.asp>
- AAHPM (American Academy of Hospice and Palliative Medicine) - [www.aahpm.org](http://www.aahpm.org)
- NHPCO (National Hospice and Palliative Care Organization) - [www.nhpco.org](http://www.nhpco.org)
- EAPC (European Association of Palliative Care) - [www.eapcnet.org](http://www.eapcnet.org)
- PCA (Palliative Care Australia) - [www.pallcare.org.au/](http://www.pallcare.org.au/)
- Canadian Palliative Care Association - <http://www.chpca.net/>
- Growthhouse - [www.growthhouse.org](http://www.growthhouse.org)
- Center to Advance Palliative Care (CAPC) - [www.capc.org](http://www.capc.org)
- Center for Palliative Care Studies - [www.medicaring.org](http://www.medicaring.org)
- Americans for Better Care of the Dying - [www.abcd-caring.org](http://www.abcd-caring.org)
- Innovations in End of Life Care (online journal) - <http://www2.edc.org/lastacts/>
- IHI (Institute for Healthcare Improvement) - [www.ihl.org](http://www.ihl.org)
- Promoting Excellence in End of Life Care - [www.promotingexcellence.org](http://www.promotingexcellence.org)
- Supportive Care of the Dying - [www.careofdying.org](http://www.careofdying.org)
- MacColl Institute for Healthcare Innovation - <http://www.improvingchroniccare.org/>
- American Alliance of Cancer Pain Initiatives - <http://www.aacpi.wisc.edu/>
- American Pain Society - <http://www.ampainsoc.org/>
- Pain and Policy Studies Group - <http://www.medsch.wisc.edu/painpolicy/>
- American Thoracic Society - [www.thoracic.org](http://www.thoracic.org)
- The National Comprehensive Cancer Network - [www.nccn.org](http://www.nccn.org).

We also conducted Internet searches using Google™ and the following search terms: guideline, clinical practice guideline, indicator, measure, quality measure, performance measure,

cancer, metastatic cancer, prostate cancer, breast cancer, lung cancer, colorectal cancer, depression, depressive symptoms, emotional depression, antidepressive agents, tricyclic antidepressants, selective serotonin re-uptake inhibitors, pain, morphine, opioids, nonsteroidal anti-inflammatory drugs, treatment of bone metastasis, radiation therapy, dyspnea, shortness of breath, anemia, erythropoietin therapy, advance care planning, advance directives, goals of care, DNR, DNI, withholding or withdrawal of treatment.

Finally, we searched the following published sources for relevant guidelines or indicators: *Directory of Clinical Practice Guidelines*, *Guide to Clinical and Preventive Services*, *Health Plan Employer Data and Information Set (HEDIS<sup>®</sup>) 2005*, *The Medical Outcomes and Guidelines Sourcebook*, *Clinical Process and Outcomes Measurement Directory*, and *Behavioral Outcomes and Guidelines Sourcebook*.<sup>44-49</sup> Whenever possible, we downloaded publications from the Internet; otherwise, we ordered them from the UCLA Biomedical Library or directly from the publishing organizations. All of these additional searches were conducted from January 2005 through March 2005.

## **Grey Literature - Measure Developers**

We sought supplemental information on measures that we identified by directly contacting developers of those measures or measure sets. In our communications, we specified which additional types of information might be helpful for this report and used a “contact form” as a guide to solicit this additional information (Appendix D<sup>\*</sup>).

## ***End-of-Life Care and Outcomes Literature Database***

We searched the reference database for the *End-of-Life Care and Outcomes Project*, a systematic review recently completed by this report’s authors, for articles coded as “cancer.”<sup>21</sup> This search yielded 389 articles that met the criteria and were screened for relevance to this project.

## **Title Screening, Article Review, and Selection of Individual Studies**

The literature review team described above selected studies for further review. The six researchers formed four teams, organized by each domain of interest. Each reviewer on each team independently reviewed the documents or studies, and the teams resolved disagreements by consensus. Dual review was used at all stages of the project. Any questions or needs for clarification that arose throughout the literature review were resolved by the principal investigators.

We adopted the following inclusion and exclusion criteria that were applied at both the title/abstract and article screening phases.

Published reports or Internet documents were accepted only if they contained either indicators or measures. An *indicator* was defined as a descriptive statement with a normative relationship to quality that includes a numerator and denominator and that is expressed as a

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>

measurable standard. As specified by the task order, we also defined a *measure* as an indicator that is fully specified for measurement, including data elements, the data collection approach, data sources, analysis, and presentation.<sup>2</sup> We generally defined any indicator that had been previously operationalized and used for quality assessment or improvement activities as a measure. A *potential indicator* was defined as a statement of a normative standard for which there exists substantial evidence of a relationship to quality of care. We also identified articles with potential indicators; however, potential indicators were not included or identified systematically. Potential indicators were identified by each team based on their working knowledge of the research literature and prioritized based on each team's opinion of the most important gaps in existing measurement. Potential indicators are based on reasoned expert judgment and are intended only as suggestions for further expert discussion. We did not attempt to express them as fully operationalized measures.

Study reports or other documents were excluded if they:

- Were non-Western (i.e., not United States, Canada, Australia, New Zealand, Great Britain, or European),
- Were published in a language other than English,
- Focused exclusively on a disease other than cancer UNLESS they were on the topic of pain or depression, or
- Focused on cancer but considered only a topic other than ACP, depression, dyspnea, or pain,
- Addressed only specific types of cancer and/or processes of care that were not generalizable across the most common cancer conditions. (e.g., particular pain syndromes for tumor subtypes).

We also excluded documents or citations that addressed only specific types of cancer and/or processes of care that were not generalizable across the most common cancer conditions (e.g., particular pain syndromes for tumor subtypes). For the domains of pain and depression, some measures or indicators were developed for populations (e.g., hospice) that generally include cancer patients, although the development or field testing of these indicators may not have explicitly included cancer. We did not exclude these documents or citations. Reviewers screened all titles identified through the formal literature review and all documents found through our Internet and other grey literature searches for pertinence to the key questions and therefore their relevance to this project. Project staff entered data from screening into an electronic database and tracked all studies through the process. Titles and abstracts were screened simultaneously at the first stage. If a title and abstract were accepted, then the full document was ordered and subjected to screening using a standardized screening form (Appendix E<sup>\*</sup>). Internet documents were also screened using a standardized screening form.

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Articles accepted at the screening stage were subjected to full abstraction using standardized abstraction forms. Some studies or documents described only indicator or measure development, whereas others described testing or use in an actual population. To the extent possible, at this stage, the following data were extracted for indicators and measures:

- A general indicator description and/or statement
- Numerator and denominator
- The disease for which the indicator or measure was specified
- Patient/population characteristics (age, race/ethnicity, and gender)
- Setting of care for the indicator or measure application
- Phase of illness to which the indicator was intended to apply
- Data source
- Data about psychometric performance – specifically, reliability and validity

For guideline statements that were abstracted, we rated the quality of the guideline reports using statements following the Appraisal of Guidelines Research and Evaluation (AGREE) and Shaneyfelt criteria.<sup>50,51</sup>

## Summarizing the Evidence for Key Questions

We report the evidence in several forms. First, the evidence tables (Appendix F\*) offer a detailed description of the individual indicators and measures that we identified, addressing each of the topic areas and attributes of indicators or measures that were specified by the task order and are important to understanding the selection of indicators for a national measure set.<sup>2,52</sup> Narrative text summarizes each of the indicators and measures, including the specification of the indicator or measure, its use or application in actual practice, and evidence supporting its relationship to quality of care and its application. We provide statistical information (e.g., background rates, reliability, validity, etc.) useful to evaluating the indicator or measure when we found that information. In addition, we provide tables of potential indicators to highlight priorities for future research in measurement in each of the topic areas. We organized the indicators according to whether they most applied to the assessment, treatment, or follow-up of a symptom, and applied an analogous approach to the advance care planning indicators. Because the strength of evidence related to available indicators and measures varied across topic areas, the degree to which each topic emphasizes existing indicators or measures versus potential measures varies accordingly.

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## Peer Review Process

We identified potential peer reviewers through project staff and in consultation with our TOO. We attempted to include representation from organizations representing adult and pediatric oncology, and palliative medicine, as well as major stakeholders in health care quality measurement. Based on these inquiries, we contacted 20 individuals with wide expertise in the field representing 17 organizations and with deep knowledge of the literature, 14 of whom agreed to participate. The final list of peer reviewers and their affiliations can be found in Appendix A\*. We mailed a copy of the draft evidence report to the peer reviewers and TEP members, with a request for their comments. Comments were compiled and addressed in Appendix G\*.

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# Chapter 3. Results

## Overview

This chapter reports the findings of our systematic review of the evidence supporting indicators and measures for the quality of care for pain, dyspnea, depression, and advance care planning in cancer care. The chapter first describes the literature review flow and then provides additional information about the specific indicators and measures that are outlined in our evidence tables (Appendix F\*). As described below, we identified 10 measure or indicator sets that were the source of most individual indicators and measures that we identified within the topic areas of pain, dyspnea, depression, and advance care planning. In general, these indicator sets were developed to comprehensively evaluate health (Quality Assurance (QA) Tools, Assessing the Care Of Vulnerable Elders (ACOVE)), overall cancer care (Georgia Cancer Coalition, Cancer Care Ontario), supportive cancer care, or palliative care (Dana-Farber Cancer Center, Cancer Care Nova Scotia, Veterans Health Administration (VHA), University Health Consortium, National Hospice and Palliative Care Organization). We successfully contacted 9 of the 10 developers of the measure or indicator sets that are described (the exception being Georgia Cancer Coalition). In addition, we noted several widely recognized measurement sets that contain potentially relevant measures (e.g., Joint Commission of Accreditation of Healthcare Organizations (JCAHO), National Community for Quality Assurance (NCQA)), but we did not abstract these indicators as these measurement systems are already widely recognized. Table 2 summarizes basic information about each measure set. The section that follows describes measures, indicators, and potential indicators (as defined in our Methods) for pain, dyspnea, depression, and advance care planning derived from these sets and other sources.

**Table 2. Overview of identified measure sets**

### Indicators

QA Tools	<p>RAND Health developed the QA Tools system as a comprehensive, clinically based system for assessing the overall quality of care for children and adults. Each QA Tools indicator is based on a focused review of the scientific literature and on the ratings of a panel of experts in the field (based on the "RAND appropriateness method"). The QA tools system includes 46 clinical areas and all four functions of medicine: screening, diagnosis, treatment, and follow-up. It also covers a variety of modes of providing care, including history, physical examination, laboratory study, medication, and other interventions and contacts.</p> <p>Relevant to supportive cancer care, QA Tools identified indicators for the following:</p> <ol style="list-style-type: none"><li>1. Pain assessment</li></ol>
ACOVE	<p>Assessing the Care Of Vulnerable Elders (called ACOVE) was intended to comprehensively address quality measurement for this population because vulnerable elders are at risk for serious declines in health and function from poor quality care and use health care resources disproportionately. ACOVE developed a method of identifying a</p>

\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>

**Table 2. Overview of identified measure sets (continued)**

**Indicators**

Dana-Farber cont'd.	<p>community-based sample of vulnerable elders, selected clinical conditions for quality measurement, and developed an evidence-based set of 236 ACOVE-1 quality-of-care process indicators to evaluate the care provided to vulnerable elders. The indicators are categorized into 22 clinical conditions of importance to vulnerable elders. Most of these quality indicators require only data from medical record review, though some require interviews or administrative data only. Relevant to supportive cancer care, ACOVE indicators addressed the following:</p> <ol style="list-style-type: none"><li>1. Pain assessment and management (although these indicators excluded patients with cancer and therefore were ineligible for the current review)</li><li>2. Depression</li><li>3. Advance care planning (as part of dementia and end-of-life care)</li><li>4. End-of-life care in general (including dyspnea)</li></ol>
Dana-Farber	<p>The Dana-Farber Cancer Institute at Harvard University has pursued an effort to develop a set of administrative data-based indicators for palliative cancer care as part of its recent research agenda. These measures focus on utilization as an outcome and address the following general aspects of supportive cancer care:</p> <ol style="list-style-type: none"><li>1. Utilization-based intensity of service use (late chemotherapy, emergency, hospital/ICU use, site of death)</li><li>2. Use of hospice</li></ol>
CCNS	<p>Cancer Care Nova Scotia (CCNS) is a Canadian provincial organization established to improve the delivery of cancer services across Nova Scotia. CCNS is actively refining a quality measure set for palliative cancer care with the aim of determining which quality indicators are measurable from administrative datasets. The project has two phases:</p> <ul style="list-style-type: none"><li>▪ Qualitative – The project systematically reviewed end-of-life quality indicators for cancer (generic indicators) and breast cancer (unique indicators). It also drew from a general literature review (project identified 90 potential indicators at this stage) and assessed the feasibility of measurement with administrative data (i.e., good communication, having advance directives – not measurable using local resources). In addition, the project conducted focus groups with patients living with metastatic cancer and bereaved caregivers, and expert panels (modified Delphi) with multidisciplinary providers. This process yielded a set of final indicators for testing.</li><li>▪ Quantitative – The project has defined a cohort of all women whose cause of death was related to breast CA over five years (1998-2002f) in Nova Scotia and in Ontario, a true population-based cohort; linked all available datasets that describe this population where feasible; and programmed measurable indicators. The project plans to validate the final indicator set by a detailed review of 100 charts in both provinces, assessing reliability using a 2<sup>nd</sup> set of abstractions.</li></ul> <p>The project identified 19 palliative cancer indicators on these topics:</p> <ol style="list-style-type: none"><li>1. Pain management</li><li>2. Nausea and vomiting</li><li>3. Advance directives</li><li>4. Utilization-based intensity of service use (site of death, hospital/ICU care, emergency, late chemotherapy use, and others)</li><li>5. Hospice and multidisciplinary service use</li><li>6. Transitions and coordination among settings and providers of care</li></ol>

**Table 2. Overview of identified measure sets (continued)**

**Indicators**

**CCO** Cancer Care Ontario (CCO) is a Canadian provincial organization whose primary mission includes the effort to drive system quality, availability, and innovation. CCO developed a set of quality measures for a range of uses organized around measures of access to care, outcomes, evidence-based practice, efficient practice, and the data gathering performance of the cancer care system. Within these areas, individual clinical indicators address aspects of prevention, early detection, treatment, and palliative care. Measures relevant to palliative cancer care include those that address the following:

1. Pain management (satisfaction)
2. Utilization-based intensity of service use (site of death, emergency, and home-based services)

**GCC** The Georgia Cancer Coalition (GCC) was created in 2001 as a legacy of the tobacco industry's Master Settlement Agreement with 50 states. GCC contracted with the Institute of Medicine (IOM) to develop a set of quality measures for evaluating and improving cancer care in Georgia. Efforts were guided by the principles and selection criteria of the National Quality Forum's Strategic Framework Board in recommending a set of 52 cancer care measures. GCC focused its 2003 review on potential measures that could be used to evaluate care for the most common cancers in Georgia and the United States as a whole – breast, colorectal, prostate, and lung cancer. GCC used various sources for measures including accreditation organizations, Federal agencies, provider and professional groups, State cancer control programs, and other sources (RAND Health, FAACT, NQF). GCC appointed an expert panel using the RAND appropriateness method to winnow an initial pool of more than 80 candidate measures. The final set included four items addressing the following:

1. Pain assessment and management
2. Use of hospice care

**VHA** In 2001, VHA, Inc initiated a rapid-cycle quality improvement program, the Transforming the Intensive Care Unit (TICU) initiative. Phase 1.0, which included 23 hospitals, focused on safety and 2 pain measures shown to be effective in pilot studies at Johns Hopkins. At the request of the participating ICUs, a key portion of phase 3.0, to be implemented in the Fall 2005, will be a palliative care bundle, which includes the pain measures and eight additional performance measures.

The measure set was developed using information from the Critical Care Peer Workgroup of Promoting Excellence in End-of-Life Care, the National Consensus Project for Quality Palliative Care, JCAHO standards, and other evidence. The measure set is currently undergoing small-scale pilot testing. It will be implemented and tested in the TICU ICUs. As with other TICU projects, outcomes will be defined and abstracted for evidence of impact from sources such as administrative data, chart review, and satisfaction surveys.

The palliative care bundle measures are as follows:

<i>Day 1:</i>	<i>Day 3:</i>	<i>Day 5:</i>
<ul style="list-style-type: none"> <li>○ Identify decisionmaker</li> <li>○ Address advance directive status</li> <li>○ Address CPR status</li> <li>○ Distribute information leaflet</li> <li>○ Assess pain regularly</li> <li>○ Manage pain optimally</li> </ul>	<ul style="list-style-type: none"> <li>○ Offer social work support</li> <li>○ Offer spiritual support</li> </ul>	<ul style="list-style-type: none"> <li>○ Family meeting</li> </ul>

**Table 2. Overview of identified measure sets (continued)**

**Indicators**

UHC	<p>The University Health Consortium (UHC), formed in 1984, is an alliance of academic health centers situated in the United States. The 2004 Palliative Care Benchmarking Project was conducted within the Clinical Process Improvement (CPI) division of the benchmarking program. The Benchmarking program provides members with the unique opportunity to evaluate and compare their clinical and operational practices with the finest university hospitals in the country. The UHC staff conducted an extensive literature review and assembled an expert panel of constituent members to choose final indicators based on the review and expert opinion. UHC collected data on a set of palliative care quality indicators from December 2003-February 2004. UHC employed its members' Clinical Data Base (CDB) to select a retrospective cohort defined on the basis of adult status, several serious chronic conditions (HIV, cancer, pulmonary disease, congestive heart failure), and mortality risk (e.g., multiple recent admissions). The charts of these patients were subjected to review (40 patient records/each of 35 participating sites). A total of 1,596 charts were included in the evaluation. Quality measures included the following:</p> <ol style="list-style-type: none"><li>1. Pain assessment and treatment</li><li>2. Dyspnea assessment and treatment</li><li>3. Psychosocial care</li><li>4. Care coordination/discharge planning</li></ol>
NHPCO	<p>The National Hospice and Palliative Care Organization (NHPCO), founded in 1978, is the largest nonprofit membership organization that represents hospice and palliative care programs and professionals in the United States. NHPCO has developed standards for hospice care from its inception. In 1998, NHPCO began to develop the National Data Set (NDS) to establish national benchmarks for hospice practice. Development was led by an expert group that included hospice and State government representatives and researchers; this group decided to focus on outcome measures. The measurement set underwent two sets of pilot testing. Data submission is currently voluntary, but enough hospices have submitted data (78 hospices in 2002) that published benchmarks are available.<sup>53</sup></p> <p>Quality measures included the following:<sup>54</sup></p> <ol style="list-style-type: none"><li>1. Comfortable dying</li><li>2. Self-determined life closure</li><li>3. Safe dying</li><li>4. Effective grieving</li><li>5. Family evaluation of hospice care</li></ol>

## Literature Flow

The literature search identified 4,580 titles. We identified an additional 389 potentially relevant articles from the database we had assembled for the *End-of-Life Care and Outcomes* review. Our web search identified 105 guidelines. An additional 109 articles were suggested from the personal libraries of the project members. Four articles were suggested by our TEP upon review of the draft version of this evidence report. In total, the RAND reviewers examined 5,187 titles.

Of the 5,187 titles identified as possibly relevant to our topics, 4,599 were excluded at abstract review, leaving 588 that might be useful to this project. Repeat review by one principal investigator (KL) excluded an additional 51 titles. Thus, the project sought to review 537 articles and guidelines.

Of the 537 articles ordered, we retrieved 536 prior to the cut-off date (June 10, 2005). Screening resulted in exclusion of 485 articles and guidelines: 347 had no indicator; 113 had no domain of interest; 8 covered a disease that was not cancer; 5 presented guidelines with no methods; 6 dealt with a non-Western location; 2 presented duplicate data; 2 represented duplicate articles; and 2 were useful for background only. (For a list of excluded studies, please refer to Appendix H\*).

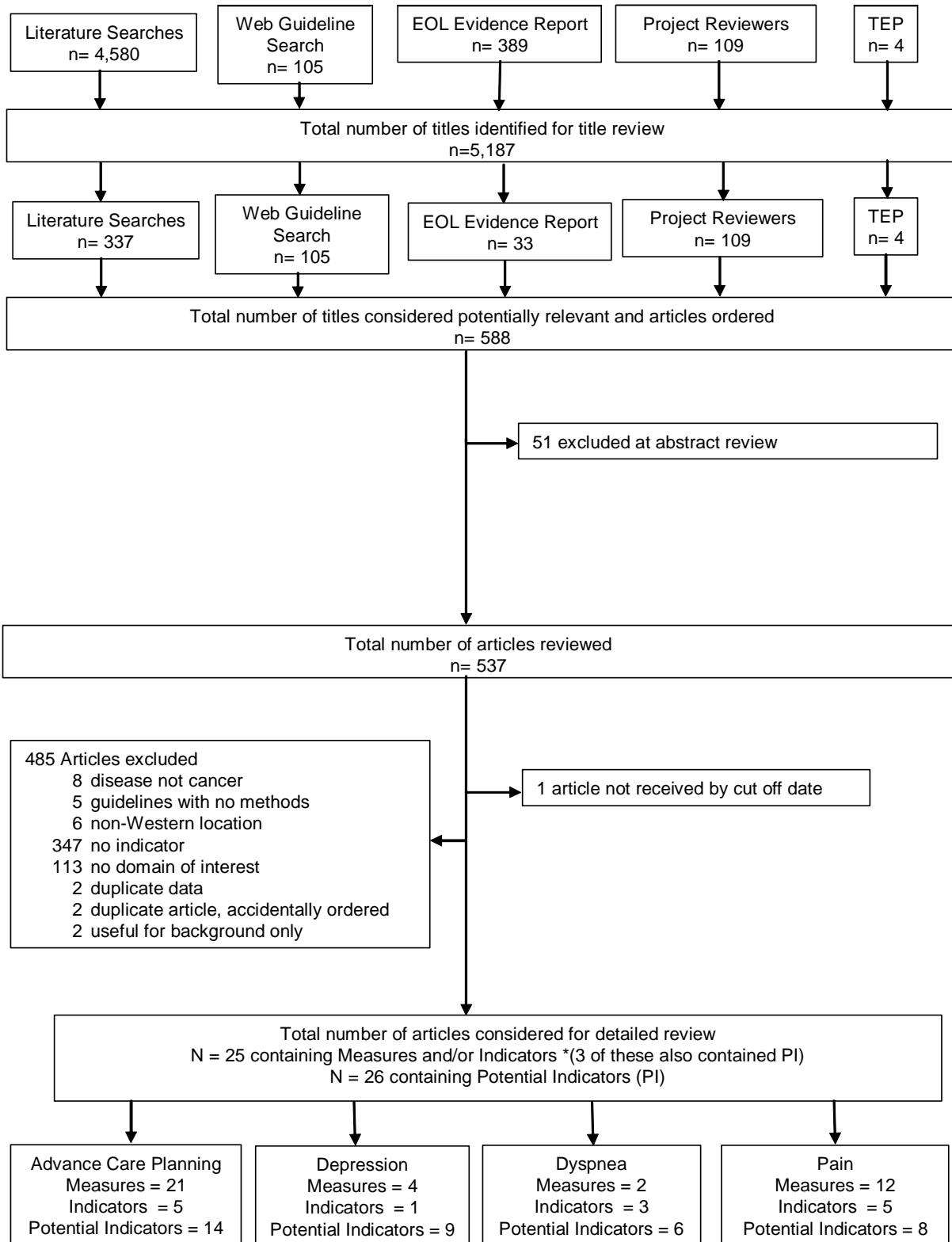
Of the remaining 51 articles, 25 contained measures and/or indicators that described their methods and were reviewed in detail. Potential indicators were identified by each team based on their working knowledge of research literature and prioritized based on each team's opinion of the most important gaps in existing measurement. The remaining 26 articles contained only potential indicators. Because one publication can report on multiple topics and may include multiple measures and/or indicators/potential indicators, the numbers in Figure 1 add up to more than the total number of articles considered for detailed review.

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>



**Figure 1. Article flow**



# Pain

## Introduction

For the review of pain measures, we reviewed all relevant clinical guidelines, indicator and measure sets, potential indicators, systematic reviews, and articles related to quality improvement initiatives and clinical trials, including one review of quality improvement initiatives for cancer pain. Please refer to Evidence Table Appendix F1\*. Pain was among the topics most commonly addressed within existing measure sets (6/8 of the sets identified). We designated most of the items we identified within these measure sets as quality measures since all of them have been operationalized and used for at least quality assessment. The exception is a handful of indicators that are either under development (e.g., Cancer Care Nova Scotia) or for which we were unclear whether or not they had previously been used for actual measurement or we were unsuccessful in obtaining information about that experience (e.g., Georgia Cancer Coalition).

The report of IOM's Committee on Assessing Improvements in Cancer Care in Georgia (National Cancer Policy Board)<sup>55</sup> (Chapter 6, Treating Cancer) has two indicators related to pain, one each for assessment and follow-up.

The performance measurement framework for Cancer Care Ontario<sup>56</sup> has a measure relevant to pain management, defined as patients' self-reported pain and perception of pain management by providers; this measure was operationalized as an indicator as "satisfaction with pain management."<sup>57</sup>

ACOVE generally excluded cancer patients, so the ACOVE set of measures for chronic pain<sup>58</sup> were not included in our review, although some of these measures may be appropriate for patients with cancer. However, ACOVE measures related to the end-of life did not exclude cancer; thus, that set includes one measure relevant to pain assessment.<sup>59</sup> This measure has also been adapted for nursing homes.<sup>60</sup>

The VHA Transforming the Intensive Care Unit (TICU) initiative includes two measures for pain assessment and follow-up that are currently being used in 30 ICUs and have evidence for efficacy in a cancer ICU.<sup>61,62</sup>

The University Health Consortium (UHC) included two measures for assessment, one for treatment, and one for follow-up. QA Tools included three items relevant to pain, although only two were accepted by the expert panel. However, the indicator not accepted by the QA Tools panel has been proposed as part of Cancer Care Nova Scotia.

The NHPCO set includes one outcome measure for pain.<sup>63</sup>

A broader cancer quality measurement set, QOPI (The Quality Oncology Practice Initiative), includes one measure for assessment of pain at the end of life. We also identified a treatment indicator in a guideline for radiation therapy.<sup>64</sup>

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>

## Measures and Indicators

**Assessment.** We identified five measures and two indicators relevant to cancer pain assessment.

*Measure - Regular Assessment of Pain.* Quality Assurance Tools (QA Tools), proposed in 2000,<sup>64</sup> includes one measure relevant to pain assessment. The numerator of this measure is “patients with the presence or absence of pain noted every six months,” and the denominator is “all patients with cancer metastatic to the bone.” The measure was limited to patients with bone metastases because this group was felt to be well defined and to have the highest prevalence of cancer pain. The prevalence of every six months was chosen as a minimum requirement, based on older versions of clinical practice guidelines from the early 1990s. Although this measure was tested as part of the QA Tools evaluation in a VA- and community-based population,<sup>65,66</sup> the numbers of patients eligible for this indicator was too small to provide any useful validity, reliability, or comparability information. This measure is intended for use in patients with any type of cancer metastatic to the bone. The measure is not in current use.

*Measure - Routine Inpatient Pain Assessment.* The University Health Consortium (UHC) Palliative Care Benchmarking Project<sup>67</sup> included two measures relevant to pain assessment. The numerator for the first measure is “persons with pain assessment within 48 hours of admission.” The denominator is “adults  $\geq 18$  years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay  $> 4$  days AND 2 prior admissions for any cause in preceding 12 months.” This denominator was developed by an expert panel to represent a potential palliative care population in hospitals. A mean of 96% (median 98.5%, range 83-100%) of charts in the UHC cohort satisfied this indicator, including 98% of cancer patients, and little variability was seen among participating sites. No reliability or validity information is available; however, the benchmarking project found that using a combination of all of the UHC measures in a “palliative care bundle” was associated with lower patient length of stay. In addition, several elements of the bundle could be used to identify hospitals with “best practices” for palliative care. Scores from the bundle were instrumental in achieving advances in palliative care at several hospitals, including justifying at least one new palliative care program. The measure is intended for use as a tool for comparing performance in all hospitals. However, it is very broad, does not include an element of timeliness (within 48 hours of admission is late for pain assessment to occur), and is not in current use.

The numerator for the second UHC pain assessment indicator (routine inpatient pain assessment with a numeric scale) is “persons assessed with a numeric pain scale.” The denominator is “adults  $\geq 18$  years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay  $> 4$  days AND 2 prior admissions for any cause in preceding 12 months in the hospital, AND reported pain within the first 48 hours of admission.” A mean of only 76% (median 85%, range 13-100%) of the charts reviewed in the UHC cohort met this criterion, including 77% of those of cancer patients. Some variability was seen among sites; at ten low-performing sites, only 15 to 70% of charts included this information. Information is the same as for the first UHC indicator; no additional reliability or validity information is available.

*Measure - Regular ICU Pain Assessment.* The VHA TICU project, initially proposed in 2002,<sup>61</sup> includes one pain assessment measure, which was modified for inclusion in the VHA TICU palliative care bundle in 2005 (Quality Indicator #5).<sup>68</sup> The numerator is “the total number of 4-hour intervals (within the first 24 hours following ICU admission) for which pain was assessed and documented, using an appropriate rating scale.” The denominator is “the total number of 4-hour intervals (within the first 24 hours following ICU admission) for patients with an ICU length of stay  $\geq$  24 hours.” Documentation of pain assessment may include (1) a numeric value of 1 to 10, or (2) pain was assessed but the patient was unresponsive (e.g., heavily sedated, comatose). A four-hour interval is defined as a four-hour interval of patient care (patient-nursing interval). The four-hour intervals are set at 8 am; 12pm; 4 pm; 8 pm; 12 am; and 4 am. An appropriate rating scale is defined as either a visual analogue scale (VAS with numeric translation of 1-10) or another numerical rating scale of 1-10. Exclusion criteria include intervals for which a patient was not physically available in the ICU (e.g. patient expired; not yet admitted to the ICU; was discharged/transferred out of the ICU (for part of the day); went into the operating room or off the unit for a procedure); and intervals for which pain was assessed, but without the use of an appropriate rating scale as defined above. This measure is supported by the JCAHO Hospital Standards RI.1.2.9, PE.1.4 and the National Consensus Project for Quality Palliative Care Clinical Practice Guideline, 2.1.<sup>69</sup> Evidence of its validity includes a rapid-cycle quality-improvement intervention in two ICUs, including a surgical cancer ICU, demonstrating that its use as part of a rapid-cycle quality improvement intervention, in which the percent of nursing intervals where pain scores were measured using a VAS scale increased from 42 to 94%, contributed to a decrease in pain scores  $\geq$ 3 from 41% to 6%.<sup>62</sup> In addition, a similar rating scale was used in an RCT of interrupted sedation in the ICU.<sup>70</sup> No reliability information is available.

This measure is intended for use in all ICU populations. As with other pain outcome measures, variability in the quality of pain assessment may limit its use for comparing performance. In the ICU population, as at the end of life or in nursing homes, many patients may have difficulty or may be unable to verbalize a numerical pain score; depending on local standards of assessment, this outcome variable may therefore apply to very different proportions of the population in different ICUs or settings. The measure also does not specify whether this score should represent minimum, maximum, or average pain. Also, the measure applies only to the first 24 hours in the ICU. This measure is currently being used as part of the VHA TICU initiative and is part of the VHA palliative care bundle, which will be initiated in September 2005.

*Measure - Assessing Pain in Patients Close to Death.* QOPI (the Quality Oncology Practice Initiative) included one end-of-life pain assessment measure in their practice-based system of quality assessment. The numerator of this measure is “medical records where there is an explicit practitioner’s notation quantifying their physical pain or lack thereof on their last visit to the office prior to death,” and the denominator is “recently deceased patients from oncology practices.”<sup>71</sup> QOPI was developed and sponsored by individual oncologists and ACSO (the American Society of Clinical Oncology). QOPI selected and developed quality measures that were easily identifiable through outpatient medical record review. The measures also had to relate to important issues, as defined by (1) consensus among QOPI participants, (2) evidence-based standards, or (3) requirements from organizations such as JCAHO. This measure was evaluated through review of 10 medical records of patients who had died in 41 oncology practices. The initial round of assessment showed that 56% of medical records met this measure,

69% met the measure in a second round 6 months later, and there was substantial variation among practices (range, 30-90%). No validity or reliability information is available.

This measure is intended for use in self-assessment in outpatient oncology practices. The retrospective nature of the measure is a drawback, since death is often not predictable, and improvements might be due to changes in documentation that do not necessarily reflect improvement in practice. This measure will be part of a new voluntary quality improvement initiative for oncology practices sponsored by ASCO, NCI, and the National Health Council, to begin in 2005. End-of-life will be the first initiative and will include this measure as well as whether the pain was quantified by either a numerical scale or another descriptor.

*Indicator - Routine Pain Assessment in Expected Dying.* The Assessing Care of the Vulnerable Elderly (ACOVE) end-of-life measure set<sup>59</sup> includes one measure relevant to assessment for pain. Its numerator is “the number of vulnerable elders with documentation of pain or lack of pain during the last three days of life.” The denominator is “vulnerable elders who are conscious during the last three days of life and who died an expected death.” Although the eight measures from the ACOVE end-of-life set were evaluated for reliability and validity<sup>72</sup> as part of the ACOVE project, this measure was not included in the evaluation. The denominator may be difficult to define, since “expected death” requires explicit documentation of that expectation in the medical record more than one day before death. This measure is intended for use in all vulnerable elders. An expert panel accepted a modified version of this indicator as part of a revised set for nursing homes.<sup>60</sup> The nursing home indicator requires a denominator of all nursing home residents who died an expected death and were conscious at all during the last seven days of life.

*Indicator - Routine Assessment of Pain.* The IOM’s Committee on Assessing Improvements in Cancer Care in Georgia (National Cancer Policy Board) proposed an indicator set in 2005 with two indicators related to pain, one of which targeted regular assessment.<sup>55</sup> The numerator for this indicator is “the number of cancer patient encounters where the patient was assessed for pain,” and the denominator is “the number of cancer patient encounters.” Available information does not specify the appropriate frequency of cancer pain assessment (i.e., every encounter) or how pain should be measured. The indicator is intended for use for all cancer patients, across the continuum of care and all health care settings. This indicator is newly proposed and information on actual use is not available.

**Treatment.** We identified three measures and one indicator relevant to cancer pain treatment.

*Measure - Responsive Pain Treatment.* QA Tools includes one measure relevant to treatment of pain, proposed in 2000.<sup>64</sup> The numerator is “patients offered a change in pain management within 24 hours of the pain complaint,” and the denominator is “all cancer patients whose pain is uncontrolled.” As with the other QA tools indicators, although this measure was tested as part of the QA Tools evaluation in VA and community-based populations,<sup>65,66</sup> the number of eligible patients was too small in these studies to determine validity or reliability. This measure is intended for use in patients with any type of cancer across the continuum of care. The measure is not in current use.

*Measure - Regular Prophylaxis of Opioid-Induced Constipation.* The UHC Palliative Care Benchmarking Project also included one measure relevant to pain treatment that addresses safety or avoiding side effects that can be effectively prevented. The numerator is “patients with a bowel regimen initiated within 24 hours of an opioid, and in whom a bowel regimen is not contraindicated.” The denominator is “adults  $\geq$  18 years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay  $>$  4 days AND 2 prior admissions for any cause in preceding 12 months in the hospital, AND treated with narcotics.” The treatment of constipation as a side effect of opioid administration was addressed in a recent systematic review.<sup>73</sup> The review found that 25-50% of cancer patients have constipation and that it is the most frequently occurring adverse effect of opioid use in advanced cancer; however, the review of 17 studies found none that directly compared patients treated with an opioid regimen with those not treated. A similar potential measure has also undergone some field testing in a population that included cancer patients as part of the JCAHO-AMA-NCQA pain management performance measure development project.<sup>74</sup> A mean of only 59% (median 59%, range 20-93%) of the charts reviewed in the UHC cohort met this criterion, and the distribution of the outcome appears broadly normal. Eighty-three percent of cancer patients met the indicator. No validity or reliability information is available for this indicator; more details on the testing of the measurement set are described in the UHC pain assessment measures. This measure is intended for use across all types of cancer. The measure set is not in current use.

*Indicator - Minimizing Radiotherapy Burden.* Cancer Care Ontario’s Program in Evidence-Based Care reported a clinical practice guideline in 2003, *Radiotherapy Fractionation for the Palliation of Uncomplicated Painful Bone Metastases, Practice Guideline Report #13-2*. This report includes an indicator relevant to the choice of radiotherapy regimen in patients with advanced cancer.<sup>75</sup> The numerator is “patients receiving single dose therapy as a single 8Gy treatment, prescribed to the appropriate target volume.” The denominator is “all adult patients with single or multiple radiographically confirmed bone metastases of any histology corresponding to painful areas in previously nonirradiated areas without pathologic fractures or spinal cord/cauda equina compression.” It does not apply to the management of malignant primary bone tumor and is intended for patients receiving radiotherapy where the objective or intent is pain relief. The report, which was based on a systematic review, also includes a number of qualifying statements. The evidence was reviewed by a four-member group and then approved by a multidisciplinary group. External review was obtained through a mailed survey of Ontario practitioners. The indicator is based on 2 systematic reviews and 16 RCTs. A meta-analysis of eight RCTs, conducted as part of the guideline process, found no significant difference in response rate between single-fraction and fractionated radiotherapy. There were no differences in quality of life (for the few studies where this was assessed) or side effects. Observed re-irradiation rates were higher with single-fraction than with multiple-fraction therapy, but details were not described. A separate systematic review and meta-analysis<sup>76</sup> derived the same conclusions about pain, but concluded that the pathologic fracture rate was significantly higher for single-fraction than for multiple-fraction treatment. The indicator is intended for use in a mixed cancer population, for palliative treatment. This indicator is relevant to the efficiency of care. The indicator is not known to be in current use.

*Indicator - Effective Treatment for Painful Bony Metastasis.* Cancer Care Nova Scotia<sup>77</sup> has proposed a set of quality indicators for palliative cancer care that includes one pain treatment indicator, adapted from a proposed QA tools indicator that was not accepted by the QA Tools expert panel and was not part of the final set.<sup>64</sup> The numerator of this indicator is “patients who are offered one of the following within one week of the notation of pain: radiation therapy to the sites of pain, or radioactive strontium therapy.” The denominator of this indicator is “patients with cancer metastatic to the bone and pain uncontrolled by opioids.” Although there is excellent meta-analysis evidence of the efficacy of radiation therapy for bone pain,<sup>76</sup> another meta-analysis found that the evidence supporting the efficacy of radioisotopes such as strontium was inconclusive,<sup>78</sup> and we did not identify any evidence that supports the use of radiation therapy only for pain uncontrolled by opioids or that supports the timing of radiation therapy. Although this indicator was proposed, based on feedback from CCNS expert panels and available datasources, the indicator will not be field tested at the current time because “uncontrolled pain” could not be operationalized. The indicator is intended for use in patients with metastatic breast cancer and addresses both effectiveness and timeliness. The indicator may be limited by the lack of definition of “pain uncontrolled by opioids.” The indicator set is proposed and is not in current use.

**Follow-up.** We identified four measures and one indicator relevant to the follow-up of cancer pain treatment.

*Measure - Timely Treatment of Pain in Hospice.* The NHPCO indicator set for hospice,<sup>54,63,79</sup> includes one outcome measure for pain. The numerator is “the proportion of patients between 48 and 120 hours after admission who report ‘yes’ when asked, ‘Was your pain brought to an acceptable level within 48 hours of your admission to the hospice program?’” The denominator is “patients admitted to hospice who answer ‘yes’ when asked, ‘Are you uncomfortable because of pain?’” The measure does not apply to patients in nursing facilities, children, non-English-speaking patients, or others who cannot self-report, because of concerns about measurement. It assumes that all patients are assessed for pain on admission to hospice, and detailed information on how to administer the measure is available.<sup>63</sup> The NHPCO chose to focus only on outcome measures, and considered and rejected alternative data collection methods for pain outcomes, including chart audits and retrospective surveys. They also chose not to use proxy reports because of issues with reliability and validity.<sup>54</sup> This concern, as well as the difficulty in assessing pain in the last days of life, led to the timing for the indicator at hospice admission. A non-numerical dichotomous rating was chosen because of concerns about the validity of numerical ratings. For construct validity, in pilot testing, more people said that they were “uncomfortable” because of their pain than said their pain was “unacceptable,” so the word “uncomfortable” was chosen as more sensitive for the denominator.<sup>54</sup> Results from the use of this measure as part of the measurement set have also been published.<sup>79</sup> For the 78 agencies that submitted data in 2002, the mean was 87% (median, 90%; 25<sup>th</sup> & 75<sup>th</sup> percentiles, 79% & 100%). These data suggest that there may be sufficient variation among hospices for this measure to be useful for comparing performance or quality improvement. No other reliability or validity information is available. A previous review of the palliative care literature found that general measures of satisfaction or subjective ratings of health care were subject to a strong ceiling effect, and items or measures that addressed specific processes tended to exhibit better variability.<sup>21</sup> This measure is intended for use in hospice care. It is limited by the inability of

many hospice patients to report their pain. In addition, as an outcome measure, it would require evaluation for whether there needs to be risk adjustment for variation among organizations. Population characteristics such as the percentage of patients who report pain on admission, patients who cannot self-report, and patients with a history of drug abuse may significantly influence results. It is currently being used by some hospice programs for internal quality assurance purposes and voluntary, confidential reporting to NHPCO.

*Measure - Effective Treatment of Pain in the ICU.* This measure, initially evaluated in 2002,<sup>61</sup> was modified for inclusion in the VHA TICU palliative care bundle in 2005 as an outcome measure for pain (Quality Indicator #6).<sup>68</sup> The numerator is “the total number of 4-hour intervals (within the first 24 hours following ICU admission) for which the documented pain score was <3.” The denominator is “the total number of 4-hour intervals (within the first 24 hours following ICU admission) with numerical pain values of 1 to 10, for patients with an ICU length of stay ≥ 24 hours.” Exclusion criteria include intervals for which a patient was not physically available in the ICU (e.g. patient expired; was not yet admitted to the ICU; was discharged/transferred out of the ICU [for part of the day]; went into the operating room or off the unit for a procedure); intervals for which a pain score was not documented; intervals for which pain was assessed, but the patient was unresponsive (e.g., heavily sedated; comatose); and intervals for which pain was assessed, but without the use of an appropriate rating scale as defined above. This measure is based upon a rapid-cycle quality-improvement intervention in two ICUs, including a surgical cancer ICU, demonstrating its responsiveness to changes in care processes (including the other VHA measure listed under assessment as well as whether house staff documented the pain score). It is also based on the JCAHO Hospital Standards RI.1.2.9., PE.1.4; and the National Consensus Project for Quality Palliative Care Clinical Practice Guideline, 2.1. No additional reliability or validity information is available.

This measure is intended for use in all ICU populations. As with other pain outcome measures, variability in the quality of pain assessment may limit its use for comparing performance. In the ICU population, as at the end of life or in nursing homes, many patients find it difficult or may be unable to verbalize a numerical pain score; depending on local standards of assessment, this measure may therefore be applicable to very different proportions of the population in different ICUs. The measure also does not specify whether this figure should be a minimum, maximum, or average pain score. It is currently being used as part of the VHA TICU initiative and is part of the VHA palliative care bundle, which will be initiated in September 2005.

*Measure - Satisfaction With Pain Treatment.* This measure is part of the indicator set proposed by Cancer Care Ontario in 2005.<sup>57</sup> The numerator of this measure is reported in three categories: “Patients where the response to the question “Do you think staff did everything they could to control your pain or discomfort?” was (1) yes, completely; (2) yes, somewhat; or (3) no.” The denominator is “outpatient cancer patients reporting mild to severe pain.” The source of this indicator is patient surveys. Information on reliability/validity as an indicator is not available. In a survey of more than 5,000 cancer outpatients in 2004, 70% of patients answered “yes, completely,” 25% answered “yes, somewhat,” and only 5% answered “no.” Variability by center was not reported, and all four provinces where the survey was done apparently had similar results.<sup>57</sup> The low number of “no” answers is consistent with previous studies of satisfaction for pain, which have found that overall satisfaction reports may not reliably correlate with actual



pain scores and may be difficult to use because of ceiling effects.<sup>21</sup> The indicator is intended for use in ambulatory/outpatient care. It may be affected by recall bias (used for care in the previous six months), low response rate among palliative care patients, and a requirement for a minimum denominator of 300 patients per participating center. It is currently being used in Ontario and three other Canadian provinces.

*Measure - Timely Treatment of Inpatient Pain.* The UHC Palliative Care Benchmarking Project,<sup>67</sup> introduced in 2004, includes one outcome measure for pain. The numerator is “persons with pain relief or reduction within 48 hours of admission to  $\leq 3$  on a 0-10 scale.” The denominator is “adults  $\geq 18$  years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay  $> 4$  days, 2 prior admissions for any cause in preceding 12 months in the hospital, AND reported pain within the 1st 48 hours of admission.” A mean of 76% (median 78%, range 46-92%) of the UHC cohort met this indicator. Only 70% of cancer patients met the indicator. There was moderate variability in this measure; although the range of performance was somewhat restricted, the distribution of results appeared to be relatively normal. As with the other UHC measures, no individual reliability or validity information is available. It is not known to be in current use.

*Indicator - Effective Treatment of Pain.* The IOM Committee on Assessing Improvements in Cancer Care in Georgia’s (National Cancer Policy Board) 2005 indicator set proposed an indicator relevant to the follow-up of pain treatment.<sup>55</sup> The numerator is “the number of cancer patients who report being in more than minor pain.” The denominator is “the number of cancer patients who are not comatose.” This indicator is based on the 2004 cancer pain guideline from the National Comprehensive Cancer Network (NCCN),<sup>80</sup> the 1996 cancer pain guideline from the World Health Organization,<sup>81</sup> the cancer pain position statement from the Oncology Nursing Society (ONS),<sup>82</sup> and the *American Pain Society Quality Improvement Guidelines* for the treatment of acute pain and cancer pain.<sup>83</sup> Evidence is based on the AHRQ evidence report on treatment of cancer pain<sup>7</sup> and NIH Consensus State of the Science Statement on symptom management in cancer.<sup>84</sup>

The indicator is intended for use for all cancer patients, across the continuum of care and all health care settings. A validated pain scale that defines “minor pain” must be used in each health care setting, and the threshold should be reported along with the indicator. Poor medical record documentation may lead to low prevalence estimates. Potential benchmark sources are baseline patient surveys and medical records. Evidence suggests that members of ethnic minority groups, women, and elderly patients may be less likely to be adequately treated for pain (Chapter 6, p. 23).<sup>55</sup> This indicator is newly proposed and information on use is not available.

## Potential Indicators and Measurement Gaps

We identified a large number of potential indicators in the substantial guideline, quality improvement, and research literature that we reviewed. Many of these guideline statements and potential indicators address specific management issues, such as the treatment of neuropathic pain, or more details on the indicators we have identified, such as more-comprehensive assessment for pain or pain outcomes.<sup>74</sup> We highlight here eight potential indicators with relatively strong supporting evidence and/or expert consensus, highlighting critical issues not

addressed by the indicators and measures listed above, that may have potential for demonstrating variability in quality and improving patient outcomes, and applicable to cancer patients across the continuum and to diverse populations.

## **Assessment**

*Physician Documentation of Pain Assessment.* The numerator is “patients where a pain assessment is documented in the physician note,” and the denominator is “all patients with cancer.” This potential indicator was used as a part of the pain continuous quality improvement study that led to the VHA pain measures<sup>61</sup> and is supported by evidence that pain assessment by nurses or aides often does not lead to documentation of pain by the physician. Improvements in pain assessment by non-physician staff may not lead to improved outcomes because the physician may not attend to the report of pain.<sup>85</sup> Another consideration with pain assessment indicators is the extent to which they might address aspects of assessment including specific symptom attributes (e.g., timing, duration, and functional impairment) and specific etiologies.

*Disparities in Pain Assessment.* The numerator is “non-white patients with cancer who are assessed for pain,” and the denominator is “all patients with cancer who are assessed for pain.” Ensuring that pain assessment is equitable across ethnic groups is important because large studies have demonstrated that members of minority groups with cancer have higher rates of inadequate pain assessment and treatment than others.<sup>86,87</sup> A recent nonsystematic review of this topic found that this disparity persists for both assessment and treatment, across multiple settings and types of pain.<sup>88</sup> Whenever possible, assessment of disparity by ethnicity should also include assessment of other contributing factors, such as socioeconomic status and access to care, since these are often the primary cause of perceived disparities by race.

*Assessment in Patients Who Have Difficulty Verbalizing Their Pain.* The numerator of this potential indicator is “patients who have difficulty verbalizing their pain but who are assessed for pain,” and the denominator is “cancer patients who have difficulty verbalizing their pain.” This potential indicator is important because many of the indicators and measures we identified exclude patients who are unable to verbalize their pain. Many cancer patients at high risk for pain would therefore be excluded from many of these measures, including infants and small children, many seriously ill or perioperative cancer patients, cancer patients with severe dementia, and many patients in the last days of life, where a decreased level of consciousness is very common. In addition, patients with some degree of cognitive impairment or sedation may also be excluded from the denominator even though many of these patients are able to report their pain.<sup>40</sup> Variable exclusion of these patients limits the usefulness of pain assessment measures for comparisons between facilities or over time. Recent systematic reviews have summarized the variety of tools available for assessing pain in older adults with cognitive impairment<sup>89</sup> and in infants.<sup>90</sup> In addition, some evidence exists that cognitively impaired adults receive less pain medication than those who are cognitively intact and that untreated pain may lead to higher rates of adverse outcomes, such as delirium.<sup>91</sup>

*Assessment for Depression in Patients With Pain.* The numerator is “patients assessed for depression,” and the denominator is “all cancer patients with pain.” This potential indicator is supported by evidence that cancer patients with pain are more likely to be depressed than cancer

patients without pain.<sup>92</sup> In addition, there is substantial descriptive evidence that the symptoms of depression and pain often occur together.<sup>10</sup>

## **Treatment**

*Educating Patients About Pain Management.* The numerator is “patients who are educated about pain management,” and the denominator is “cancer patients with pain.” This guidance is included in many cancer pain guidelines, some of which also include education of caregivers. A related potential outcome measure, that patients should be adequately informed and knowledgeable about pain management, is included in the 2005 American Pain Society Recommendations for Improving the Quality of Acute and Cancer Pain Management,<sup>74</sup> based on an expert review of the measurement tools used in 20 quality improvement studies in pain management.<sup>93</sup> A systematic review of educational interventions for patients and family caregivers found eight studies, two of which were randomized, controlled trials; both of these and all of the nonrandomized studies where pain management education was measured found a significant impact of education on pain.<sup>94</sup>

*Use of Opioids for Severe, Persistent Pain.* The numerator of this potential indicator is “patients who are treated with opioids,” and the denominator is “cancer patients with severe, persistent pain.” This potential indicator is supported by a number of clinical practice guidelines for pain, including the World Health Organization<sup>81</sup> and NCCN.<sup>80</sup> One of the pilot measures that was field-tested as part of the JCAHO-AMA-NCQA initiative also relates to this issue,<sup>74</sup> but it needs further development before use as a measure. A randomized trial in advanced cancer patients comparing the use of strong opioids to the WHO stepped-care approach where patients are started on non-opioids, then given weak opioid medications, found that patients treated with opioids had better pain outcomes.<sup>95</sup>

*Use of Long-Acting Pain Medications.* The numerator is “all adults who are prescribed long-acting opioids,” and the denominator is “all adults with cancer who have persistent pain and are prescribed opioids.” This expert guidance is in numerous pain guidelines, including the Agency for Health Care Policy and Research cancer pain guideline<sup>96</sup> and the American Geriatrics Society cancer pain guideline for older adults.<sup>97</sup> A systematic review of the cancer pain literature found only two relevant trials, which showed no difference between long-acting and around-the-clock short-acting formulations.<sup>7</sup> However, the expert consultants for the Cancer Symptom Management State-of-the-Science Statement<sup>84</sup> also included this recommendation because improved adherence with long-acting drugs in clinical practice may improve outcomes.

*Procedure-Related Pain in Children.* The numerator is “all children who receive appropriate preparation and/or anesthesia” and the denominator is “all children with cancer receiving painful procedures.” We chose to highlight this potential indicator because it is emphasized in guidelines for cancer pain in children but is typically not mentioned in guidelines for adults. The World Health Organization<sup>34</sup> describes this area as important because the pain from procedures is often worse than that from the cancer and because inadequate pain control may lead to anxiety, reduced adherence, and poorer relationships with health care providers.

In addition, many pharmacological and nonpharmacological approaches, including the presence of parents whenever possible, local anesthetics, and opioids when needed, can reduce

procedural pain. An assessment tool for postoperative pain management in children has been developed and psychometrically tested in children as young as eight years old.<sup>98</sup> Many randomized, controlled trials have demonstrated that use of pharmacologic measures such as topical anesthetics not only reduces pain, but reduces procedure time and improves procedure success rates.<sup>99</sup> Such an indicator might also be reasonable to consider for adults.

## Dyspnea

### Introduction

We failed to identify any quality measures that were developed specifically for dyspnea in cancer. Please refer to the Evidence Table in Appendix F2\*. Two measures were developed and tested as part of the UHC Project on palliative care for dyspnea assessment and dyspnea reduction/relief within 48 hours of hospital admission.<sup>67</sup> The UHC indicators were used in an adult population with cancers that included lung, gastrointestinal, breast, male reproductive, and nervous system neoplasms – approximately 25% of the UHC cohort had cancer.

We identified two indicators for dyspnea applicable to the cancer population derived from the Assessing Care of Vulnerable Elders (ACOVE) project<sup>59</sup> and one indicator developed for COPD from the RAND QA Tools project that is applicable to patients with cancer and hypoxia.<sup>65</sup>

### Measures and Indicators

**Assessment.** We identified one measure and zero indicators relevant to dyspnea assessment.

*Measure - Regular Assessment of Dyspnea.* The University Health System Consortium (UHC) Palliative Care Benchmarking Project used a performance measure across an alliance of academic health centers in the United States in 35 participating hospitals for dyspnea assessment within 48 hours of admission.<sup>67</sup> The numerator is “persons with dyspnea assessment within 48 hours of admission.” The specific criteria for how dyspnea assessment was operationalized were not described in available reports (other than the use of a 10-point scale). The denominator is “adults 18 years of age and older, with admission for congestive heart failure (DRG 127), cancer (DRG 82, 203, 172, 274, 346, 10), HIV (DRG 489), or respiratory illness (DRG 475, 483) and a length of stay more than 4 days and 2 prior hospital admissions for any cause in the preceding 12 months.” This denominator was developed by an expert panel to represent a potential palliative care population in hospitals. No reliability or validity information is available; however, the benchmarking project found that a combination of use of all of the UHC measures in a “palliative care bundle” was associated with shorter patient length of stay. In addition, several elements of the bundle could be used to identify hospitals with “best practices” for palliative care. Scores from the bundle were instrumental in achieving advances in palliative care at several hospitals, including justifying at least one new palliative care program.

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>

The dyspnea assessment measure is intended for use as a tool for comparing performance in all hospitals. The data for this measure come from billing, administrative, and clinical databases combined in the UHC data set. The UHC report indicates that a mean of 91% (median 95%, range 53-100%) of patients was assessed for dyspnea within 48 hours with the average rate for cancer being 89.9%. The measure criterion appears broad and does not include an element of timeliness (within 48 hours of admission may be too long for dyspnea assessment to occur). Further details about operationalization and details on psychometric testing are needed. The measure is not known to be in use.

**Treatment.** We identified zero measures and three indicators relevant to dyspnea treatment.

*Indicator - Effective Dyspnea Treatment in Expected Dying When Forgoing Ventilator.* ACOVE describes a set of quality indicators for adults age 65 years and older in 2001.<sup>59</sup> The numerator is “whether or not the patient received or had an order for an opioid, benzodiazepine, or barbiturate infusion to reduce dyspnea and the chart documented whether the patient has dyspnea.” The denominator is “all non-comatose vulnerable elders who are not expected to survive or those for whom a mechanical ventilator is withdrawn or intubation is withheld.” The indicator is designed to be evaluated by retrospective chart review and is most applicable to hospitalized patients; however, the indicator could be applied to any setting where ventilator withdrawal or withholding could occur. The withdrawal and withholding for mechanical ventilation indicator is supported by documentation of variation and inadequate management of dyspnea,<sup>100,101</sup> best-practice recommendations,<sup>102,103</sup> and statements from professional societies.<sup>59,104,105</sup>

*Indicator - Regular Treatment and Follow-up of Dyspnea in Expected Dying.* A second ACOVE indicator addresses the follow-up of dyspnea treatment at the end of life.<sup>59</sup> The numerator is “whether or not the medical record documents how dyspnea was treated and followed up.” The denominator is “all vulnerable elders who had dyspnea in the last seven days of life and died expected deaths.” The indicator is designed to be evaluated by retrospective chart review and is applicable to any setting of care. This indicator was based on the premise that symptoms such as dyspnea should be a focus of end-of-life care and consensus calling for improvement in the care and management of dyspnea. In supporting documentation, the developers stated that dyspnea can be effectively treated with oxygen and pharmacologic agents.<sup>59</sup> Like the withholding and withdrawal of ventilation indicator, this indicator was not evaluable in the community-based study of ACOVE measures.<sup>72</sup>

*Indicator - Treatment of Dyspnea Caused by Hypoxia.* QA Tools did not include indicators for dyspnea within its multiple cancer sets.<sup>64-66,106</sup> However, within the category of chronic obstructive pulmonary disease (COPD), one indicator for hypoxia is applicable to cancer patients with dyspnea caused by hypoxia.<sup>65,66,107</sup> The numerator is “whether home oxygen therapy was used.” The denominator is “all patients with baseline room air oxygen saturation < 88% at rest.” The original indicator in the QA Tools project for patients with COPD read as follows: “COPD patients should receive home oxygen if their baseline room air oxygen saturation is <88% at rest (not during an exacerbation).”<sup>65</sup> This indicator was based on multiple studies demonstrating benefit to both survival in hypoxic patients and subjective improvement of dyspnea symptoms through oxygen therapy.<sup>107</sup> More recent data supporting use of oxygen for symptomatic improvement in hypoxic patients exists, including a recent review by a working group of the

scientific committee of the Association of Palliative Medicine.<sup>108</sup> This review included primarily patients with COPD and demonstrated more consistent symptom improvement with oxygen for those with hypoxia.

The indicator is designed to be evaluated by retrospective chart review. This indicator was used in the COPD population for outpatient care during routine clinical interactions that did not occur during an exacerbation, however it may be pertinent to other settings such as physician offices, home health care, and home hospice. The indicator was operationalized by looking at the lowest oxygen saturation at least two weeks before the close of the study and scored as meeting the criterion if an order, prescription, or discharge order for home oxygen was identified within two weeks of a saturation value less than 88% or a note that the patient was already on home oxygen that was not discontinued. Reliability was based on a 4% duplicate abstraction from the medical record and demonstrated a kappa of 0.83 for agreement on the condition (COPD), a kappa of 0.76 for agreement on eligibility for the indicator, and a kappa of 0.80 for scoring. To become a measure for cancer care, the numerator and denominator of this indicator would need to be explicitly operationalized and tested in cancer populations.

**Follow-up.** We found one measure and zero indicators related to follow-up for dyspnea.

*Measure - Timely Treatment of Inpatient Dyspnea.* The UHC Palliative Care Benchmarking Project used a second performance measure regarding dyspnea relief or reduction of dyspnea.<sup>67</sup> The numerator is “persons with dyspnea relief or reduction within 48 hours of admission.” Significant reduction was operationalized as a 3-or-more-point reduction in dyspnea on a 10-point scale. The denominator is “adults 18 years of age and older, with admission for congestive heart failure (DRG 127), cancer (DRG 82, 203, 172, 274, 346, 10), HIV (DRG 489), or respiratory illness (DRG 475, 483) and a length of stay more than 4 days and 2 prior admissions for any cause in the preceding 12 months and reported dyspnea within the first 48 hours of admission.” No reliability or validity information is available. Information is the same as for the other UHC dyspnea indicator. The UHC report indicates that 62% of patients assessed had dyspnea within 48 hours after admission and that of these, 77% overall and 77% of cancer patients had relief or reduction of these symptoms. There was substantial variation in results with a range of 37.5% to 96.6% criteria met across the 35 hospitals participating in the benchmarking project. Further details about operationalization and details on psychometric testing are lacking. The indicator set is not known to be in use.

## Potential Indicators and Measurement Gaps

**Assessment.** We identified a large number of potential indicators in the substantial guideline, quality improvement, and research literature that we reviewed. We highlight here six potential indicators with relatively strong supporting evidence and/or expert consensus, highlighting critical issues not addressed by the indicators and measures listed above. These indicators have potential for demonstrating variability in quality and improving patient outcomes, and are applicable to cancer patients across the continuum and to diverse populations.

Although guidelines and evidence support assessment of dyspnea,<sup>15,18,21,109</sup> future research is needed to understand the most appropriate approach and instruments for assessment (i.e., provider observation, single-item symptom measures, or multi-item self-report effects of

dyspnea) in particular settings and diseases<sup>1</sup> as well as operating characteristics as quality indicators.<sup>15,16,109</sup> Subsequent research is indicated for indicators in dyspnea assessment. In the interim, it would be reasonable to develop and use a general indicator that at least some form of dyspnea symptom assessment was performed for all cancer patients.

*Assessment for Treatable Causes of Dyspnea.* The numerator is “all patients who have been assessed for treatable causes of dyspnea.” The denominator is “all cancer patients with dyspnea.” We identified four reports on the assessment of underlying causes of dyspnea.<sup>14,109-111</sup> The American College of Chest Physicians (ACCP) and American Thoracic Society (ATS) have recommended specific assessment for potentially correctable causes of dyspnea in this setting.<sup>109,110</sup> A prospective observational study demonstrated potentially correctable causes for dyspnea such as hypoxia (40%), anemia (20%), and bronchospasm (52%).<sup>14</sup> Another report supports the use of spirometry to detect any airway obstruction in patients with dyspnea.<sup>111</sup> A reasonable potential indicator would be to use medical record review to document that correctable conditions were sought in evaluation of dyspnea in cancer patients. Some consideration of time windows for recent evaluation would be important in operationalizing this as a standard.

**Treatment.** We identified eight potential indicators related to the treatment of dyspnea, from seven reports.<sup>110,108,109,112-115</sup> As with the general research gap in assessment of dyspnea, the operationalization of how much and when to assess for response to therapy requires future research and refinement of quality indicators.

*Treatment for Malignant Pleural Effusions.* The numerator is “patients who have had thoracentesis and appropriate subsequent therapy (pleurodesis or chemotherapy) as indicated.” The denominator is “cancer patients with dyspnea and malignant pleural effusions.” Evidence-based guidance from the ACCP Lung Cancer Guidelines, published by the American College of Chest Physicians includes (1) Patients with malignant pleural effusions that cause dyspnea initially should be drained by thoracentesis; (2) Patients with non-small cell lung cancer and better performance status and recurrent malignant pleural effusions, and whose lungs re-expand with initial thoracentesis or thoracoscopy, should be followed up by pleurodesis;<sup>110</sup> and (3) Patients with small cell lung cancer receive systemic chemotherapy when malignant effusions are present to relieve the symptoms of dyspnea.<sup>110</sup> Potential indicators for these specific conditions could be developed and tested. This guidance is clinically applicable to managing dyspnea in other cancers that cause malignant pleural effusions (breast, gastrointestinal, prostate, melanoma, others).

*Bronchoscopic Therapy.* The numerator is “patients who are offered, or who have, bronchoscopic therapy.” The denominator is “cancer patients with central airways obstruction.”

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<sup>1</sup> Measures may include the Lung Cancer Symptom Scale, Oxygen Cost Diagram, Baseline Dyspnea Index, Transition Dyspnea Index, University of California Shortness of Breath Questionnaire, Borg or Modified Borg Dyspnea Scale, Visual Analogue Scale, Chronic Respiratory Disease Questionnaire, Saint George Respiratory Questionnaire, Pulmonary Functional Status Scale, Breathing Problems Questionnaire, Modified Medical Research Council [Dyspnea Scale], American Thoracic Shortness of Breath Scale, and many other candidates including single item symptom scales, severity of symptom tools, generic health-related quality of life instruments, dyspnea related quality of life instruments, generic palliative care and satisfaction measures, symptom specific treatment response measures, and quality of dying measures.<sup>15, 16, 109</sup>

The ACCP<sup>110</sup> also present evidence based on a review of the literature that bronchoscopic therapy can reduce dyspnea in the presence of central airway obstruction, recommending that patients with central airway obstruction should have bronchoscopy and that in patients with central airway obstruction, rapid relief of dyspnea can be accomplished by removal of intraluminal tumor and/or by inserting a stent. A potential indicator may be that if a patient has cancer and central airway obstruction, then bronchoscopy and bronchoscopic therapy should be considered. This potential indicator is most applicable to lung cancer.

*Patient Education and Non-Pharmacologic Interventions.* The numerator is “patients who have received education about their dyspnea.” The denominator is “all cancer patients with dyspnea.” Kvale and colleagues<sup>110</sup> recommended that all lung cancer patients with dyspnea receive non-pharmacologic, non-interventional treatments including patient education to reduce the dyspnea symptoms. Patient education can encompass breathing control education, relaxation techniques, and psychosocial support. The evidence for this potential indicator was poor based on their review of the literature, and these interventions were felt to have poor supporting evidence but moderate net benefit due to the lack of side effects. This indicator could be broadly formulated based on clinical practice to all forms of malignancy with dyspnea.

*Palliative Radiation and Chemotherapy.*<sup>113,114</sup> The numerator is “patients who are offered or have received appropriate palliative chemotherapy or palliative radiation therapy.” The denominator is “all patients with particular malignancies.” The Lung Cancer Guidelines published by the American College of Chest Physicians<sup>114</sup> present evidence that chemotherapy can reduce dyspnea symptoms among patients with Stage IV non-small cell lung cancer. Socinski et al., identified seven studies that explored the palliation of symptoms by chemotherapy; four of the seven reduced dyspnea symptoms in over half of the patients enrolled.<sup>114</sup> Palliative chemotherapy should be considered for patients who are deemed suitable for treatment, including other malignancies.

The American Society of Clinical Oncology published a guideline for the treatment of unresectable non-small cell lung cancer<sup>113</sup> in 2003 in which they cite research that radiotherapy can provide relief from dyspnea symptoms. However, the evidence cited in this report included only nonrandomized comparisons to conventional therapy. This indicator may likely be operationalized only in retrospective medical record review with fulfillment of criteria as consideration for therapy.

*General Approaches.* The numerator is “patients who have had oxygen, bronchodilators, corticosteroids, opioids, or antibiotics attempted. The denominator is “patients with cancer and dyspnea (and possibly co-morbid conditions such as COPD).”<sup>110</sup> The evidence for the effectiveness of particular interventions is modest, but the net benefit may be moderate.<sup>110</sup> The ATS endorsed oxygen therapy, opioids, anxiolytics, and bronchodilator trials to diminish dyspnea symptoms among terminally ill patients with lung disease.<sup>109</sup> Several systematic reviews support the efficacy of opioids and oxygen in patients with advanced illness including cancer.<sup>21,112,116</sup> A reasonable criterion may be to consider whether therapy was considered, offered, or tried. The operationalization of this indicator would require further specification based on underlying disease, the physiologic mechanism of dyspnea, and particular therapeutic interventions (for example, specifying concomitant obstructive lung disease when evaluating use of bronchodilators).



# Depression

## Introduction

For the condition of depression, we searched for measures and indicators restricted to the condition of cancer. We identified one measure and three indicators that were relevant. Please refer to the Evidence Table in Appendix F3\*.

The UHC Palliative Benchmarking Project has evaluated one indicator related to formal psychosocial assessment in mixed hospitalized populations that include cancer patients.<sup>67</sup>

ACOVE's end-of-life indicators addressed spiritual assessment prior to death, which we considered broadly applicable.<sup>59</sup> ACOVE also included measures and indicators for depression, as did QA Tools.<sup>65,72</sup> Some of these may be regarded as relevant, although we included only two additional ACOVE indicators, because one explicitly addressed depression in the elderly in the context of a new cancer diagnosis, and the other addressed somatic symptoms in vulnerable elders that overlap with presenting symptoms of cancer. QA Tools relied on AHCPH depression guidelines that emphasized cancer as an associated risk factor, although none of its indicators address this situation directly.

## Measures and Indicators

**Assessment.** We identified one measure and one indicator relevant to cancer and depression assessment.

*Measure - Regular Assessment for Psychosocial Well-Being.* The UHC Palliative Care Benchmarking Project<sup>67</sup> included one measure relevant to depression assessment. The numerator is “persons with a formal psychosocial assessment (usually an assessment by a social worker) up to one year prior to admission during a previous admission OR within four days of the index admission.” The denominator is “adults  $\geq 18$  years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay  $> 4$  days AND 2 prior admissions for any cause in preceding 12 months.” This denominator was developed by an expert panel to represent a potential palliative care population in hospitals. Only a mean of 25% (median 17%, range 0-95%) of the UHC sample met the criteria for this indicator. This indicator identified four high performing facilities where more than 60% of patients had been assessed in the prior year. No reliability or validity information is available; however, the benchmarking project found that a combination of use of all of the UHC measures in a “palliative care bundle” was associated with lower patient length of stay. In addition, several elements of the bundle could be used to identify hospitals with “best practices” for palliative care. Scores from the bundle were instrumental in achieving advances in palliative care at several hospitals, including justifying at least one new palliative care program. Finally, results for the “bundle” varied significantly among the 35 hospitals participating in the project. It is intended for use as a tool for comparing performance in all hospitals. The measure is not known to be in current use.

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>

*Indicator - Regular Spiritual Assessment in Expected Dying.* ACOVE identified one indicator relevant to depression assessment. The numerator is “vulnerable elders with a documentation of a spiritual assessment in the medical record.” The denominator is “vulnerable elders who were conscious during the last three days of life and who died an expected death.” Although eight items from the ACOVE end-of-life set were evaluated for reliability and validity<sup>72</sup> as part of the ACOVE project, this indicator was not included in the evaluation. The denominator may be difficult to define, since “expected death” requires explicit medical record documentation more than one day before death that the patient is expected to die. This measure is intended for use in all vulnerable elders. An expert panel accepted a modified version of this indicator as part of a revised set for nursing homes.<sup>60</sup> The nursing home indicator requires a denominator of “nursing home residents who died expected deaths and were conscious at all during the last seven days of life.” The numerator for the adapted measure requires that pain, spirituality, and emotional distress all have been addressed. Neither indicator is in current use.

**Treatment.** We identified two measures relevant to depression treatment among cancer patients.

*Measure - Regular Assessment or Treatment of Depression in Newly Diagnosed Cancer.* ACOVE identified two indicators relevant to both depression assessment and treatment.<sup>117,60</sup> For the first indicator, the numerator is “patients asked about or treated for depression, or referred to a mental health professional within two months of the diagnosis of a condition.” The denominator includes “all persons diagnosed with stroke, myocardial infarction, dementia, malignancy (excluding skin cancer), chronic pain, alcohol or substance abuse or dependence, anxiety disorder, or personality disorder.” These conditions were accepted for the indicator on the basis of their association with incident or prevalent depression. Although 13 indicators from the ACOVE depression set were evaluated for reliability and validity in a community population,<sup>72</sup> this indicator was not included, although it was operationalized for cancer patients. No information on reliability and validity is available for this indicator. The indicator is not in use.

A second ACOVE measure (*routine assessment or treatment of depression in symptomatic patients*) relevant to depression assessment and treatment addressed both affective and somatic symptoms among vulnerable elders.<sup>117,60</sup> The numerator is “patients asked about or treated for depression, or referred to a mental health professional within two weeks of presentation.” The denominator is “vulnerable elders with new onset of one of the following symptoms-sad mood, feeling down, insomnia or difficulties with sleep, apathy or loss of interest in pleasurable activities, reports of memory loss, unexplained weight loss of more than 5% of body weight in the past month or 10% over one year, or unexplained fatigue or low energy.” This indicator was included in the 13 indicators from the ACOVE depression set, although ACOVE field evaluation excluded patients undergoing active cancer treatment. Only 26 of the 34 quality indicators triggered were passed.<sup>72</sup> No information on reliability or validity is available. This indicator is not in use.

**Follow-up.** We identified zero measures and zero indicators relevant to the follow-up of depression treatment in cancer patients.

## Potential Indicators and Measurement Gaps

Within the literature that we identified, only the ACOVE set provided measures and indicators for depression among a population that did not include cancer patients, per se or was not limited to cancer patients; thus we considered these as potential indicators. Quite a number of other measurement sets address depression care in general. ACOVE provides only a general example of that class of non-cancer depression indicators that might be considered. However, many of these indicators may not be appropriate for hospice or similar settings, since some of them address issues such as follow-up within months of depression diagnosis, and life expectancy in such settings may be very short. Nevertheless, within ACOVE, we identified the following additional potential indicators for cancer care.

**Assessment.** We identified three potential indicators relating to initial depression assessment.

*Appropriate Diagnosis.* Two ACOVE indicators are based on the assumption that depression diagnosis should document the presence or absence of major affective symptoms and suicidality. Both of these indicators use as a denominator population “all vulnerable elders with a new diagnosis of depression.” The first addresses the need to distinguish between major depression and other affective syndromes and uses as a numerator “patients where the medical record documents at least three of nine DSM-IV target symptoms within the first month of diagnosis.” The second indicator addresses the need to evaluate suicidality and uses as a numerator “patients where the medical record on day of diagnosis documents the presence or absence of suicidal ideation and psychosis.” These indicators are based on the findings that only patients with major depression are known to respond to medication<sup>117</sup> and that evidence of psychosis and suicidality should be considered in the approach to treatment.<sup>117</sup> The documentation of depressive symptoms may differ somewhat for cancer patients, especially late stage patients where fatigue and other manifestations of illness overlap with the “vegetative symptoms.”

*Evaluating Suicidality.* One ACOVE indicator addresses the need to evaluate and treat suicidality appropriately when it is present in a patient with newly diagnosed depression. The numerator for this indicator is “patients where the medical record documents that the person has no immediate plans for suicide or that the patient was referred for evaluation for psychiatric hospitalization.” Expert opinion supports this approach even though ethical considerations make studies of interventions difficult. Suicide is a disproportionate concern among the elderly in general, and cancer patients in particular.<sup>117</sup>

**Treatment.** We identified 2 potential indicators that were related to initial treatment.

*Use of the Most Appropriate Anti-Depressants.* Two ACOVE indicators address the appropriate use of medication in patients newly treated for depression. The denominator for both of these indicators is “vulnerable elders being treated for depression with antidepressants.” The numerator for the first potential indicator is “patients where the following medications are not used as first or second-line therapy: tertiary amine tricyclics, monoamine oxidase inhibitors (unless atypical depression is present), benzodiazepines, or stimulants (except methylphenidate).” This indicator is based on the fact that for the most part, antidepressants

have equal efficacy, although side-effect profiles differ and are generally worse for older antidepressants highlighted by the indicator.<sup>117</sup>

*Dose Titration.* The denominator for this indicator is “vulnerable elders being treated for depression with antidepressants.” The numerator for the second potential indicator is “patients with antidepressants started at appropriate doses, and with an appropriate titration schedule to a therapeutic dose, therapeutic blood level, or remission of symptoms by 12 weeks.” Many studies demonstrate that older patients do not receive appropriate follow-up including therapeutic doses of antidepressant medications.<sup>117</sup>

**Follow-up.** We identified four potential indicators that were related to follow-up of initial treatment.

*Addressing Non-Responders to Initial Treatment.* The numerator for this potential indicator is “patients with antidepressant treatment, psychotherapy, or electroconvulsive therapy (ECT) offered within two weeks after depression diagnosis unless there is documentation within that period that the patient has improved, or unless the patient has substance abuse or dependence, in which case treatment may wait until eight weeks after the patient is in a drug or alcohol free state.” The denominator is “vulnerable elders with a new diagnosis of depression.” This indicator addresses the fact that psychotherapy may be the initial treatment attempted in depression, and that although the time-course of response is unclear, other treatments should be started within weeks of diagnosis if it is ineffective.<sup>117</sup>

*Addressing Partial Responders to Treatment.* Two ACOVE indicators addressed the appropriate care for patients who were only partial responders to initial pharmacotherapy at 6 and 12 weeks. The denominators for those potential indicators are “vulnerable elders who have only had a partial response to therapy (at each time period).” For the first indicator that addresses week-6 nonresponders, the numerator is “patients with one of the following treatment options initiated by the eighth week of care: medication dose should be optimized or the patient should be referred to a psychiatrist (if initial treatment was medication); or medication should be initiated or referral to a psychiatrist should be offered (if initial treatment was psychotherapy alone).” The second indicator addresses partial responses at 12 weeks. The numerator for this indicator is “patients with one of the following options instituted by the 16<sup>th</sup> week of treatment: switch to a different medication class or add a second medication to the first (if initial treatment includes medication); add psychotherapy (if the initial treatment was medication); try medication (if initial treatment was psychotherapy without medication); consider ECT; or refer to a psychiatrist.”

*Maintaining Effective Anti-Depressant Care.* This potential indicator addresses the need for maintenance therapy. The denominator is “vulnerable elders who have responded successfully to antidepressant medication treatment.” The numerator is “patients continued on the drug at the same dose for at least six months, and making at least one clinician contact (office visit or phone) during that period.” This potential indicator acknowledges uncertainty in the exact amount of time that therapy should be continued in responders but upholds a lower limit of six months.<sup>117</sup>

# Advance Care Planning

## Introduction

The review of literature in the area of advance care planning was not limited only to cancer. We identified a total of 30 indicators concerning the identification and documentation in the patient's medical record of advance directives, designation of a proxy decisionmaker, preferences for care in cognitively impaired elderly, referral to hospice, and utilization-based indicators of high intensity care. Please refer to the Evidence Table in Appendix F4\*. We included utilization indicators because much of the literature on advance care planning has focused on avoiding (e.g., resuscitation) or facilitating (e.g., hospice referral) particular treatment or utilization outcomes. However, we acknowledge that such indicators are limited as patient-centered metrics and may inadequately account for patient preferences. Furthermore, measures of particular types of utilization (e.g., hospitalization) may also reflect structural factors or the adequacy of alternative services. For that reason, other investigators might have made a reasonable decision to exclude such outcomes from consideration, although we included them for completeness. The indicators tended to overlap significantly and, where there was overlap, the primary differences were in care setting (e.g., ICU vs. nursing home, nursing home vs. hospital)<sup>68</sup> or populations (e.g., dementia vs. incapacitated patients).<sup>118</sup> In addition, the literature on advance directive/advance care planning overlaps with the literature on good end-of-life/palliative care standards. Where appropriate, these overlapping indicators will be discussed together. Some items that did not clearly address "assessment," "application," or "follow-up" but crossed all domains are addressed separately. Finally, indicators may identify potential standards for hospital, system,<sup>67</sup> or regional<sup>55,119,120</sup> performance.

## Measures and Indicators

**Assessment.** We identified eight measures and four indicators relevant to advance care planning assessment.

*Measure - Regular Identification of a Surrogate in Outpatient Setting.* ACOVE's end-of-life indicators included one measure addressing the identification of a surrogate decisionmaker among outpatients.<sup>59,72</sup> The numerator is "the number of vulnerable elderly patients with medical record documentation of their surrogate decisionmaker's name and contact information, or of a discussion with the patient of who would be surrogate, or documentation of a search for a surrogate, or an indication that there is no identified surrogate." The denominator is "all vulnerable elderly outpatients." No clinical trials or observational studies have examined this issue, yet documentation is an important tool for clinician access to an incapacitated patient's decisionmaker,<sup>21,121</sup> and many consensus statements promote designation of a surrogate decisionmaker (e.g., AGS Ethics Committee, 1995). One prospective study of physicians discussing advance directives with patients revealed that the physicians recognized the correct surrogate decisionmaker 89% of the time after such a discussion.<sup>122</sup> Only 4% of 370 eligible

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>

charts in the 420-person ACOVE community-based sample passed this indicator.<sup>72</sup> No reliability or validity information is available for the individual measure. The measure is not in use.

*Measure - Regular Identification of a Surrogate Among Hospital Admissions With Impaired Cognition*<sup>ii</sup>. One ACOVE measure addresses surrogacy among patients admitted to the hospital.<sup>59,72</sup> The numerator is “the number of vulnerable elders (among those with the denominator conditions) who have chart documentation within 48 hours of either an advance directive indicating the patient’s surrogate decisionmaker, a discussion about who would be a surrogate decision maker or a discussion about a search for a surrogate, or an indication that there is no identified surrogate.” The denominator is “all vulnerable elders with dementia, coma, or altered mental status admitted to a hospital who survive 48 hours.” This indicator has implications for cancer patients who may have temporary (e.g., delirium) or durable cognitive impairment. Research has shown that the majority of patients admitted to the hospital have neither named a surrogate decision maker nor expressed their treatment preferences in a written document.<sup>123</sup> However, observational data suggest that physician understanding of patient resuscitation preference (a component of advance directives) is associated with a better match between those preferences and resuscitation attempts and is associated with less end-of-life resource use.<sup>124-126</sup> Only 25% of 20 eligible charts in ACOVE’s 420-person community-based sample passed this indicator.<sup>72</sup> No reliability or validity data are available on this individual item. The measure is not in use.

*Measure - Regular Assessment of Preferences Among Inpatients With Dementia.* One ACOVE measure addresses documentation of preferences among inpatients with severe dementia.<sup>59,72</sup> The numerator is “the number of severely demented elders with documentation in their medical record that the patient’s prior preferences for care have been considered or that these preferences could not be elicited or are unknown.” The denominator is “all vulnerable elderly patients with severe dementia admitted to the hospital who survive 48 hours.” This indicator has implications for cancer patients who may develop cognitive impairment associated with their cancer (e.g., delirium). Aggressive medical interventions and inadequate pain management are common in hospitalized dementia patients.<sup>127</sup> This measure could be evaluated among only 2 of 420 cases in ACOVE’s community-based cohort.<sup>72</sup> No reliability or validity information is available for the specific measure. The measure is not in use.

*Measure - Regular Assessment of Preferences in an ICU.* This ACOVE measure addresses documentation of preferences in an ICU.<sup>59,72</sup> The numerator for this indicator is “the number of vulnerable elders admitted directly to the intensive care unit from an outpatient or ER setting and surviving 48 hours with documentation in the medical record that the patient’s preferences for care have been considered or that these preferences could not be elicited or are unknown within 48 hours of admission.” The denominator for this indicator is “all vulnerable elderly patients admitted directly to the ICU from the outpatient setting or emergency department and who

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<sup>ii</sup> Dementia and altered mental status were defined as: diagnosis of dementia OR MD or RN note on Day 1 or 2 of cognitive impairment (confused, disoriented, O<sub>x</sub>2, O<sub>x</sub>1, unable to follow commands) OR neurologic change (somnolent, lethargic, poorly arousable, semicomatose, stuporous, obtunded, comatose) OR inattentive, restless, agitated.

survive 48 hours.” Only 6 of 420 patients in ACOVE’s community sample were eligible for this measure, and 17% passed.<sup>72</sup> No reliability or validity data are available for this specific measure. The measure is not in use.

*Measure - Regular Assessment of Preferences in Hospice.* NHPCO<sup>54</sup> measure addresses common decisions about activities of daily living, life closure, and care received by patients and family members facing a terminal illness. The numerator for this indicator is “the number of hospice patients who received care (either hospitalization or resuscitation) consistent with their expressed preferences as assessed at the time of admission.” The denominator is “all patients admitted to hospice.” Experts identified a number of global categories of decisionmaking, such as determination of the degree of symptom management desired, setting goals in relation to sentinel events, expressing or not expressing religious and spiritual needs, determination of one’s wishes for the site of death, hospitalization, and CPR.<sup>63</sup> The intent of this indicator is to assist hospice patients in identifying care preferences and then meeting these needs by conducting a comprehensive assessment, including physical, functional, emotional, and spiritual and preferences, and allowing full autonomy to the patient and family to make decisions about how the remainder of the patient’s life is to be spent upon admission. Hospices report these data voluntarily to NHPCO. In 2002, 120 agencies reported this measure, and the mean and median values were 97%. No reliability or validity data are available. This measure is in current use as a voluntary reporting standard.

*Measure - Regular Patient Participation in Decisions To Limit Treatment.* This ACOVE measure focuses on ensuring participation in decisions for the withdrawal or withholding of life-sustaining treatments (LST), which is consistent with ethical and professional guidelines.<sup>59,72</sup> The numerator is “the number of vulnerable elderly patients with documentation in the medical record of participation in the decision or why the patient did not participate in a decision regarding LST.” The denominator is “all vulnerable elderly patients in the hospital or nursing home with written orders to withdraw or withhold a LST.” A small study comparing chart documentation to patient recall about life-sustaining treatment decisions showed that medical record documentation reflected patient understanding of these decisions.<sup>128</sup> Ten of the 420 cases in ACOVE’s community-based sample met criteria for the measure, and 70% passed.<sup>72</sup> No reliability or validity information is available on this specific measure. The measure is not in use.

*Measure - Regular Family Meetings Among Hospitalized Patients.* The numerator for this UHC measure is “the number of adults admitted to the hospital with documentation in the medical record that the health care team conducted a patient/family meeting within one week of admission that included discussion of the patient’s treatment preferences and/or a plan for discharge disposition.”<sup>67</sup> The denominator is adults  $\geq 18$  years of age, with admission for CHF (DRG 127), cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay  $> 4$  days AND 2 prior admissions for any cause in preceding 12 months.” This indicator is similar to the ACOVE measures<sup>59,72</sup> that specify documentation of patient participation in decisionmaking (implying communication of some sort between the patient and provider team) and the VHA indicators<sup>68</sup> that specify conducting an interdisciplinary team meeting with the family within 120 hours of ICU admission. A mean of 39% (median 41%, range 0-93%) of the UHC cohort met this indicator. Only 55% of cancer patients met the

indicator. The distribution of results appeared to be broadly normal. As with the other UHC measures, no individual reliability or validity information is available. It is not known to be in current use.

*Measure - Timely and Effective Discharge Planning.* The numerator for this UHC measure is the number of adults admitted to the hospital with documentation in the medical record of a plan for discharge disposition within four days of admission.”<sup>67</sup> The denominator is “adults  $\geq 18$  years of age, with admission for CHF (DRG 127), cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay  $> 4$  days AND 2 prior admissions for any cause in preceding 12 months.” This measure implies that all patients who enter the hospital and stay at least one week should receive a plan for discharge disposition within four days of admission. Planning for discharge is usually not explicitly included in discussions of advance directives, although many critically ill patients frequently move in and out of the hospital and across a variety of health care settings as they progress on a downward trajectory toward death. This explicit recognition of the importance of planning for care after leaving the hospital is a contribution to the advance directives discussion. A mean of 53% (median 53%, range 18-94%) of the UHC cohort met this indicator. Only 62% of cancer patients met the indicator. The distribution of results appeared to be broadly normal. As with the other UHC measures, no individual reliability or validity information is available. It is not known to be in current use.

*Indicator - Regular Identification of a Surrogate in the ICU.* This VHA indicator focuses on the identification of a medical decisionmaker (family member or other appropriate surrogate) and is similar to the ACOVE indicator<sup>68,72,129</sup> identifying a surrogate/proxy for community-dwelling or hospitalized vulnerable elders. Other than setting, the major difference with the ACOVE indicators is the timeframe identified for performance of the indicator (24 vs. 48 hours): The denominator is “the total number of ICU patients with a stay of  $\geq 24$  hours.” The numerator is “the number of patients who have documentation on the status of identification of a health care proxy (or other appropriate surrogate decisionmaker) within 24 hours.” Support for this indicator is derived from JCAHO Hospital Standard RI.1.2.3, literature focusing on the withdrawal of life-support in the ICU,<sup>130</sup> and practice guidelines.<sup>100</sup> This measure is currently being used as part of the VHA TICU initiative and is part of the VHA palliative care bundle, which will be initiated in September 2005.

*Indicator - Regular Assessment of Advance Directives for ICU Patients.* This VHA indicator focuses on the specification and documentation of the patient’s advance directive if admitted to the ICU within 24 hours of admission.<sup>68</sup> The numerator for this indicator is “the number of patients admitted to the ICU with documentation of the patient’s advance directive (written or oral instructions from the patient specifying the type of medical treatment that is desired if the patient becomes incapacitated, including a living will, durable power of attorney (note State-specific status) or any document that State law recognizes as an “advance directive” entered in the medical record within 24 hours following admission.” The denominator is “the total number of patients with an ICU length of stay greater than 24 hours.” Support for this indicator is derived from JCAHO Hospital Standard RI.1.2.5; the National Consensus Project for Quality Palliative Care Clinical Practice Guideline 1.2, 8.1<sup>69,131</sup> and literature on decision making and medical outcomes.<sup>132,133</sup> This measure is currently being used as part of the VHA TICU



initiative and is part of the VHA palliative care bundle, which will be initiated in September 2005.

*Indicator - Regular Assessment of Specific Resuscitation Preferences in the ICU.* This VHA indicator focuses on the percent of patients with documentation in the medical record of resuscitation status within 24 hours following admission to the ICU.<sup>68</sup> The numerator for this indicator is “the number of patients admitted to the ICU with documentation of the patient’s advance directive (written or oral instructions from the patient specifying the type of medical treatment that is desired if the patient becomes incapacitated, including a living will, durable power of attorney (note State-specific status) or any document that State law recognizes as an ‘advance directive’) entered in the medical record within 24 hours following admission.” The denominator is “the total number of patients with an ICU length of stay greater than 24 hours.” Support for this indicator is derived from the literature on decisionmaking and medical outcomes.<sup>132</sup> This measure is currently being used as part of the VHA TICU initiative and is part of the VHA palliative care bundle, which will be initiated in September 2005.

*Indicator - Regular Clinician-Patient-Family Communication in the ICU.* This VHA indicator addresses inadequate communication among patients, family members, and health care providers in ICUs.<sup>68,134</sup> The numerator for this indicator is “the number of patients admitted to the ICU who survive more than 5 days (120 hours) with documentation in the medical record that an interdisciplinary team meeting (with at least the attending physician (primary care or ICU attending) and a nurse) and the patient and/or family was conducted within 72 hours of ICU admission and involved a discussion addressing each of the following topics: the patient’s condition (diagnosis and prognosis), goals of treatment, the patient’s and family’s needs and preferences, and the patient’s and family’s understanding of the patient’s condition and goals of treatment at the conclusion of the meeting.” The denominator is “total number of patients with an ICU length of stay more than 5 days (120 hours).” Support for this indicator is derived from JCAHO Standards RI.1.2.2.-RI.1.2.8, RI.1.3.6; NCP\_CPG 1.3.<sup>135,136</sup> A joint meeting with the surrogate and family members and the health care team, labeled a “family conference,” should be used to answer any questions family members might have regarding the condition of the patients and to explore goals of care. The literature identifies various elements of good communication as well as barriers to advance directive discussions.<sup>137-141</sup> This measure is currently being used as part of the VHA TICU initiative and is part of the VHA palliative care bundle, which will be initiated in September 2005.

**Application.** We identified two measures and zero indicators addressing the application of existing care plans.

*Measure - Documentation of Care Preferences Across Venues.* Several ACOVE measures address advance directive continuity.<sup>59,72</sup> The goal of advance care planning is to ensure that patient’s preferences for care are identified and followed. The denominator is “all vulnerable elderly with an advance directive in the outpatient, inpatient, or nursing home medical record or who report the existence of an advance directive in an interview, and are receiving care in another venue.” The numerator is “those cases with documentation in their medical record of the existing advance directive at the second venue or documentation acknowledging the existing advance directive, its contents, and the reason that it is not included in the medical record.” Five

observational studies have documented that even when advance directives are completed, patients' physicians often do not know that they exist,<sup>126,142,143</sup> and the directives are not always documented in the patients' charts<sup>144</sup> or transferred from outpatient to inpatient settings.<sup>145</sup> This measure passed in 25% of the 8 cases among 420 community-dwelling elderly in the ACOVE study.<sup>72</sup> No reliability or validity information is available on the specific measure. The measure is not in use.

*Measure - Documentation of Specific Life Sustaining Preferences.* This ACOVE measure addresses the need to document decisions a vulnerable elder makes concerning future health states.<sup>59,72</sup> The numerator is "patients with one of the following documented in the medical record: a discussion of life-sustaining treatment preferences, an advance directive, or that the patient discussed this topic with the physician or does not wish to discuss this topic." The denominator is "all vulnerable elderly patients who indicate (during an interview) that they would rather die than live permanently comatose, ventilated, or tube fed." Observational studies show that large proportions of patients would prefer to die than live permanently comatose, mechanically ventilated, or tube fed and that physicians and surrogate decision makers often do not know patients' preferences about life-sustaining treatments.<sup>59</sup> Consensus statements promote the documentation of these preferences (e.g., The American Geriatric Society Ethics Committee, 1995). Of the 238 of 420 eligible patients in ACOVE's community-based sample, only 12% passed the measure.<sup>72</sup> No reliability or validity information is available on this specific measure. The measure is not in use.

**Follow-up.** We identified 14 separate measures (covering 10 general categories) and 7 indicators (covering 8 general categories) addressing follow-up. Many of these administrative measures and indicators are closely related. For example, Cancer Care Ontario<sup>119</sup> and CCNS<sup>146</sup> are both using indicators and measures very similar to those developed by investigators at the Dana-Farber Cancer Institute.<sup>146</sup> For that reason, these similar measures and indicators are discussed together whenever possible.

*Measure - Consistency of Preferences With Use of Ventilator Support.* This ACOVE measure focuses on consistency between use of ventilator support and documented preferences.<sup>59,72</sup> The numerator is "the number of records with documentation of the goals of care and the patient's decision for mechanical ventilation or why this information is unavailable." The denominator is "all hospitalized vulnerable elders requiring mechanical ventilation (except short-term and post operative mechanical ventilation)." This indicator is intended for use with all vulnerable elderly patients requiring mechanical ventilation, including cancer patients. Practices concerning withdrawal of treatment for patients receiving mechanical ventilation vary widely.<sup>123,135,143,147,148</sup> Practices regarding withholding of specific treatments among surveyed physicians also varied greatly.<sup>100</sup> The SUPPORT study found that a primary predictor of whether a ventilator was withdrawn was the existence of communication about care preferences.<sup>149</sup> Only 2 of 420 persons in ACOVE's community-based study met criteria for the measure. No reliability or validity information is available on this specific measure. The measure is not in use.

*Measure - Late Life Hospital Use.*<sup>77,150</sup> Several measures or indicators address late-life hospital use. One measure was developed by Dana-Farber Cancer Institute<sup>146</sup> investigators, and a closely related measure is in use by Cancer Care Ontario.<sup>119</sup> A similar indicator is in the process of

being operationalized by CCNS.<sup>146</sup> The numerator for the Dana-Farber measure is “the proportion of cancer decedents with more than one hospitalization or ER visit in the last month of life. The denominator is “all cancer decedents.” Support for its validity comes from literature reviews; focus groups of patients, caregivers, and providers; expert panel review; and quantitative analysis of the indicator in Medicare claims data. This measure was evaluated in a Medicare-SEER database, and using the highest performing decile of this measure implied that in high performing health care service areas (HCSAs), fewer than 4% of cancer decedents would have more than one hospitalization or emergency room visit in the last month of life. When a sample of 150 charts at Dana-Farber were abstracted as the gold standard against which the sensitivity and specificity of the measure would be determined, this measure was determined to have a sensitivity of 0.96, specificity of 1.00, and accuracy of 0.097. As a measure of variability, investigators determined the 5<sup>th</sup>/95<sup>th</sup> percentile ratio (2.38) (range: 1.85-3.16). The Cancer Care Ontario measure is “hospital use in days by stage of cancer.” The populations for the “stage of cancer” consist of those in initial care (within six months of diagnosis), continuing care, and terminal care (within six months of death). A separate category, investigative care, is defined as patients with a benign outcome. Provincial resource use in 2002 indicated that as a proportion of total cost, the terminal phase of care used 29 to 42% of resources across Ontario. The initial phase of care used 31 to 38% of total resources.<sup>120</sup> A closely related indicator, hospital days near the end of life, is being operationalized by CCNS.

*Measure - Late Life ICU Use.*<sup>77,146,150</sup> Several measures or indicators address late-life ICU use. One measure was developed by Dana-Farber Cancer Institute. A similar indicator is currently being operationalized by CCNS. The numerator for the Dana-Farber measure is “the proportion of cancer decedents with admission to the ICU in the last month of life.” The denominator is “all cancer decedents.” Support for its validity comes from literature reviews; focus groups of patients, caregivers, and providers; expert panel review; and quantitative analysis of the indicator in Medicare claims data. This measure was evaluated in a Medicare-SEER database and, using the highest performing decile of this measure, the data implied that in high performing HCSAs fewer than 4% of cancer decedents would have more than one ICU admission in the last month of life. When a sample of 150 charts at Dana-Farber were abstracted as the gold standard against which the sensitivity and specificity of the measure was determine, this measure was determined to have a sensitivity of 0.87, specificity of 0.97, and accuracy of 0.095. As a measure of variability, investigators determined the 5<sup>th</sup>/95<sup>th</sup> percentile ratio (3.28) (range: 2.38-4.67). A closely related indicator, ICU days near the end of life is being operationalized by CCNS. Neither the measure nor the indicator are currently in use.

*Measure - Late Life Rate of Emergency Care.* This measure was developed by Dana-Farber Cancer Institute<sup>77,146,150</sup> investigators, and a closely related measure is in use by Cancer Care Ontario.<sup>119</sup> A similar indicator is currently being operationalized by CCNS.<sup>146</sup> The numerator for the Dana-Farber measure is “the proportion of cancer decedents with more than one emergency room visit in the last month of life.” The denominator is “all cancer decedents.” Support for its validity comes from literature reviews; focus groups of patients, caregivers, and providers; expert panel review; and quantitative analysis of the indicator in Medicare claims data. This measure was evaluated in a Medicare-SEER database, and, using the highest performing decile of this measure, the data suggested that in high performing HCSAs, fewer than 4% of cancer decedents would have more than one emergency room visit in the last month of

life. When a sample of 150 charts at Dana-Farber were abstracted as the gold standard against which the sensitivity and specificity of the measure was determined, this measure was determined to have a sensitivity of 0.82, specificity of 0.96, and accuracy of 0.89. As a measure of variability, investigators determined the 5<sup>th</sup>/95<sup>th</sup> percentile ratio (2.78) (range: 2.04-3.88). The Cancer Care Ontario measure is “the rate of cancer patients utilizing an emergency room in the last two weeks of life.” The denominator is “all cancer patients dying in a hospital.” Provincial rates of this measure varied between about 20% and 25% in 2002. A closely related indicator, the frequency of emergency visits, is being operationalized by CCNS.

*Measure - New Chemotherapy Regimen in Last 30 Days of Life.*<sup>77,150</sup> This measure was developed at the Dana-Farber Cancer Institute<sup>146</sup> and a closely related indicator is being operationalized in ongoing work by CCNS.<sup>77</sup> The numerator is “the number of dying cancer patients started on a new chemotherapy regimen in the last 30 days of life.” The denominator is “all deceased cancer patients.” A high proportion (more than 2%) of cancer patients receiving a new chemotherapy regimen in the last 30 days of life indicates poor quality care.<sup>120</sup> Support comes from literature reviews; focus groups of patients, caregivers, and providers; expert panel review; and quantitative analysis of the indicator in Medicare claims data. This measure was normed in a Medicare-SEER database and, using the highest performing decile of this measure, the data implied that in high performing HCSAs, fewer than 2% of patient would initiate new chemotherapy regimens in the last month of life. A sample of 150 charts at Dana-Farber were abstracted as the gold standard against which the sensitivity and specificity of the measure was determined. This measure was determined to have a sensitivity of 0.83, specificity of 0.94, and accuracy of 0.85. As a measure of variability, investigators determined the 5<sup>th</sup>/95<sup>th</sup> percentile ratio (3.19) (range: 2.03-5.41). CCNS is operationalizing a closely related indicator – the interval between new chemotherapy and death. This measure is not in use.

*Measure - Chemotherapy in Last 14 Days of Life.*<sup>77,150</sup> This measure is derived from the Dana-Farber Cancer Institute<sup>146</sup> measure set and a closely related indicator is being operationalized in ongoing work by CCNS.<sup>77,120</sup> The numerator is “the number of dying cancer patients receiving chemotherapy in the last 14 days of life.” The denominator is “all deceased cancer patients.” A high proportion (more than 10 %) of cancer patients receiving chemotherapy in the last 14 days of life indicates poor quality care. Support for this indicator comes from literature reviews; focus groups of patients, caregivers, and providers; expert panel review; and quantitative analysis of the indicator in Medicare claims data. This indicator was normed in a Medicare-SEER database and, using the highest performing decile of this measure, the data suggest that in high performing HCSAs, fewer than 10% of patients would receive chemotherapy in the last 14 days of life. When a sample of 150 charts at Dana-Farber were abstracted as the gold standard against which the sensitivity and specificity of the measure was determined, this measure was determined to have a sensitivity of 0.92, specificity of 0.94, and accuracy of 0.92. As a measure of variability, investigators determined the 5<sup>th</sup>/95<sup>th</sup> percentile ratio (2.24) (range: 1.74-2.97). CCNS is evaluating a closely related indicator, using a “short” interval between the last chemotherapy and death. This measure is not in use.

*Measure - Admission to Hospice.*<sup>150</sup> This measure was developed by investigators at the Dana-Farber Cancer Institute<sup>146</sup> and is currently being operationalized as an indicator by CCNS<sup>77,120</sup> and Cancer Care Ontario.<sup>77</sup> A closely related measure was also selected for use by the Georgia

Cancer Coalition.<sup>55</sup> The numerator is “the number of cancer patients not admitted to hospice.” The denominator is “all deceased cancer patients.” Numerous observational studies as well as several recent methodologically rigorous systematic reviews qualitatively support the effectiveness of hospice and palliative care in addressing the full range of quality-of-care domains.<sup>4,21</sup> Support for the validity of this item comes from literature reviews; focus groups of patients, caregivers, and providers; expert panel review; and quantitative analysis of the indicator in Medicare claims data. This measure was normed in a Medicare-SEER database and, using the highest performing decile of this measure the data suggested that in high performing HCSAs, fewer than 45% of patients would die without being admitted to hospice. When a sample of 150 charts at Dana-Farber were abstracted as the gold standard against which the sensitivity and specificity of the measure was determined, this measure was determined to have a sensitivity of 0.24, specificity of 0.96, and accuracy of 0.88. As a measure of variability, investigators determined the 5<sup>th</sup>/95<sup>th</sup> percentile ratio (5.00) (range: 3.76-6.89). Several closely related indicators are being evaluated and operationalized by CCNS, including enrollment in hospice, access to palliative care or palliative physician assessment, and periodic palliative care. The Georgia Cancer Coalition has operationalized this item as “the rate of cancer deaths in hospice.” Using a SEER-Medicare dataset, the proposed numerator is “the number of adults with cancer discharged due to death” and the denominator is “the number of adults with cancer (ICD-10 codes C00-C97, ICD-9 140-208).”<sup>55</sup> No reliability or validity information is available other than from the Dana-Farber experience. This item is not known to be in current use as a measure.

*Measure - Late Referral to Hospice.*<sup>77,150</sup> This measure was developed by investigators at the Dana-Farber Cancer<sup>146</sup> and is very similar to a measure developed by CCNS<sup>146</sup> and the Georgia Cancer Coalition.<sup>55</sup> The numerator is “the number of dying cancer patients referred to hospice or palliative care less than three days before death.” The denominator is “all deceased cancer patients.” A high proportion (more than 8 %) of dying cancer patient being referred to hospice or palliative care less than three days before death indicates poor quality care.<sup>146</sup> Support for the validity of this measure comes from literature reviews; focus groups of patients, caregivers, and providers; expert panel review; and quantitative analysis of the indicator in Medicare claims data. This measure was normed in a Medicare-SEER database, and using the highest performing decile of this measure, the data implied that in high performing HCSAs, fewer than 8% of dying patients would be admitted to hospice in the last three days of life. When a sample of 150 charts at Dana-Farber were abstracted as the gold standard against which the sensitivity and specificity of the measure was determined, this measure was determined to have a sensitivity of 0.97, specificity of 1.00, and accuracy of 0.97. As a measure of variability, investigators determined the 5<sup>th</sup>/95<sup>th</sup> percentile ratio (2.39) (range: 1.99-2.95). The Georgia Cancer Coalition has operationalized a closely related measure as cancer patients who receive hospice care for at least seven days. They propose to report this measure separately for inpatient and outpatient settings and to operationalize it using SEER Medicare data; the denominator is “the number of adults with cancer (ICD-10 codes C00-C97, ICD-9 140-208).”<sup>55</sup> With the exception of the data from the Dana-Farber experience, no reliability or validity information is available. This item is not known to be in current use as a measure.

*Measure - Site of Death.*<sup>150</sup> This measure was developed by investigators at the Dana-Farber Cancer Institute<sup>146</sup> and is also being used as an indicator by CCNS<sup>77</sup> and as a measure by Cancer Care Ontario.<sup>119,120</sup> In the case of the Dana-Farber measure, the numerator is “number of cancer

patients who die in the hospital.” The denominator is “all deceased cancer patients.” This item focuses on high rates of hospital cancer deaths (greater than 17%)<sup>150</sup> as indicating poor quality care. Support for this item comes from literature reviews; focus groups of patients, caregivers, and providers; expert panel review; and quantitative analysis of the indicator in Medicare claims data. The British Gold Standards Framework of dying has embraced a similar metric. This measure was normed in a Medicare-SEER database, and using the highest performing decile of this measure, the data implied that high performing HCSAs would have fewer than 17% inpatient deaths among cancer patients. When a sample of 150 charts at Dana-Farber were abstracted as the gold standard against which the sensitivity and specificity of the measure was determined, this measure was determined to have a sensitivity of 0.95, specificity of 1.00, and accuracy of 0.97. As a measure of variability, investigators determined the 5<sup>th</sup>/95<sup>th</sup> percentile ratio (2.49) (range: 2.05-3.12). Cancer Care Ontario is currently using this measure to evaluate provincial cancer care. About 56% of patients died in the hospital in Ontario, and rates varied between approximately 45% and 60% province-wide. Patients who died in the hospital were less likely to receive home care in the last six months, palliative care assessments, or physician house calls in the last two weeks of life.<sup>119</sup> The same item is currently being operationalized as a set of comprehensive administrative data-based indicators for CCNS.

*Measure - Safe Dying in Hospice.* This measure was developed by investigators at the NHPCO.<sup>63</sup> The numerator is “the number of deceased hospice patient’s caregivers with documentation in the patient’s medical record who were contacted and surveyed as to the quality of care provided by the hospice using the following question: “If you cared for the patient at home, did hospice increase your confidence to safely care for your loved one as death approached?” The denominator is “all caregivers of hospice patients.” This indicator is based on the assumption that caregivers who lack confidence or unsafe environments will aggravate dying or may hasten death. The “high risk, high volume, problem prone” home care environments are those in which there may be variable, uncertain, or absent caregiver competencies. Family caregivers, who may be uneducated in health care delivery, stressed by the anticipation of a loved one’s anticipated death, and fatigued by the labor associated with care of a physically dependent person, are given significant responsibility for the care of the patient. For the 116 agencies that voluntarily reported this information in 2002, the mean and median values were 98% for caregivers reporting safe dying experience.<sup>54,79</sup>

*Indicator - Care Consistency With Documented Care Preferences.* The numerator for this ACOVE measure is “the number of vulnerable elders whose specific treatment preferences were followed. The denominator is “all vulnerable elderly patients in any health care setting with specific treatment preferences documented in their medical record.”<sup>59</sup> The assumption is that the patient’s preferences and designated surrogate will be elucidated and documented within the patient’s medical record, usually within a specified timeframe that depends on the site within the hospital, or there will be documentation as to why surrogate and preferences were not able to be obtained. Thus, the documentation in patients’ records of their preferences would provide the standard by which care consistency would be evaluated. Both patients and health care providers believe that end-of-life discussions are important and should be held while the patient is still able to meaningfully and actively participate in decision making. However, studies have shown that these conversations are not common.<sup>141</sup> Moreover, research assessing the effectiveness of written advance directives in the care of seriously ill, hospitalized patients shows that even if the

patient has completed an advance directive, and it is accessible in the patient's chart, physician-patient communication or decision making about resuscitation was not substantially enhanced. Current practice patterns indicate that increasing the frequency of advance directives is unlikely to be a substantial element in improving the care of seriously ill patients.<sup>151</sup> Recent efforts to improve end-of-life care have focused on the application of documented preferences, as there is a strong theoretical basis and expert consensus that patient preferences should drive care. Danis and colleagues (1991)<sup>124</sup> showed a high correlation between documented care preferences and life-sustaining treatments. However, similar work has not been performed in the outpatient or hospital settings. No trials have studied whether documentation improves the concordance of care with values and preferences. This indicator was not tested in ACOVE's community-based sample and is not in current use.

## Potential Indicators and Measurement Gaps

We reviewed a number of sets of proposed potential indicators, clinical practice guidelines, and quality improvement studies that did not meet the standards set for inclusion of relevant indicators. Overall, guidelines did not rise to the level of indicators because of the lack of specification of various elements required for this review: patient population, denominator, conceptual clarity, or data source information. We identified fourteen potential indicators. These potential indicators overlapped with those identified in the indicator table and also addressed a number of gaps in the indicator literature, including the special population of children with cancer.<sup>152-155</sup>

Although many of the issues in advance care planning in adults are similar to those in children, indicators for children may need to differ in some respects (Potential Indicators #1; #7, #8, #10, #11, #12). Potential indicators identified for children are derived from the Initiative for Pediatric Palliative Care (IPPC) Quality Domains of Children Living with Life-Threatening Conditions<sup>152</sup> (Potential Indicator #1, #11, #12, #13), the Society of Industrial and Organization Psychology (SIOP) Working Committee on Psychosocial Issues in Pediatric Oncology<sup>154</sup> (Potential Indicator #7), the American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care<sup>155</sup> (Potential Indicator #8), and a literature review on key components of quality pediatric end-of-life care<sup>153</sup> (Potential Indicator #11). These potential indicators overlap with those identified for adults but address children's needs in light of their developmental level, and include assessment of needs, documentation of advance directives, support of the child and family, and continuity-of-care plans across provider sites.

Another potential indicator focused on adults in the ICU<sup>135</sup> (Potential Indicator #2). This indicator was derived from the American College of Physicians intervention literature and specified the components of the clinical identification of end-of-life ICU patients and the components of end-of-life care planning.

A number of potential indicators were identified from palliative care guidelines (Indicator #3, #4, #5, #14)<sup>69,131,156</sup> and focused on end-of-life palliative care for hospitalized patients. These indicators were derived from the National Consensus Project for Quality Palliative Care Clinical Practice Guidelines<sup>69,131</sup> and the Palliative Care Australia Standards for Palliative Care Provision.<sup>156</sup> Continuity of patient information across settings was addressed in Potential Indicator #6<sup>148</sup> and was derived from the intervention literature.

The use and withdrawal of feeding tubes in institutionalized patients (hospital, nursing home) is addressed in Potential Indicator #9.<sup>157</sup>

A final potential indicator was identified from the National Consensus Project<sup>69,131</sup> (Indicator #14) and focused on the treatment of the body in a culturally sensitive and respectful manner after a patient has died.

Cancer Care Ontario<sup>119</sup> is using several measures related to waiting times for chemotherapy and radiotherapy that could be adapted for supportive or palliative care with appropriate denominator adjustments.

## Measure That Crosses All Domains

**Follow-up.** We identified one composite measure that crosses all domains.

*Measure - Family Evaluation of Hospice Care (FEHC).* The FEHC is a 61-item survey administered after the death of a hospice patient to assess family members' perceptions of care provided by the hospice. The survey is based on the After-Death Bereaved Family Interview, which was developed based on a systematic review of the measurement literature relative to end-of-life care, consensus conferences, and focus groups.<sup>158</sup> Please refer to the Evidence Table in Appendix F5\*. The numerator is "the percentage of respondents reporting opportunity for improvement in attention to family needs for support, attending to family needs for information, provision of desired physical comfort and emotional support, and mean overall satisfaction." The denominator is "family members of hospice decedents." Although there are individual questions that relate to pain, depression, dyspnea, advance care planning, and other domains, and might be used for independent performance measurement, the FEHC is intended to be administered as a complete instrument or as modules and is therefore described here as a composite measure. The measure is intended for a mixed-hospice population. Hospices submit data voluntarily to NHPCO. In the first half of 2004, 352 hospices submitted data on 29,292 patients: 51% had cancer, 93% were white, 3% were African-American, and 3% were Hispanic.<sup>158</sup> For pain, 6% of family members reported unmet need (25th and 75th percentiles among hospices with more than 30 observations, 4% and 8%); for dyspnea, 5% (3% and 7%); and for emotional support, 9% (5% and 13%). Some questions related to advance care planning as well, such as satisfaction questions about respecting patient wishes and dying on one's own terms, but these values are reported only as a composite with other questions. Validity and reliability information are not available for this measure, although it is derived from other measures that have undergone extensive psychometric testing. Finally, little variation was found among hospices on this survey. However, these results are from early adopters; thus, it is possible that more variation would have been found if the survey had been administered among all hospices. It continues to be in voluntary use by hospices and NHPCO.

## Summary

We identified a number of measures and many indicators addressing the domains of pain, dyspnea, depression, and advance care planning within supportive and palliative cancer care. Many of these measures or indicators were developed and evaluated in populations that included cancer patients, although few were developed for quality assessment or improvement of cancer

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\* Appendixes cited in this report are provided electronically at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf>



care exclusively, and even fewer have proven their usefulness in application. Existing measures and indicators address both processes and outcomes of care. Canadian health care systems have been among the early adopters in initiating supportive and palliative cancer measurement, although ongoing US measurement efforts include the Georgia Cancer Coalition, and the VHA health care system, which are actively implementing measurement systems for cancer care and palliative care respectively. Some of these measures are mature enough for widespread application in quality improvement, but few have met all the criteria for public reporting and accountability.

## Chapter 4. Discussion

We identified a remarkable number of measures or indicators that address aspects of pain, dyspnea, depression, and advance care planning. However, in all domains, we found very few items that had been developed for and tested specifically in a cancer population and none for pediatric care. We also found few that were developed for or had been tested across the full trajectory of cancer care. Early stage indicators or measures were particularly lacking. With regard to settings of care, the fewest measures were found for outpatient care, even though patients receive most of their care in that setting. For all symptom domains, the evidence base for measurement is certainly strongest in the area of assessment, with relative shortcomings in treatment and follow-up. Our systematic review should have also uncovered evidence that these measures promote quality assessment and improvement, but there has been little investment in implementing these measures. For example, although a few carefully conducted trials have been conducted for control of pain in seriously ill or cancer patients, only one has used quality indicators as the mechanism for quality improvement,<sup>62</sup> and the generalizability of other studies to routine practice and to a cancer population<sup>159,160</sup> is unclear, although these studies were effective in reducing the severity of pain in a population and do include potential indicators.

An important limitation of our report is that, for the topics of pain and depression, we did not search for indicators for conditions other than cancer. The ability to use indicators or measures developed generically for these conditions and apply them to patients with cancer rests on the assumptions that the physiologic processes of pain and depression are essentially similar across disease conditions and that there are no particular measurement challenges in translating them from one population to another. This assumption requires certain caveats, such as the short time frames available for treatment in palliative care when these indicators or measures are applied to late-phase disease, and the fact that generic indicators or measures may not address short-term interventions. While these are empirically testable propositions, health care systems instituting measures for these conditions should be aware that they may not want to limit themselves to the disease-specific indicator or measures we have identified. NQF in particular has reviewed a large number of mental health indicators that may be readily applied to palliative conditions.

### Future Research

#### Field Testing in Relevant Populations

The lack of reported experience with these tools may not be surprising, as the measures or indicators we identified were largely developed in the last five years, reflecting the newness of the field of supportive cancer care.<sup>21</sup> In addition, the science of quality improvement in particular has suffered from confusion about optimal methodological approaches.<sup>161</sup> It is encouraging that some of the measures or indicators that we identified have been recently implemented or will be implemented in the near future for monitoring and improving population care (e.g., in Georgia, Ontario, Nova Scotia, and in the VHA system), which should offer opportunities for nurturing a fundamental knowledge base to foster improving the delivery of supportive or palliative cancer care. An especially important endeavor to foster progress in

measurement would be to apply the better- developed general measure and indicator sets (e.g., ACOVE) to supportive or palliative care populations with cancer.

An important objective of future testing is to obtain more robust information about the performance characteristics of the strongest measures. Even given limitations, many of them may be useful now for institutional-level quality assessment and improvement activities. However, most of these measures lack even basic published information about reliability and validity. Before they are deployed at higher levels of the health care system, information about their ability to discriminate quality performance and responsiveness to change will be required. In addition, testing in a variety of settings and institutions may also be needed. Differences in instrumentation, data source, and data collection protocols may significantly affect the performance and feasibility of measures, and research on these methodological issues and how they affect palliative care evaluation is needed. Furthermore, health care systems must consider the cost and feasibility of data collection and must be assured that measures are low risk for perverse incentives and that they can provide timely feedback on performance so that measurement can contribute to operational decisionmaking.

## **The Need for Measures To Address Impaired Self-Report**

None of the indicators address how to evaluate symptoms among individuals with impaired self-report, which can be due to either temporary (e.g., delirium) or durable factors (e.g., dementia, brain metastasis). There is no doubt that delirium is common among cancer patients, although its incidence and prevalence are not well studied. Some recent reports noted a prevalence of 18-50% among patients with cancer in general,<sup>162-164</sup> and observed rates are even higher in certain treatment settings such as the intensive care unit or in the nursing home, where almost 60% of the population is also living with dementia. The clinical needs of these populations are undoubtedly profound; a recent description of the clinical profile of cancer patients in US nursing homes reveals that, of the 190,976 cases, 51% of cases surviving more than one assessment had persistent pain, 25% of all cases were using oxygen, only 45% had DNR orders, and only 29% of those who were defined as “terminally ill” received hospice services.<sup>165</sup> A major effort to expand basic research in this area and ultimately address it through quality measurement would benefit many people at the end of life.<sup>166,167</sup>

Considering the example of pain, health professionals’ estimates of patient’s pain correlate poorly with patient self-reports, and discrepancies between patients and physicians in perceptions of pain severity are predictive of inadequate management.<sup>8</sup> Without regular screening for pain, many patients with significant pain do not have pain documented in the medical record and do not receive analgesia.<sup>85</sup> Patient vulnerability makes data collection challenging even among patients capable of self-report, yet many patients who need palliative care are incapable of self-report at least part of the time, often at times when they are also at great risk of pain. Research that addresses methodological challenges of obtaining patient reports and methods that allow monitoring of pain without self-report are an urgent need. All of the pain quality improvement interventions identified in this review that succeeded in reducing population pain intensity in different settings also included increasing the frequency of pain assessment as a key component of the intervention.<sup>62,159,160</sup>

## **The Lack of Pediatric Measures**

A related and obvious shortcoming we noted is the complete absence of pediatric measures or indicators. As in the case of many adults, care assessment in young children is challenged by their inability to self report. Cancer represents the second leading cause of death among children ages 5-15 in the United States.<sup>168</sup> However, profound challenges and serious deficiencies in the care of pediatric cancer cases have been noted.<sup>169,170</sup> It is insufficient to propose that adult measures or indicators could simply be adopted for pediatric care, as the kinds of disease, challenges of symptom reporting and intervention, and basic approach to care differ so significantly between pediatric and adult oncology care. Many but not all of the adult measures have potentially useful analogues in the pediatric population,<sup>171</sup> but substantial basic research will be needed to translate such efforts into useful pediatric tools. A comprehensive review in 2003 found only 22 research studies and 6 guideline statements in the area,<sup>153</sup> and most of this limited literature addresses pain, to the exclusion of other symptoms or experiences.<sup>152</sup> In addition, a systematic review of measure and indicator sets relevant to pediatrics found no measures or indicators for end-of-life care.<sup>34,172-175</sup>

## **Defining the “End-of-Life”**

The lack of consensus on definitions of “end-of-life” presents what has been called the “denominator” problem. Of central importance is the continuing challenge of establishing a consistent and accepted definition of end-of-life that is not confined to that of the “imminently” dying. The correct definition of the end-of-life may well depend upon what use is to be made of the definition. For the measures reviewed, many of the indicators explicitly define end-of-life retrospectively (e.g., last six months of life). While appropriate for evaluating “aggressive treatment” in the last days before death, this definition does not provide guidance on important clinical services such as pain prevention or the timing of advance care planning. In addition, retrospective analyses may introduce a number of biases, since the timing of death is often not predictable. Prospective indicators, such as the quality of the discussion about whether the patient wants chemotherapy, would account for patient preferences. The ACOVE indicators come closer to a prospective method by identifying “vulnerable community-dwelling elders” for which the identification and documentation of life-sustaining treatment decisions may be most appropriate. Prospective analyses for cancer will require methodological work to define which cancer patients (certain types that are usually fatal, those at advanced stage) should be in the denominator for measures of the aggressiveness of care.

## **The Publication Gap for Quality Measurement**

An important finding of our report was that much of the evidence on the measures that we identified was unpublished. Additional information that might inform the evidence base for these measures, (i.e., from local quality assessment and improvement efforts) probably exists but is likely unpublished and compiled by non-academic organizations. Further, much of the actual experience with measures and measurement probably exists in an anecdotal rather than archival form. We found that a strategy that consisted of an Internet search coupled with networking widely with organizations and individuals in the fields of oncology and supportive or palliative

care was relatively effective for identifying such information. Future systematic reviews should be aware of this important issue and make an explicit effort to capture this unpublished information. Methods for systematically compiling and analyzing this type of data might help to improve the evidence base for quality measurement. Methods or other strategies to better promote the use of candidate measures in quality improvement work or to otherwise link measurement development work to quality improvement projects in cancer, such as the Veterans Administration Collaborative,<sup>160</sup> might help to provide the information on measure responsiveness that is needed.

## **Strengthening Quality Measurement of Depression in Cancer**

Given the strength of the literature on measurement in mental health in general and the recognized importance of depression in the care of cancer patients, surprisingly few indicators have been evaluated for depression in advanced cancer. This lack of indicators is striking because indicators for mental health are well represented within available measure sets in general. Indicators developed for other settings may be appropriate but have not been tested in this population. Furthermore, depression is widely recognized to be an important influence on the experience of cancer. Certainly, many of the drugs used to treat depression are relevant within the scope of cancer care, especially for earlier stage disease. More fundamental clinical research is needed to address late stage disease – such as the optimal approach to screening and the usefulness of short-term treatment, which has not, for the most part, been addressed by this literature.<sup>21</sup> Further research on similarities between measurements in cancer populations and those in non-cancer populations might allow elements of this work to be used as supporting evidence for particular measures. This effort may be particularly important for areas where there is significant non-cancer-related evidence, such as in patients with cognitive impairment.

## **Building an Evidence Base To Compare Population Subgroups**

We found insufficient evidence to comment on important differences by population. This finding is not surprising, as the tools for examining these differences are limited by the lack of basic knowledge.<sup>21</sup> However, an important priority for future research is evaluating measures in important sub-populations (i.e., by race/ethnicity, age, language, and gender). With regard to pain, members of minority groups with cancer have higher rates of inadequate pain assessment and treatment than others.<sup>86, 87</sup> A recent nonsystematic review of the topic of cancer pain found that differences in pain management persist for both assessment and treatment, across multiple settings and types of pain.<sup>88</sup> Older cancer patients<sup>8</sup> and cancer patients in nursing homes<sup>87</sup> are also less likely to receive adequate pain treatment. This issue was addressed in some of the guidelines we reviewed (e.g., the Oncology Nursing Society Position in Cancer Pain Management)<sup>82</sup> but has not been operationalized into indicators. It is important to define subgroups of cancer by stage of illness and to understand the performance of indicators among major subgroups.

Durable improvement in symptom assessment will require measures that are capable of being implemented with other routine metrics of performance in important care settings. For example, improvements in pain management often decay over time. In one study to increase daily pain assessment, performance on the indicator was 82% after an educational intervention but decreased to 59% over a seven-month period.<sup>9</sup> Evaluations of the use of pain assessment in

clinical settings have shown good feasibility with minimal burden for staff.<sup>9</sup> However, in one study with a high prevalence of unreported pain, training of home health aides to document pain scores resulted in a large increase in screening; however, physician documentation increased by only 5- to 8%.<sup>85</sup> In addition, although most of the indicators or measures that we identified were focused on the inpatient setting, much routine cancer care occurs in the ambulatory setting, and we found fewer indicators or measures to address outpatient performance.

## Conclusions

Over time, measures should become available for an increasing number of areas of clinical performance in supportive or palliative cancer care. Research is needed to ensure that valid and reliable measures are available to address the full spectrum of palliative domains, including the most important symptoms that patients face: spiritual well-being and caregiver burdens, including bereavement. Measures are needed for the major settings where patients receive care (i.e., the outpatient setting) as well as those that follow patients across care venues. More patient-centered measures that address the actual processes important to high quality symptom control and care planning are needed. Especially in terms of treatment, current indicators do not fully reflect progress in adult supportive or palliative care, particularly with regard to pain, dyspnea, and depression care.<sup>21</sup> However, a thoughtful application of existing measurement will ensure that some palliative measures are useful now for most (adult) cancer patients.

Unlike other tools for quality evaluation where incentives are relatively strong in the private sector for improved quality management (e.g., those for prevention or treatment of hypertension or diabetes), the adoption of quality metrics for supportive and palliative care is particularly dependent on federal endorsement. Almost all elder care is the ultimate responsibility of the federal government through Medicare, Medicaid, or the VA systems. The absence of supportive or palliative measures within the recent National Healthcare Quality Report is particularly notable in that regard.<sup>176</sup> Strong federal leadership of both research and the application of measurement in clinical care will be needed to make progress in this important area. However, the number of measures and indicators that we have identified and the recency of progress in this area suggest that now is a promising time to initiate these efforts within our health care system.



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# **APPENDIXES**

to

**“Cancer Care Quality Measures:  
Symptoms and End of Life Care”**

**Prepared by the Southern California Evidence-based Practice Center  
(Contract #290-02-003)**

# Appendix A. Technical Expert Panel Members and Peer Reviewers

**Table A1. Technical Expert Panel members**

<u>Name</u>	<u>Institution</u>
Steve Asch, M.D., M.P.H.	VAGLHS
Marilyn Bookbinder, R.N., Ph.D.	Beth Israel Medical Center
June Dahl, Ph.D.	University of Wisconsin-Madison
Perry Fine, M.D.	University of Utah
Laura Hanson, M.D., M.P.H.	University of North Carolina at Chapel Hill
Jimmie Holland, M.D.	Memorial Sloan Kettering Cancer Center
Joan Teno, M.D., M.S.	Brown Medical School
Jean Kutner, M.D., M.S.P.H.	University of Colorado Health Sciences Center
Charles Cleeland, Ph.D.	UTMD Anderson Cancer Center
Jennifer Malin, M.D.	UCLA School of Medicine, RAND
Molla Donaldson, Dr.P.H., M.S.	National Cancer Institute (Fed Reviewer)
Patricia Ganz, M.D.	UCLA Schools of Medicine and Public Health
Rodger Winn, Ph.D.	National Quality Forum

**Table A2. Peer Reviewers**

<u>Name</u>	<u>Institution</u>
Adalsteinn Brown, A.B., D.Phil.	University of Toronto
Ellen Stovall	National Coalition for Cancer Survivorship (NCCS)
Eva Grunfeld, M.D., D.Phil.	Cancer Care Nova Scotia
Joanne Wolfe, M.D.	Harvard University-Pediatrics
Judi L. Person, M.P.H.	National Hospice and Palliative Care Organization (NHPCO)
Lindsey Bramwell, M.P.H., R.N., CDR, U.S.P.H.S.	CMS (Fed Reviewer)
Anna Lythgoe, R.N., M.S.N.	VHACO, Office of Quality and Performance
Phil Madvig, M.D.	Kaiser Permanente



# Appendix B. TEP Worksheet

## Indicator Worksheet—Cancer Care Quality Measures: Symptoms and End of Life Care Established Indicator Worksheet

TEP Member	Indicator statement	Numerator	Denominator	Source	Guideline at SCEPC?

# Appendix C. Literature Search Strategies

## SEARCH METHODOLOGIES – END OF LIFE CANCER MEASUREMENT CINAHL

### DATABASE SEARCHED & TIME PERIOD COVERED:

CINAHL – 1995-2005

### OTHER LIMITERS:

ENGLISH  
HUMAN

### SEARCH STRATEGY #1 (PAIN NOT PALLIATIVE)

(neoplasm\$ or cancer\$ or tumour\$ or tumor\$ or carcinoma\$ or adenocarcinoma\$ or malignan\$).mp. [mp=title, cinahl subject headings, abstract, instrumentation]

AND

(guideline\$ or audit\$ or outcome\$ or peer review\$ or professional review\$ or evaluat\$ or benchmark\$ or utilization review\$ or consensus or perform\$ or quality).mp.

AND

((quality or perform\$) and (measur\$ or indicator\$ or assess\$)).mp.

AND

pain.mp.

**NUMBER OF ITEMS RETRIEVED : 414**

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### SEARCH STRATEGY #2 (DEPRESSION):

(neoplasm\$ or cancer\$ or tumour\$ or tumor\$ or carcinoma\$ or adenocarcinoma\$ or malignan\$).mp.

AND

(guideline\$ or audit\$ or outcome\$ or peer review\$ or professional review\$ or evaluat\$ or benchmark\$ or utilization review\$ or consensus or perform\$ or quality).mp.

AND

((quality or perform\$) and (measur\$ or indicator\$ or assess\$)).mp.

AND

(depression or depressive or sadness).mp.

**NUMBER OF ITEMS RETRIEVED: 215**

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**DATABASE SEARCHED & TIME PERIOD COVERED:**

CINAHL – 1995-2005

**OTHER LIMITERS:**

ENGLISH  
HUMAN

**SEARCH STRATEGY #3 (DYSPNEA)**

(dyspnea or shortness of breath or difficulty breathing or breathless\$.mp.

AND

(guideline\$ or audit\$ or outcome\$ or peer review\$ or professional review\$ or evaluat\$ or benchmark\$ or utilization review\$ or consensus).mp.

AND

((quality or perform\$) and (measur\$ or indicator\$ or assess\$)).mp.

**NUMBER OF ITEMS RETRIEVED : 278 (78 were duplicates)**

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**DATABASE SEARCHED & TIME PERIOD COVERED:**

CINAHL – 1995-2005

**OTHER LIMITERS:**

ENGLISH  
HUMAN

**SEARCH STRATEGY #4 (ADVANCE DIRECTIVES)**

(advance directive\$ or withdraw\$ care or living will or resuscitat\$).mp.

AND

(guideline\$ or audit\$ or outcome\$ or peer review\$ or professional review\$ or evaluat\$ or benchmark\$ or utilization review\$ or consensus).mp.

AND

((quality or perform\$) and (measur\$ or indicator\$ or assess\$)).mp.

**NUMBER OF ITEMS RETRIEVED : 182**

**SEARCH METHODOLOGIES – END OF LIFE CANCER MEASUREMENT  
REVISIONS – DYSPNEA & ADVANCE DIRECTIVES “NOT” CANCER**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PUBMED – 1995-2005

**OTHER LIMITERS:**

ENGLISH

HUMAN

**SEARCH STRATEGY #1 (DYSPNEA)**

guideline\*[tiab] OR quality of health care OR guideline adherence OR medical audit OR nursing audit OR outcome and process assessment, health care OR commission on professional and hospital activities OR peer review, health care OR professional review organizations OR program evaluation OR benchmarking OR quality assurance, health care OR guidelines[mh] OR practice guidelines OR total quality management OR quality indicators, health care OR utilization review OR practice guideline[pt] OR consensus development conference[pt] OR (communication AND physician\* AND (patient\* OR consumer\*))

AND

(quality OR perform\*) AND (measur\* OR indicator\* OR assess\*)

AND

dyspnea OR shortness of breath OR difficulty breathing OR breathless\*

NOT

case report\*

**NUMBER OF ITEMS RETRIEVED : 887**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PUBMED – 1995-2005

**OTHER LIMITERS:**

ENGLISH

HUMAN

**SEARCH STRATEGY #2 (ADVANCE DIRECTIVES)**

guideline\*{tiab} OR quality of health care OR guideline adherence OR medical audit OR nursing audit OR outcome and process assessment, health care OR commission on professional and hospital activities OR peer review, health care OR professional review organizations OR program evaluation OR benchmarking OR quality assurance, health care OR guidelines[mh] OR practice guidelines OR total quality management OR quality indicators, health care OR utilization review OR practice guideline[pt] OR consensus development conference[pt] OR (communication AND physician\* AND (patient\* OR consumer\*))

AND

(quality OR perform\*) AND (measur\* OR indicator\* OR assess\*)

AND

advance care OR advance directive\* OR withdrawal of care OR living will OR "do not resuscitate"

NOT

case report\*

**NUMBER OF ITEMS RETRIEVED : 486**

**SEARCH METHODOLOGIES – END OF LIFE CANCER MEASUREMENT  
PAIN NOT PALLIATIVE/DEPRESSION – PUBMED**

**SEARCH STRATEGY #1 (PAIN NOT PALLIATIVE):**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PUBMED 1995-2005

**OTHER LIMITERS:**

ENGLISH

HUMAN

NOT CASE REPORTS

**SEARCH STRATEGY:**

neoplasms[mh] OR neoplasm\*[tiab] OR cancer\* OR tumour\* OR tumor\* OR carcinoma\* OR adenocarcinoma\* OR malignan\*

AND

pain[mh] OR pain[ti]

AND

quality of health care OR guideline adherence OR medical audit OR nursing audit OR outcome and process assessment, health care OR commission on professional and hospital activities OR peer review, health care OR professional review organizations OR program evaluation OR benchmarking OR quality assurance, health care OR guidelines[mh] OR practice guidelines OR total quality management OR quality indicators, health care OR utilization review OR practice guideline[pt] OR consensus development conference[pt] OR (communication AND physician\* AND (patient\* OR consumer\*))

AND

(quality OR perform\*) AND (measur\* OR indicator\* OR assess\*)

NOT

case report\*

**NUMBER OF ITEMS RETRIEVED: 691**

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**SEARCH STRATEGY #2 (DEPRESSION):**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PUBMED 1995-2005

**OTHER LIMITERS:**

ENGLISH

HUMAN

NOT CASE REPORTS

**SEARCH STRATEGY:**

neoplasms[mh] OR neoplasm\*[tiab] OR cancer\* OR tumour\* OR tumor\* OR carcinoma\* OR adenocarcinoma\* OR malignan\*

AND

depressive disorders OR depression OR sadness

AND

quality of health care OR guideline adherence OR medical audit OR nursing audit OR outcome and process assessment, health care OR commission on professional and hospital activities OR peer review, health care OR professional review organizations OR program evaluation OR benchmarking OR quality assurance, health care OR guidelines[mh] OR practice guidelines OR total quality management OR quality indicators, health care OR utilization review OR practice guideline[pt] OR consensus development conference[pt] OR (communication AND physician\* AND (patient\* OR consumer\*))

AND

(quality OR perform\*) AND (measur\* OR indicator\* OR assess\*)

NOT

case report\*

**NUMBER OF ITEMS RETRIEVED: 468**

**SEARCH METHODOLOGY – END OF LIFE CANCER MEASUREMENT - DEPRESSION  
PSYCINFO**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PSYCINFO – 1995-2005

**OTHER LIMITERS:**

ENGLISH

HUMAN

**SEARCH STRATEGY**

(kw: neoplasm\* OR kw: cancer\* OR kw: tumour\* OR kw: tumor\* OR kw: carcinoma\* OR kw: adenocarcinoma\* OR kw: malignan\*)

AND

(kw: guideline\* OR kw: audit OR kw: outcome\* OR (kw: peer and kw: review) OR (kw: professional and kw: review) OR kw: evaluat\* OR kw: benchmark\* OR (kw: utilization and kw: review) OR kw: consensus)

AND

((kw: quality OR kw: perform\*) AND (kw: measur\* OR kw: indicator\* OR kw: assess\*))

AND

((kw: depressive and kw: disorders) OR kw: depression OR kw: sadness)

**NUMBER OF ITEMS RETRIEVED: 86**



**SEARCH METHODOLOGIES – END OF LIFE CANCER MEASUREMENT  
PSYCINFO**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PSYCINFO – 1995-2005

**OTHER LIMITERS:**

ENGLISH

**SEARCH STRATEGY #1 (PAIN NOT PALLIATIVE):**

(kw: neoplasm\* OR kw: cancer\* OR kw: tumour\* OR kw: tumor\* OR kw: carcinoma\* OR kw: adenocarcinoma\* OR kw: malignan\*)

AND

(kw: guideline\* OR kw: audit OR kw: outcome\* OR (kw: peer and kw: review) OR (kw: professional and kw: review) OR kw: evaluat\* OR kw: benchmark\* OR (kw: utilization and kw: review) OR kw: consensus)

AND

((kw: quality OR kw: perform\*) AND (kw: measur\* OR kw: indicator\* OR kw: assess\*))

AND

Kw: pain

**NUMBER OF ITEMS RETRIEVED: 92**

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**SEARCH STRATEGY #2 (DEPRESSION):**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PSYCINFO – 1995-2005

**OTHER LIMITERS:**

ENGLISH

(kw: neoplasm\* OR kw: cancer\* OR kw: tumour\* OR kw: tumor\* OR kw: carcinoma\* OR kw: adenocarcinoma\* OR kw: malignan\*)

AND

(kw: guideline\* OR kw: audit OR kw: outcome\* OR (kw: peer and kw: review) OR (kw: professional and kw: review) OR kw: evaluat\* OR kw: benchmark\* OR (kw: utilization and kw: review) OR kw: consensus)

AND

((kw: quality OR kw: perform\*) AND (kw: measur\* OR kw: indicator\* OR kw: assess\*))

AND

((kw: depressive and kw: disorders) OR kw: depression OR kw: sadness)

**NUMBER OF ITEMS RETRIEVED: 86**

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**SEARCH STRATEGY #3 (DYSPNEA):**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PSYCINFO- 1995-2005

**OTHER LIMITERS:**

ENGLISH

**SEARCH STRATEGY:**

(kw: dyspnea OR (kw: shortness and kw: breath) OR (kw: difficulty and kw: breathing) OR kw: breathless\*)

AND

(kw: guideline\* OR kw: audit OR kw: outcome\* OR (kw: peer and kw: review) OR (kw: professional and kw: review) OR kw: evaluat\* OR kw: benchmark\* OR (kw: utilization and kw: review) OR kw: consensus)

AND

((kw: quality OR kw: perform\*) AND (kw: measur\* OR kw: indicator\* OR kw: assess\*))

**NUMBER OF ITEMS RETRIEVED: 25**

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**SEARCH STRATEGY #4 (ADVANCE DIRECTIVES):**

**DATABASE SEARCHED & TIME PERIOD COVERED:**

PSYCINFO- 1995-2005

**OTHER LIMITERS:**

ENGLISH

**SEARCH STRATEGY:**

((kw: advance and kw: care) OR (kw: advance and kw: directive\*) OR (kw: withdrawal and kw: care) OR (kw: living and kw: will) OR kw: do w1 resuscitate)

AND

(kw: guideline\* OR kw: audit OR kw: outcome\* OR (kw: peer and kw: review) OR (kw: professional and kw: review) OR kw: evaluat\* OR kw: benchmark\* OR (kw: utilization and kw: review) OR kw: consensus)

AND

((kw: quality OR kw: perform\*) AND (kw: measur\* OR kw: indicator\* OR kw: assess\*))

**NUMBER OF ITEMS RETRIEVED: 66**

# Appendix D. RAND SCEPC Cancer Quality Measures Project – Measure Developer Contact Form

## Measure Developer Contact Form

Article ID		Reviewer	
Journal Article Ref		Name of contact and Organization	
Phone		Email	
Domain		Indicator (code from long form)	
1 Is this indicator currently in use?		By What organization(s)?	
		Contact information:	
2 Can you describe your experience with the use of this indicator? (numerator, denominator, setting of care, data source, reliability, validity)			
Measurement properties	Numerator: (Enter code)		Patient interview/survey
	Denominator: (Enter code)		Provider interview/survey
			Family interview/survey
Setting	Home care		Administrative
	Hospice		Chart
	Nursing home		Other
			Not Reported
	Ambulatory/OutPt care		Data collection specified
	Hospital (Non-ICU)		Reliability
	Hospital (ICU)		Construct validity
			Discriminant validity
	Home		Other validity
	Community		Not reported
Unclear/Not specified			
Other (Enter code:)			
Other (Specify:)			
3 Can you describe any practical concerns related to its implementation or your experience with it to date?			
Any improvements in its specification or use?			
4 Can you provide any written documentation or are you aware of other published documents that describe experience with this indicator?			
5 Are you (or other organizations) currently using any other indicators to evaluate palliative care quality? (describe numerator & denominator of any indicator related to pain, depression, dyspnea, or advance care planning here).			

Last saved: 4/25/2005

# Appendix E. Cancer Measure Review Article Screener

	<b>Cancer Measures Review Article Screener</b>	Reviewers:	Assigned on:
<b>Article ID</b>			
Citation:			

<p>1. Reviewer: <span style="float: right;">Circle one</span></p> <p>Dy.....1 Mularski..... 5</p> <p>Hughes.....2 Shugarman ..... 6</p> <p>Lorenz .....3 Wilkinson..... 7</p> <p>Lynn .....4</p> <p>Other (specify: _____)..... 8</p> <p>2. Is the article/report related background or generalizability? <span style="float: right;">Circle one</span></p> <p>Yes..... 1</p> <p>No..... 2</p> <p>3. Location of study: <span style="float: right;">Check all that apply</span></p> <p>US..... <input type="checkbox"/></p> <p>Canada, Europe, Australia, NZ ..... <input type="checkbox"/></p> <p>Unclear..... <input type="checkbox"/></p> <p>Other..... <input type="checkbox"/></p> <p><b>(If OTHER is the only box checked then STOP)</b></p> <p>4. Domain(s) studied: <span style="float: right;">Check all that apply</span></p> <p>Advance care planning..... <input type="checkbox"/></p> <p>Depression..... <input type="checkbox"/></p> <p>Dyspnea..... <input type="checkbox"/></p> <p>Pain..... <input type="checkbox"/></p> <p>Other / Unclear..... <input type="checkbox"/></p> <p><b>(If OTHER/UNCLEAR is the only box checked then STOP)</b></p> <p>5. Disease studied: <span style="float: right;">Circle one</span></p> <p>Cancer..... 1</p> <p>Not Cancer..... 2</p> <p>Mixed or not specified ..... 3</p> <p><b>(If PAIN or DEPRESSION are the only domains checked and disease is NOT CANCER then STOP)</b></p> <p>6. Study population: <span style="float: right;">Circle one</span></p> <p>Adults..... 1</p> <p>Children..... 2</p> <p>Adults and children..... 3</p> <p>Unclear..... 4</p>	<p>7. Does the article/report contain quality indicator(s)? <span style="float: right;">Circle one</span></p> <p>Yes..... 1</p> <p>No..... 2 (STOP)</p> <p>8. If this is a guidelines report, does the report specify any methods? <span style="float: right;">Circle one</span></p> <p>Yes..... 1</p> <p>No..... 2 (STOP)</p> <p>Not guidelines report..... 3</p> <p><b>(If methods are referenced but in another report/website, then circle YES and write the citation/web site that contains the methods in the NOTES box below.)</b></p> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p><b><u>McGlynn's definition of a quality measure</u></b></p> <p>Quality measures generally consist of a descriptive statement or indicator... a list of data elements that are necessary to construct and/or report the measure, detailed specifications that direct how the data elements are to be collected (including the source of the data), the population on whom the measure is constructed, the timing of data collection and reporting, the analytic models used to construct the measure, and the format in which the results will be presented. Measures may also include thresholds, standards, or other benchmarks of performance.</p> <p>An example from Beth McGlynn: I consider a quality indicator to be the statement "Persons with a myocardial infarction should receive aspirin within 2 hours of presentation" and a quality measure to be the specifications necessary to get the right data elements, collect data and calculate the measure (so how is an MI defined, who is excluded, etc and whether it is from a medical record, claims, survey source etc.)</p> </div> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p><b><u>Guideline definition as defined by Hasenfeld R and Shekelle P:</u></b></p> <p>"any document that identified itself as such, or contained specific recommendations for healthcare decisions that were not authored by one or more people writing as individuals (to distinguish the document from a review article)."</p> </div>
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NOTES:

# Appendix F1. Quality Measures and Indicators for Supportive Cancer Care: Pain

## Assessment

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
1	QA Tools RAND <sup>1</sup> McGlynn, E.A. <sup>2</sup> Asch, S.M. <sup>3</sup>	<b>(Measure)</b> Regular assessment of Pain.	All patients with metastatic cancer to bone.	Patients with the presence or absence of pain noted at least every 6 months.	Mixed cancer	McGlynn, E. A.: Adult White Other (Non-White) 60% Male Average age is 45.5 Age ranges from 18 to 97 Asch, S. M.: 100% Male Average age is 63.0	McGlynn, E. A.: Community Asch, S. M.: Community (including veteran sample)	McGlynn, E. A.: Chart Reliability reported Asch, S. M.: Chart
2	UHC Maxwell, T. <sup>4</sup>	<b>(Measure)</b> Routine inpatient pain assessment.	Adults > or = 18 years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay > 4 days, 2 prior admissions for any cause in preceding 12 months in the hospital.	Pain assessment within 48 hours of admission on chart review.	CHF Mixed cancer HIV Mixed respiratory diseases	Adult Average age is 58.4 Lower boundary for age is 18	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported
3	UHC Maxwell, T. <sup>4</sup>	<b>(Measure)</b> Routine inpatient pain assessment with a numeric scale.	Adults > or = 18 years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay > 4 days, 2 prior admissions for any cause in preceding 12 months in the hospital , AND reported pain within the 1st 48 hours of admission.	Persons assessed with a numeric pain scale.	CHF Mixed cancer HIV Mixed respiratory diseases	Adult Average age is 58.4 Lower boundary for age is 18	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported

## Assessment

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
4	VHA VHA Updated March 2005 <sup>5</sup> Pronovost, P.J. <sup>6</sup> Erdek, M.A. <sup>7</sup>	<b>(Measure)</b> Regular ICU pain assessment.	4 hour periods during which the patients physically present in the ICU, including the initial period if at least present for 2 hours.	Total number of 4-hour intervals (within the first 24 hours following ICU admission) for which pain was assessed and documented, using an appropriate rating scale.	Mixed ICU Population	Not Reported	Hospital (ICU)	Data source not reported  Reliability / Validity not reported
5	QOPI Neuss, M.N. <sup>8</sup>	<b>(Measure)</b> Assessing pain in patients close to death.	Recently deceased patients from oncology practices.	Medical records where there is an explicit practitioner's notation quantifying their physical pain or lack thereof on their last visit to the office prior to death.	Mixed cancer	Not Reported	Ambulatory / outpatient care	Chart  Reliability / Validity not reported
6	ACOVE End of Life Wenger, N.S. <sup>9</sup> Saliba, D. <sup>10</sup>	(Indicator) Routine pain assessment in expected dying.  IF a VE who was conscious during the last 3 days and died an expected death THEN the medical record should contain documentation about pain or lack of pain during the last 3 days of life.	Vulnerable elders who are conscious during the last 3 days of life.	Number of vulnerable elders with documentation of pain or lack of pain during the last 3 days of life.	Not Reported	Wenger, N. S.:  Adult  36% Male  Average age is 81.0	Wenger, N. S.:  Not Reported  Saliba, D.:  Nursing home	Patient interview / survey  Chart  Reliability / Validity not reported
7	Cancer Care Georgia National Cancer Policy Board (NCPB) <sup>11</sup>	(Indicator) Routine assessment of pain.	Number of cancer patient encounters.	Number of cancer patient encounters where patient where patient was assessed for pain.	Mixed cancer	Not Reported	Not Reported	Data source not reported  Reliability / Validity not reported

## *Treatment*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
8	QA Tools RAND <sup>1</sup> McGlynn, E.A. <sup>2</sup> Asch, S.M. <sup>3</sup>	<b>(Measure)</b> Responsive pain treatment.	All cancer patients whose pain is uncontrolled.	Patients offered a change in pain management within 24hours of the pain complaint.	Mixed cancer	McGlynn, E. A.: Adult White Other (Non-White) 60% Male Average age is 45.5 Age ranges from 18 to 97 Asch, S. M.: 100% Male Average age is 63.0	McGlynn, E. A.: Community Asch, S. M.: Community (including veteran sample)	McGlynn, E. A.: Chart Reliability reported Asch, S. M.: Chart
9	UHC Maxwell, T. <sup>4</sup>	<b>(Measure)</b> Regular prophylaxis of opiate-induced constipation.	Adults > or = 18 years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay > 4 days, 2 prior admissions for any cause in preceding 12 months in the hospital , AND treated with narcotics.	Proportion with a bowel regimen ordered within 24 hours of the opioid ordered and not contraindicated.	CHF Mixed cancer HIV Mixed respiratory diseases	Average age is 58.4 Lower boundary for age is 18	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported
10	Wu, J.S. <sup>12</sup>	(Indicator) Minimizing radiotherapy burden.	All adult patients with single of multiple radiographically confirmed bone metastases of any histology corresponding to painful areas in previously nonirradiated areas without pathologic fractures or spinal cord/cauda equina compression. It does not apply to the management of malignant primary bone tumor. For patients receiving radiotherapy where the objective / intent is pain relief.	% of those patients receiving single dose therapy as a single 8Gy treatment, prescribed to the appropriate target volume.	Mixed cancer	Adult	Not Reported	Data source not reported Reliability / Validity not reported



## *Treatment*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
11	Cancer Care Nova Scotia Grunfeld, E. <sup>13</sup>	(Indicator) Effective treatment for painful bony metastasis.	Patients with uncontrolled bone pain.	Patients who are offered within one week of the notation of pain: - radiation therapy to the sites of pain.	Mixed cancer	All patients in the population with cancer	Not Reported	Cancer registry, administrative claim data, hospital discharge abstract  Reliability / Validity not reported

## Follow-up

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
12	NHPCO National Hospice and Palliative Care Organization (NHPCO) <sup>14</sup> Connor, S.R. <sup>15</sup> Ryndes, T. <sup>16</sup>	<b>(Measure)</b> Timely treatment of pain in hospice.	Patients admitted to hospice who answer 'yes' when asked "Are you uncomfortable because of pain?".	The proportion of patients between 48 and 120 hours after admission who report 'yes' when asked "Was your pain brought to an acceptable level within 48 hours of your admission to the hospice program?".	Mixed hospice population	NHPCO: Adult Connor, S. R.: Adult White African American Hispanic Asian Native American / Eskimo 44% Male	Hospice	Patient interview / survey Reliability / Validity not reported
13	VHA Updated March 2005 <sup>5</sup> Pronovost, P.J. <sup>6</sup> Erdek, M.A. <sup>7</sup>	<b>(Measure)</b> Effective treatment of pain in the ICU.	Total number of 4-hour intervals (within the first 24 hours following ICU admission) with numerical pain values of 1 to 10, for patients with an ICU length of stay $\geq 24$ hours.	Total number of 4-hour intervals (within the first 24 hours following ICU admission) for which the documented pain score was $< 3$ .	Mixed ICU Population	Not Reported	Hospital (ICU)	Data source not reported Reliability / Validity not reported
14	Cancer Care Ontario <sup>17</sup>	<b>(Measure)</b> Satisfaction with pain treatment.	Outpatient cancer patients reporting mild to severe pain.	Patients where the response to the question "Do you think staff did everything they could to control your pain or discomfort?" was (1) yes, completely; (2) yes, somewhat; or (3) no.	Mixed cancer	Not Reported	Ambulatory / outpatient care	Patient interview / survey Reliability / Validity not reported
15	UHC Maxwell, T. <sup>4</sup>	<b>(Measure)</b> Timely treatment of inpatient pain.	Adults $\geq 18$ years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay $> 4$ days, 2 prior admissions for any cause in preceding 12 months in the hospital, AND reported pain within the 1st 48 hours of admission.	Persons with pain relief or reduction within 48 hours of admission $< \text{or} = 3$ on 0-10 scale.	CHF Mixed cancer HIV Mixed respiratory diseases	Adult Average age is 58.4 Lower boundary for age is 18	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported

*Follow-up*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
16	Cancer Care Georgia National Cancer Policy Board (NCPB) <sup>11</sup>	(Indicator) Effective treatment of pain.	Number of cancer patients who are not comatose.	Number of cancer patients who report being in more than minor pain.	Mixed cancer	Not Reported	Not Reported	Data source not reported Reliability / Validity not reported

***Potential Indicators  
Assessment***

<b>No.</b>	<b>Measure or Indicator Set/ Reference / Year</b>	<b>Description / Original Source Wording</b>	<b>Denominator</b>	<b>Numerator</b>
17	Erdek, M.A. <sup>7</sup>	Physician documentation of pain assessment.	All patients with cancer.	Patients where a pain assessment is documented in the physician note.
18	Green, C.R. <sup>18</sup>	Disparities in pain assessment.	All patients with cancer who are assessed for pain.	Non-white patients with cancer who are assessed for pain.
19	Ferrell, B.R. <sup>19</sup>	Assessment in patients who cannot verbalize their pain.	Cancer patients who have difficulty verbalizing their pain.	Patients who are assessed for pain.
20	Carr, D.B. <sup>20</sup>	Assessment for depression in patients with pain.	All cancer patients with pain.	Patients assessed for depression.

***Potential Indicators  
Treatment***

<b>No.</b>	<b>Measure or Indicator Set/ Reference / Year</b>	<b>Description / Original Source Wording</b>	<b>Denominator</b>	<b>Numerator</b>
21	Allard, P. <sup>21</sup> Gordon, D.B. <sup>22</sup>	Education about pain management.	Cancer patients with pain.	Patients who are educated about pain management.
22	Marinangeli, F. <sup>23</sup> Gordon, D.B. <sup>22</sup>	Use of opioids for severe, persistent pain.	Cancer patients with severe, persistent pain.	Patients who are treated with opioids.
23	NIH State-of-the-Science Statement <sup>24</sup>	Use of long-acting pain medications.	All adults with cancer who have persistent pain and are prescribed opioids.	Adults who are prescribed long acting opioids.
24	World Health Organization (WHO) <sup>25</sup>	Procedure-related pain in children.	All children with cancer receiving painful procedures.	Children who receive appropriate preparation and/or anesthesia.

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# Appendix F2. Quality Measures and Indicators for Supportive Cancer Care: Dyspnea

## *Assessment*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
1	UHC Maxwell, T. <sup>1</sup>	<b>(Measure)</b> Regular assessment of dyspnea.	Adults > or = 18 years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay > 4 days AND 2 prior admissions for any cause in preceding 12 months in the hospital.	Dyspnea assessment within 48 hours of admission.	CHF Mixed cancer HIV Mixed respiratory diseases	Adult  Average age is 58.4  Lower boundary for age is 18	Hospital (non-ICU) Hospital (ICU)	Chart  Reliability / Validity not reported



## *Treatment*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
2	ACOVE End of Life Wenger, N.S. <sup>2</sup>	(Indicator) Effective dyspnea treatment in expected dying.  IF a noncomatose vulnerable elder is not expected to survive and a mechanical ventilator is withdrawn or intubation is withheld, THEN the patient should receive (or have orders available for) an opiate of benzodiazepine or barbiturate infusion to reduce dyspnea, and the chart should document whether the patient has dyspnea.	Noncomatose vulnerable elders who are not expected to survive and a mechanical ventilator is withdrawn or intubation is withheld.	Patient received or had ordered an opiate or benzodiazepine or barbiturate infusion to reduce dyspnea and the chart documented whether the patient has dyspnea.	Not Reported	Adult	All settings	Chart Reliability / Validity not reported
3	ACOVE End of Life Wenger, N.S. <sup>2</sup>	(Indicator) Regular treatment and follow-up of dyspnea in expected dying.  IF a vulnerable elder who had dyspnea in the last 7 days of life died an expected death, THEN the chart should document how the dyspnea was treated and follow-up should be documented about the dyspnea.	Vulnerable elders who had dyspnea in the last 7 days of life and died expected deaths.	Chart documents how dyspnea was treated and follow-up about the dyspnea.	Not Reported	Adult	All settings	Chart Reliability / Validity not reported
4	QA Tools Golomb, B. <sup>3</sup> McGlynn, E.A. <sup>4</sup> Asch, S.M. <sup>5</sup>	(Indicator) Treatment of dyspnea caused by hypoxia.	Patients with dyspnea and baseline room air oxygen saturation < 88% at rest.	Therapy with home oxygen was used.	COPD	Adult	Not Reported	Chart Reliability / Validity not reported

### *Follow-up*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
5	UHC Maxwell, T. <sup>1</sup>	<b>(Measure)</b> Timely treatment of inpatient dyspnea.	Adults > or = 18 years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay > 4 days, 2 prior admissions for any cause in preceding 12 months in the hospital , AND reported dyspnea within the 1st 48 hours of admission.	Dyspnea relief or reduction within 48 hours of admission.	CHF Mixed cancer HIV Mixed respiratory diseases	Adult Average age is 58.4 Lower boundary for age is 18	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported

**Potential Indicators  
Assessment**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
6	Dudgeon, D.J. <sup>6</sup> Kvale, P.A. <sup>7</sup> Dyspnea. Mechanisms, assessment, and management: a consensus statement. American Thoracic Society <sup>8</sup> Ferguson, G.T. <sup>9</sup>	<p>The optimal treatment for breathlessness is correction of the cause.</p> <p>In all patients with lung cancer, potentially correctable causes of dyspnea, such as localized obstruction of a major airway, a large pleural effusion, or an exacerbation of coexisting COPD, should be sought initially.</p> <p>Diagnostic testing ... to identify the specific nature of the disorder ... is the cornerstone of the assessment of dyspnea and leads to a correct diagnosis in many, but not all, cases. Correction or amelioration of the disorder follows and generally reduces the intensity of dyspnea, increases the comfort with which patients perform activities, and increases their capacity to exercise.</p> <p>Spirometry ... is recommended for patients with respiratory symptoms such as chronic cough, episodic wheezing, and exertional dyspnea in order to detect airways obstruction.</p>	Patients with dyspnea.	Evaluation was performed to search for correctable conditions as causative for dyspnea.	Mixed cancer Lung cancer COPD	Adult	Not Reported	Data source not reported Reliability / Validity not reported

***Potential Indicators  
Treatment***

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
7	Kvale, P.A. <sup>7</sup>	<p>Patients with malignant pleural effusions that cause dyspnea initially should be drained by thoracentesis.</p> <p>Patients with NSCLC and better performance status and recurrent malignant pleural effusions, and whose lungs re-expand with initial thoracentesis or thoracoscopy, should be followed up by pleurodesis.</p> <p>In patients with SCLC, the treatment of choice for malignant effusions is systemic chemotherapy.</p>	Patients with cancer and dyspnea caused by malignant pleural effusion.	Therapy with thorocentesis and appropriate subsequent therapy (pleurodesis, chemotherapy, or other)	Lung cancer Mixed cancer	Adult	Not Reported	Data source not reported Reliability / Validity not reported
8	Kvale, P.A. <sup>7</sup>	<p>For patients with central airway obstruction, bronchoscopy should be done to determine the type of airway obstruction (extraluminal tumor compression of the major airways, intraluminal tumor growth, or both).</p> <p>In patients with central airway obstruction, rapid relief of dyspnea can be accomplished via bronchoscopy with removal of intraluminal tumor (laser, electrocautery, APC) and/or by inserting a stent.</p>	Patients with cancer and dyspnea caused by central airway obstruction.	Diagnostic bronchoscopy and bronchoscopic therapy (laser, electrocautery, stent, argon plasma coagulation, cryotherapy, brachytherapy, and/or photodynamic therapy) was offered or received.	Mixed cancer	Adult	Not Reported	Data source not reported Reliability / Validity not reported
9	Kvale, P.A. <sup>7</sup>	For all lung cancer patients with dyspnea, nonpharmacologic, noninterventional treatments including patient education and intervention by allied health personnel should be used to help control dyspnea, including breathing control, activity pacing, relaxation techniques, fans, and psychosocial support.	Patients with cancer and dyspnea.	Therapy with nonpharmacologic and noninterventional approaches (including breathing control, activity pacing, relaxation techniques, fans, and psychosocial support), including patient education, was received.	Mixed cancer	Adult	Not Reported	Data source not reported Reliability / Validity not reported

**Potential Indicators  
Treatment**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
10	Socinski, M.A. <sup>10</sup> Pfister, D.G. <sup>11</sup>	Data from case series and randomized trials show that chemotherapy can have a palliative effect on disease-related symptoms [especially dyspnea, cough, and chest pain] and can improve QOL compared to BSC in stage IV NSCLC patients who are deemed suitable for treatment.  Brachytherapy, photodynamic therapy, and the laser ... have been found to produce effective palliation of symptomatic endobronchial disease, with palliation of cough, hemoptysis, and dyspnea.	Patients with appropriate malignancies and dyspnea.	Palliative chemotherapy or radiotherapy (external beam, brachytherapy, and photodynamic therapy) was offered or received for patients who are deemed suitable for treatment.	Mixed cancer	Not Reported	Not Reported	Data source not reported Reliability / Validity not reported
11	Kvale, P.A. <sup>7</sup> Dyspnea. Mechanisms, assessment, and management: a consensus statement. American Thoracic Society <sup>8</sup> Jennings, A.L. <sup>12</sup> Booth, S. <sup>13</sup>	For all lung cancer patients with dyspnea, pharmacologic approaches for the management of dyspnea may include oxygen, bronchodilators, corticosteroids, antibiotics, and opioids.  It is reasonable to recommend a trial of anxiolytic therapy on an individual basis, particularly in those with morbid anxiety or respiratory panic attacks.  Bronchodilators have been shown ... to improve dyspnea [in those with obstructive lung disease].  This review shows statistically strong evidence for a small and probably clinically significant effect of oral or parenteral opioids in the treatment of breathlessness.  Opiates acutely relieve dyspnea and improve exercise performance ...; despite safety concerns, these drugs do have a place in the management of patients in the terminal phase of their illness.  Oxygen therapy may be one part of the palliative or supportive care of patients with cancer.	Patients with cancer and dyspnea.	Therapy with pharmacologic approaches (including oxygen, bronchodilators, corticosteroids, antibiotics, anxiolytics, and opiates) were offered or received in appropriate conditions as part of the palliative management.	Lung cancer Mixed cancer CHF COPD Infection	Adult	Not Reported	Data source not reported Reliability / Validity not reported

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## Appendix F3. Quality Measures and Indicators for Supportive Cancer Care: Depression

### *Assessment*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
1	UHC Maxwell, T. <sup>1</sup>	<b>(Measure)</b> Regular assessment for psychosocial well-being.	Adults > or = 18 years of age, with admission for CHF (DRG 127), Cancer (DRG 82, 203, 172, 274, 346, 10) HIV (DRG 489) OR respiratory (DRG 475, 483) AND length of stay > 4 days, 2 prior admissions for any cause in preceding 12 months in the hospital.	Formal psychosocial assessment up to 1 year prior to admission during a previous hospitalization OR within 4 days of index admission.	CHF Mixed cancer HIV Mixed respiratory diseases	Adult Average age is 58.4 Lower boundary for age is 18	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported
2	ACOVE End of Life Wenger, N.S. <sup>2</sup> Saliba, D. <sup>3</sup>	(Indicator) Regular spiritual assessment in expected dying.  IF a vulnerable elder who was conscious during the last 3 days of life died an expected death, THEN the medical record should contain documentation about spirituality or how the patient was dealing with death or religious feelings.	Vulnerable elder who was conscious during the last 3 days of life.	Vulnerable elder with documentation of spiritual assessment in the medical record.	Not Reported	Not Reported	All settings	Patient interview / survey Chart Reliability / Validity not reported

## *Treatment*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
3	ACOVE Wenger, N.S. <sup>2</sup> Saliba, D. <sup>3</sup> Nakajima, G.A. <sup>4</sup>	<b>(Measure)</b> Regular assessment or treatment of depression in newly diagnosed cancer.	Vulnerable elders presenting with onset or discovery malignancy (excluding skin cancer) and other conditions*.	Patients asked about or treated for depression, or referred to a mental health professional within two months of diagnosis of a condition.	Saliba, D.:  Mixed nursing home population for 11 diagnoses, not cancer	Adult	All settings	Patient interview / survey Chart Reliability / Validity not reported
4	ACOVE Wenger, N.S. <sup>2</sup> Saliba, D. <sup>3</sup> Nakajima, G.A. <sup>4</sup>	<b>(Measure)</b> Routine assessment or treatment of depression in symptomatic patients.	Vulnerable elders presenting with new onset of one the following symptoms: sad mood, feeling down; insomnia or difficulties with sleep; apathy or loss of interest in pleasurable activities; complaints of memory loss; unexplained weight loss of greater than 5% in the past month or 10% over one year; or unexplained fatigue or low energy.	Patients asked about or treated for depression, or referred to a mental health professional within two weeks of presentation.	Saliba, D.:  Mixed nursing home population for 11 diagnoses, not cancer	Adult	All settings	Patient interview / survey Chart Reliability / Validity not reported

\* Other conditions include stroke, myocardial infarction, dementia, chronic pain, alcohol or substance abuse or dependence, anxiety disorder, or personality disorder.



***Potential Indicators  
Assessment***

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
5	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder has thoughts of suicide THEN the medical record should document, on the same date, that the patient either has no immediate plan for suicide, or that the patient was referred for evaluation for psychiatric hospitalization.	Vulnerable elders with thoughts of suicide.	Patients where medical record documents, on the same date, that the patient either has no immediate plan for suicide, or that the patient was referred for evaluation for psychiatric hospitalization.	Not Reported	Adult	All settings	Chart Reliability / Validity not reported
6	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder receives a diagnosis of a new depression episode THEN the medical record should document at least three of the nine Diagnostic and Statistical Manual (DSM) IV target symptoms for major depression within the first month of diagnosis.	Vulnerable elders with diagnosis of a new depression episode.	Patients where the medical record documents at least three of the nine DSM-IV target symptoms for major depression within the first month of diagnosis.	Not Reported	Adult	All settings	Chart Reliability / Validity not reported
7	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder receives a diagnosis of a new depression episode THEN the medical record should document, on the day of diagnosis, the presence or absence of suicidal ideation.	Vulnerable elders with diagnosis of a new depression episode.	Patients where the medical record document on the day of diagnosis the presence or absence of suicidal ideation and psychosis (consisting of, at a minimum, auditory hallucinations or delusions).	Not Reported	Adult	All settings	Chart Reliability / Validity not reported

***Potential Indicators  
Treatment***

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
8	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder is being treated for depression with antidepressants THEN the antidepressants should be prescribed at appropriate starting doses, and they should have an appropriate titration schedule to a therapeutic dose, therapeutic blood level, or remission of symptoms by 12 weeks.	Vulnerable elders being treated for depression with antidepressants.	Patients with antidepressants prescribed at appropriate starting doses, and with an appropriate titration schedule to a therapeutic dose, therapeutic blood level, or remission of symptoms by 12 weeks.	Not Reported	Adult	All settings	Chart Reliability / Validity not reported
9	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder has no meaningful symptom response after 6 weeks of treatment THEN one of the following should be initiated by the eighth week of treatment: Optimization of medication (i.e., alter dose of initial medication; change to or add a different medication); psychiatric referral (if initial treatment was medication); or medication trial (if initial treatment was psychotherapy alone).	Vulnerable elders with depression and no meaningful symptom response after 6 weeks of treatment.	Patients with one of the following treatment options initiated by the 8th week of treatment: medication dose should be optimized or the patient should be referred to a psychiatrist (if initial treatment was medication); or medication should be initiated or referral to a psychiatrist should be offered (if initial treatment was psychotherapy alone).	Not Reported	Adult	All settings	Chart Reliability / Validity not reported

**Potential Indicators  
Follow-up**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
10	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder responds only partially after 12 weeks of treatment THEN at least one of the following treatment options should be instituted by the 16th week of treatment: switch to a different medication class or add a second medication to the first (if initial treatment includes medication); add psychotherapy (if the initial treatment was medication); a trial of medication (if initial treatment was psychotherapy without medication), consider electroconvulsive therapy, or referral to a psychiatrist.	Vulnerable elders responding only partially after 12 weeks of treatment.	Patients with one of the following treatment options instituted by the 16th week of treatment: switch to a different medication class or add a second medication to the first (if initial treatment includes medication); add psychotherapy (if the initial treatment was medication); try medication (if initial treatment was psychotherapy without medication); consider ECT; or refer to a psychiatrist.	Not Reported	Adult	All settings	Chart Reliability / Validity not reported
11	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder has responded to antidepressant medication THEN he or she should be continued on the drug at the same dosage for at least 6 months, and at least one physician documentation about depression should occur during that time period	Vulnerable elders responding to antidepressant medication.	Patients continued on the drug at the same dose for at least six months, and making at least one clinician contact (office visit or phone) during that time period.	Not Reported	Adult	All settings	Chart Reliability / Validity not reported
12	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder is diagnosed with depression THEN antidepressant treatment, psychotherapy, or electroconvulsive therapy should be offered within 2 weeks after diagnosis unless there is documentation within that period that the patient has improved, or unless the patient has substance abuse or dependence, in which case treatment could wait until 8 weeks after the patient is in a drug- or alcohol-free state.	Vulnerable elders with diagnosis of a new depression episode.	Patients with antidepressant treatment, psychotherapy, or electroconvulsive therapy (ECT) be offered within two weeks after diagnosis unless there is documentation within that period that the patient has improved, or unless the patient has substance abuse or dependence, in which case treatment may wait until eight weeks after the patient is in a drug or alcohol free state.	Not Reported	Adult	All settings	Chart Reliability / Validity not reported

***Potential Indicators  
Follow-up***

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
13	ACOVE End of Life Nakajima, G.A. <sup>4</sup>	IF a vulnerable elder is started on an antidepressant medication THEN the following medications should not be used as first- or second-line therapy: tertiary amine tricyclics (amitriptyline, imipramine, doxepin, clomipramine, trimipramine); monoamine oxidase inhibitors (MAOIs) (unless atypical depression is present); benzodiazepines; or stimulants (except methylphenidate).	Vulnerable elders being treated for depression with antidepressants.	Patients where the following medications are not used as first- or second-line therapy: tertiary amine tricyclics, monoamine oxidase inhibitors (unless atypical depression is present), benzodiazepines, or stimulants (except methylphenidate).	Not Reported	Adult	All settings	Chart Reliability / Validity not reported

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# Appendix F4. Quality Measures and Indicators for Supportive Cancer Care: Advanced Care Planning

## Assessment

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
1	ACOVE End of Life Wenger, N.S. <sup>1</sup> Wenger, N.S. <sup>2</sup>	<b>(Measure)</b> Regular identification of a surrogate in the outpatient setting.  All vulnerable elders should have in their outpatient chart one of the following: 1) an advance directive indicating the patient's surrogate/proxy decision-maker, 2) documentation of a discussion about who would be a surrogate decision maker or a search for a surrogate, or 3) indication that there is no identified surrogate upon entry to facility or transfer to new unit or site.	All vulnerable elderly patients in an outpatient setting.	Number of vulnerable elderly patient's with documentation in their medical record of their proxy or surrogate decision-maker's name and contact information, or of a discussion with patient of who would be surrogate, or documentation of a search for a surrogate, or an indication that there is no identified surrogate.	Mixed disease	Adult 36% Male Average age is 81.0	Home care Hospice Ambulatory / outpatient care Hospital (non-ICU) Hospital (ICU) Home Community	Patient interview / survey Chart Reliability / Validity not reported
2	ACOVE End of Life Wenger, N.S. <sup>1</sup> Wenger, N.S. <sup>2</sup>	<b>(Measure)</b> Regular identification of a surrogate among hospital admissions with impaired cognition.  IF a vulnerable elder with dementia, coma, or altered mental status is admitted to the hospital, THEN within 48 hours of admission the medical record should 1) contain an advance directive indicating the patient's surrogate decision maker, 2) document a discussion about who would be a surrogate decision maker or a discussion about a search for a surrogate, or 3) indicate that there is no identified surrogate.	All vulnerable elders with dementia, coma, or altered mental status admitted to the hospital.	Number of vulnerable elders with dementia, coma, or altered mental status admitted to a hospital with documentation within 48 hours of admission of 1) an advance directive indicating the patient's surrogate decision maker, 2) a discussion about who would be a surrogate decision maker or a discussion about a search for a surrogate, or 3) indicate that there is no identified surrogate.	Mixed disease	Adult 36% Male Average age is 81.0	Ambulatory / outpatient care Hospital (non-ICU) Hospital (ICU)	Patient interview / survey Chart Reliability / Validity not reported

## Assessment

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
3	ACOVE End-of Life Wenger, N.S. <sup>1</sup> Wenger, N.S. <sup>2</sup>	<b>(Measure)</b> Regular assessment of preferences among inpatients with dementia.  IF a vulnerable elder has a diagnosis of severe dementia is admitted to the hospital and survives 48 hours, THEN within 48 hours of admission, the medical record should document that the patient's the patient's prior preferences for care have been considered or that these preferences for care could not be elicited or are unknown.	All vulnerable elders with severe dementia admitted to a hospital and surviving 48 hours.	Number of vulnerable elders with severe dementia admitted to a hospital and surviving 48 hours with documentation that the patient's prior preferences for care have been considered or that these preferences could not be elicited or are unknown.	Mixed disease	Adult 36% Male Average age is 81.0	Hospice Ambulatory / outpatient care Hospital (non-ICU) Hospital (ICU) Home	Patient interview / survey Chart Reliability / Validity not reported
4	ACOVE End of Life Wenger, N.S. <sup>1</sup> Wenger, N.S. <sup>2</sup>	<b>(Measure)</b> Regular assessment of preferences in an ICU.  IF a vulnerable elder is admitted directly to the intensive care unit from an outpatient or ER setting and survives 48 hours, THEN within 48 hours of admission, the medical record should document that the patient's preferences for care have been considered or that these preferences could not be elicited or are unknown.	All vulnerable elderly patients admitted directly to the ICU from an outpatient or ER setting and surviving 48 hours.	Number of vulnerable elders admitted directly to the intensive care unit from an outpatient or ER setting and surviving 48 hours with documentation in the medical record that the patient's preferences for care have been considered or that these preferences could not be elicited or are unknown within 48 hours of admission.	Mixed disease	Adult 36% Male Average age is 81.0	Hospice Ambulatory / outpatient care Hospital (non-ICU) Hospital (ICU)	Patient interview / survey Chart Reliability / Validity not reported

## Assessment

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
5	Ryndes, T. <sup>3</sup> National Hospice and Palliative Care Organization (NHPCO) <sup>4</sup>	<b>(Measure)</b> Regular assessment of preferences in hospice.	All patients admitted to hospice.	Number of hospice patients with documentation in their medical record that they were assessed upon admission including physical, functional, emotional and spiritual needs and preferences with full autonomy to make decisions about how the remainder of their life is to be spent; any living will or advance directive information, and/or an assigned power of attorney for health care.	Mixed disease	Adult	Home	Chart Construct validity Discriminant validity Other validity Reliability / Validity not reported
6	ACOVE End of Life Wenger, N.S. <sup>1</sup> Wenger, N.S. <sup>2</sup>	<b>(Measure)</b> Regular patient participation in decisions to limit treatment.  IF a vulnerable elder with decision-making capacity has orders written in the hospital or the nursing home to withhold or withdraw a particular treatment (e.g., a do-not-resuscitate order or an order not to initiate dialysis), THEN the medical record should document 1) patient participation in the decision or 2) why the patient did not participate in the decision.	All vulnerable elderly patients in the hospital or nursing home with written orders to withdraw or withhold a LST.	Number of vulnerable elderly patients with decision-making capacity with written orders to withhold or withdraw a particular LST with documentation in the medical record of 1) patient participation in the decision or 2) why the patient did not participate in the decision.	Mixed disease	Adult 36% Male Average age is 81.0	Hospital (non-ICU) Hospital (ICU)	Patient interview / survey Chart
7	UHC Maxwell, T. <sup>5</sup>	<b>(Measure)</b> Regular family meetings among hospitalized patients.	All adults admitted to the hospital.	Number of adults admitted to the hospital with documentation in the medical record that the health care team conducted a patient/family meeting within 1 week of admission that included discussion of the patient's treatment preferences and/or a plan for discharge disposition.	Mixed disease	Adult	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported
8	UHC Maxwell, T. <sup>5</sup>	<b>(Measure)</b> Timely and effective discharge planning.	All adults admitted to the hospital.	Number of adults admitted to the hospital with documentation in the medical record of a plan for discharge disposition within 4 days of admission.	Mixed disease	Adult	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported



## Assessment

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
9	VHA Update March 2005 <sup>6</sup>	(Indicator) Regular identification of a surrogate in the ICU.	Total number of patients with an ICU length of stay > 24 hours.	Number of ICU patients with documentation in the chart of status of identification of a health care proxy (or other appropriate surrogate decision-maker) including one or more of the following: 1) documentation that the patient has a health care proxy, 2) documentation that the patient declined to appoint a health care proxy, 3) documentation that the care team discussed health care proxy appointment with the patient and/or family, 4) documentation that the patient has an appropriate surrogate decision-maker other than a health care proxy.	Not Reported	Adult	Hospital (ICU)	Chart Reliability / Validity not reported
10	VHA Update March 2005 <sup>6</sup>	(Indicator) Regular assessment of advance directives for ICU patients.	Total number of patients with an ICU length of stay > than 24 hours.	Number of patients admitted to the ICU with documentation of the patient's advance directive (written or oral instructions from the patient specifying the type of medical treatment that is desired if the patient becomes incapacitated, including a living will, durable power of attorney (note state-specific status) or any document that state law recognizes as an "advance directive") entered in the medical record within 24 hours following admission.	Not Reported	Adult	Hospital (ICU)	Chart Reliability / Validity not reported
11	VHA Update March 2005 <sup>6</sup>	(Indicator) Regular assessment of specific resuscitation preferences in the ICU.	Total number of patients with an ICU length of stay > than 24 hours.	Number of patients admitted to the ICU with resuscitation status including one or more of the following: 1) documentation of a directive to attempt resuscitation in the event of an arrest, 2) documentation of a directive to forego attempts to resuscitate in the event of an arrest, 3) documentation that the care team discussed resuscitation status with the patient and/or family) documented in the medical record within 24 hours of admission.	Not Reported	Adult	Hospital (ICU)	Chart Reliability / Validity not reported

## *Assessment*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
12	VHA Update March 2005 <sup>6</sup>	(Indicator) Regular clinician-patient-family communication in the ICU.	Total number of patients with an ICU length of stay > than 120 hours.	Number of patients admitted to the ICU who survive > than 5 days (120 hours) with documentation in the medical record that an interdisciplinary team meeting (with at least the attending physician (primary care or ICU attending) and a nurse) and the patient and/or family was conducted within 120 hours of ICU admission and involved a discussion addressing each of the following topics: 1) the patient's condition (diagnosis and prognosis), 2) goals of treatment; 3) the patient's and family's needs and preferences, 4) the patient's and family's understanding of the patient's condition and goals of treatment at the conclusion of the meeting.	Not Reported	Adult	Hospital (ICU)	Chart  Reliability / Validity not reported

## Application

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
13	ACOVE End of Life Wenger, N.S. <sup>1</sup> Wenger, N.S. <sup>2</sup>	<b>(Measure)</b> Documentation of care preferences across venues.  IF a vulnerable elder has an advance directive in the outpatient, inpatient, or nursing home medical record or the patient reports the existence of an existing advance directive in an interview, and the patient receives care in a second venue, THEN 1) the existing advance directive should be present in the patient's medical record in the second venue or 2) documentation should acknowledge its existence, its contents, and the reason that it is not in the current medical record.	All vulnerable elderly patients with existing advance directives in another setting admitted to an outpatient, inpatient, or nursing home setting.	Number of vulnerable elderly patients admitted to the outpatient, inpatient, or nursing home and reporting the existence of an advance directive in another setting with documentation in their medical record of 1) the existing advance directive or 2) documentation acknowledging the existing advance directive, its contents, and the reason that it is not included in the medical record.	Mixed disease	Adult 36% Male Average age is 81.0	Home care Hospice Ambulatory / outpatient care Hospital (non-ICU) Hospital (ICU) Home Community	Patient interview / survey Chart Reliability / Validity not reported
14	ACOVE End of Life Wenger, N.S. <sup>1</sup> Wenger, N.S. <sup>2</sup>	<b>(Measure)</b> Documentation of specific life sustaining preferences.  IF a vulnerable elder indicates (during an interview) that he/she would rather die than live permanently comatose, ventilated, or tube fed, THEN 1) the chart should document a discussion of life-sustaining treatment preferences, 2) the chart should contain an advance directive, or 3) the patient should indicate (during the interview) that he/she discussed these topics with the physician or does not wish to discuss the topics.	All vulnerable elders in any setting.	Number of vulnerable elders in any setting indicating that he/she would rather die than live permanently comatose, ventilated, or tube fed with one of the following documented in their medical record: 1) a discussion of life-sustaining treatment preferences, 2) an advance directive, or 3) that the patient discussed this topic with the physician or does not wish to discuss this topic.	Mixed disease	Adult 36% Male Average age is 81.0	Home care Hospice Ambulatory / outpatient care Hospital (non-ICU) Hospital (ICU) Home Community	Patient interview / survey Chart Reliability / Validity not reported

## Follow-up

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
15	ACOVE End of Life Wenger, N.S. <sup>1</sup> Wenger, N.S. <sup>2</sup>	<b>(Measure)</b> Consistency of preferences with use of ventilatory support.  IF a vulnerable elder requires mechanical ventilation during a hospitalization (except short-term and post operative mechanical ventilation), THEN within 48 hours of the initiation of mechanical ventilation the medical record should document the goals of care for the patient and the patient's preference for mechanical ventilation or why this information is unavailable.	All hospitalized vulnerable elders requiring mechanical ventilation (except short-term and post operative mechanical ventilation).	Number of hospitalized vulnerable elders requiring mechanical ventilation (except short-term and post operative mechanical ventilation) with documentation in the patient record of the goals of care and the patient's decision for mechanical ventilation or why this information is unavailable.	Mixed disease	Adult 36% Male Average age is 81.0	Hospital (non-ICU) Hospital (ICU)	Patient interview / survey Chart Reliability / Validity not reported
16	Earle, C.C. <sup>7</sup> Earle, C.C. <sup>8</sup> Grunfeld, E. <sup>9</sup>	<b>(Measure)</b> Late life hospital use.	All deceased cancer patients.	Number of dying cancer patients with > 1 hospital admission in the last month of life.	Mixed cancer	Adult Grunfeld, E.: All patients in the population with cancer	Hospital (non-ICU) Hospital (ICU)	Administrative Chart Other Grunfeld, E.: Cancer registry, administrative claim data, hospital discharge abstract
17	Earle, C.C. <sup>7</sup> Earle, C.C. <sup>8</sup> Grunfeld, E. <sup>9</sup>	<b>(Measure)</b> Late life ICU use.	All deceased cancer patients.	Number of dying cancer patients with 1 ICU admission in the last month of life.	Mixed cancer	Adult Grunfeld, E.: All patients in the population with cancer	Hospice	Administrative Chart Other Grunfeld, E.: Cancer registry, administrative claim data, hospital discharge abstract

## Follow-up

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
18	Dana Farber Cancer Center Earle, C.C. <sup>7</sup> Earle, C.C. <sup>8</sup> Grunfeld, E. <sup>9</sup> Cancer Care Ontario <sup>10</sup>	<b>(Measure)</b> Late life rate of emergency care.	All deceased cancer patients.	Number of dying cancer patients with > 1 emergency room visit in the last month of life.	Mixed cancer	Adult Grunfeld, E.:  All patients in the population with cancer	Hospital (non-ICU)  Hospital (ICU)	Administrative Chart Other Reliability / Validity not reported Grunfeld, E.:  Cancer registry, administrative claim data, hospital discharge abstract
19	Earle, C.C. <sup>7</sup> Earle, C.C. <sup>8</sup> Grunfeld, E. <sup>9</sup>	<b>(Measure)</b> New chemotherapy regimen in last 30 days of life.	All deceased cancer patients.	Number of dying cancer patients started on a new chemotherapy regimen in the last 30 days of life.,	Mixed cancer	Adult Grunfeld, E.:  All patients in the population with cancer	Ambulatory / outpatient care  Hospital (non-ICU)  Hospital (ICU)	Administrative Chart Other Reliability / Validity not reported Grunfeld, E.:  Cancer registry, administrative claim data, hospital discharge abstract
20	Earle, C.C. <sup>7</sup> Earle, C.C. <sup>8</sup> Grunfeld, E. <sup>9</sup> Cancer Care Ontario <sup>11</sup>	<b>(Measure)</b> Chemotherapy in last 14 days of life.	All deceased cancer patients.	Number of dying cancer patients receiving chemotherapy in the last 14 days of life.	Mixed cancer	Adult Grunfeld, E.:  All patients in the population with cancer	Hospital (non-ICU)  Hospital (ICU)	Administrative Chart Other Reliability / Validity not reported Grunfeld, E.:  Cancer registry, administrative claim data, hospital discharge abstract

## *Follow-up*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
21	Earle, C.C. <sup>7</sup> Earle, C.C. <sup>8</sup> Grunfeld, E. <sup>9</sup> Cancer Care Ontario <sup>11</sup> National Cancer Policy Board (NCPB) <sup>9</sup>	<b>(Measure)</b> Admission to hospice.	All deceased cancer patients.	Number of cancer patients who die in the hospital.	Mixed cancer	Adult Grunfeld, E.:  All patients in the population with cancer	Hospice	Administrative Chart Other Reliability / Validity not reported Grunfeld, E.: Cancer registry, administrative claim data, hospital discharge abstract
22	Earle, C.C. <sup>7</sup> Earle, C.C. <sup>8</sup> Grunfeld, E. <sup>9</sup> National Cancer Policy Board (NCPB) <sup>9</sup>	<b>(Measure)</b> Late referral to hospice.	All deceased cancer patients.	IF a dying cancer patients referred to hospice or palliative care < 3 days before death.	Mixed cancer	Adult Grunfeld, E.:  All patients in the population with cancer	Hospice	Administrative Chart Other Reliability / Validity not reported Grunfeld, E.: Cancer registry, administrative claim data, hospital discharge abstract
23	Earle, C.C. <sup>7</sup> Earle, C.C. <sup>8</sup> Grunfeld, E. <sup>9</sup> Cancer Care Ontario <sup>10</sup> Cancer Care Ontario <sup>11</sup>	<b>(Measure)</b> Site of death.	All deceased cancer patients.	Number of cancer patients who die in the hospital.	Mixed cancer	Adult Grunfeld, E.:  All patients in the population with cancer	Hospital (non-ICU) Hospital (ICU)	Administrative Chart Other Reliability / Validity not reported Grunfeld, E.: Cancer registry, administrative claim data, hospital discharge abstract

### *Follow-up*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
24	Ryndes, T. <sup>3</sup> National Hospice and Palliative Care Organization (NHPCO) <sup>4</sup> Connor, S. <sup>12</sup>	<b>(Measure)</b> Safe dying in hospice.	All Caregiver's of Hospice patients who died while in hospice.	Number of deceased hospice patient's caregivers with documentation in the patient's medical record who were contacted and surveyed as to the quality of care provided by the hospice using the following question: If you cared for the patient at home, did hospice increase your confidence to safely care for your loved one as death approached?.	Mixed disease	Adult	Home	Chart Construct validity reported Discriminant validity reported
25	ACOVE End of Life Wenger, N.S. <sup>2</sup>	(Indicator) Care consistency with documented care preferences.  If a vulnerable elder has specific treatment preferences (e.g., a do-not-resuscitate order, no tube feeding, or no hospital transfer) documented in a medical record, THEN these treatment preferences should be followed.	All vulnerable elderly patients in any health care setting with specific treatment preferences documented in their medical record.	Number of vulnerable elders with specific treatment preferences documented in their medical record with those treatment preferences having been followed.	Mixed disease	Adult	Hospice Ambulatory / outpatient care Hospital (non-ICU) Hospital (ICU)	Chart

***Potential Indicators  
Assessment***

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
1	Dokken, D.L. <sup>13</sup>	IF a child with life threatening illness is admitted to any health care setting, THEN the needs of each child are supported through periodic assessment and reassessment of the child's physical, social, emotional, developmental, spiritual, and educational strengths and needs in light of the child's developmental level and diagnosis and, based on the assessed needs, development and implementation of interventions involving experts in relevant areas (e.g., child life, chaplancy, physical and occupational therapy, psychology, etc.) should be conducted.	All Children With Life Threatening Illness Admitted to Any Health Care Setting.	Number of children with life threatening illness admitted to any health care setting with documentation in the medical record that the needs of each child were periodically assessed (including child's physical, social, emotional, developmental, spiritual, and educational strengths and needs in light of the child's developmental level and diagnosis) and, based on the assessed needs, there is evidence of the development and implementation of interventions involving experts in relevant areas (e.g., child life, chaplancy, physical and occupational therapy, psychology, etc.).	Not Reported	Children	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported



**Potential Indicators  
Application**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
2	Lilly, C.M. <sup>14</sup>	IF an ICU patient has a poor prognosis (e.g., a condition associated with a high probability of death, who had a predicted length of ICU stay longer than 5 days, a predicted mortality of greater than 25% as estimated by the attending physician, or a change in functional status that is potentially irreversible and sufficient to preclude eventual return to home) or a deteriorating condition (a progressive worsening of a patient's condition that predisposes the patient to death), THEN the attending physician should assess the patient's medical condition, review the case with the patient's primary care physician and agree on a recommended care plan, review any known advance directives, and conduct a family meeting with the patient's family (including health care proxy), where possible, the patient, the patient's nurse, and the hospital house officer in order to 1) review the medical facts and options for treatment, 2) to discuss the patient's perspectives on death and dying, chronic dependence, loss of function, and the acceptability of the risks and discomforts of critical care; 3) to agree on a care plan; and 4) to agree on criteria by which the success or failure of this care plan would be judged using defined "clinical events" as milestones indicating that the care plan had been effective or not and the time frame for their occurrence.	All ICU patients.	umber of ICU patients with a poor prognosis (e.g., a condition associated with a high probability of death, who had a predicted length of ICU stay longer than 5 days, a predicted mortality of greater than 25% as estimated by the attending physician, or a change in functional status that is potentially irreversible and sufficient to preclude eventual return to home) or a deteriorating condition (a progressive worsening of a patient's condition that predisposes the patient to death) with documentation in the medical record that the attending physician assessed the patient's medical condition, reviewed the case with the patient's primary care physician, reviewed any known advance directives, and conducted a family meeting with the patient's family (including health care proxy).	Mixed disease	Adult White African American Hispanic 59% Male Average age is 59.0 Age ranges from 45 to 75	Hospital (ICU)	Data Collection specified Reliability / Validity not reported

**Potential Indicators  
Application**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
3	National Comprehensive Cancer Network (NCCN) <sup>15</sup>	All cancer patients with advanced, symptomatic, progressive disease and/or those with a life expectancy of <12 months, or with serious comorbid conditions, or the patient or family requests palliative care should receive a palliative care assessment, including symptoms, advance care planning discussion (living will, power of attorney, DNR orders, hospice preference), resource management/social support (caregivers, family, financial, community, cultural, spiritual, religious), and the benefits and risks of anticancer therapy to identify patient and family goals and expectations, referral for complex palliative care, discuss palliative care options (including hospice), elicit personal values and preferences of patient and family for end of life care, encourage communication of wishes between patient and family, and encourage the designation of a health care proxy.	All cancer patients with advanced, symptomatic, progressive disease and/or those with a life expectancy of <12 months, or with serious comorbid conditions, or the patient or family requests palliative care.	Number of cancer patients with advanced, symptomatic, progressive disease and/or those with a life expectancy of <12 months, or with serious comorbid conditions, or the patient or family requests palliative care with documentation in the chart that they received a palliative care assessment (including symptoms and advance care planning discussions of living will, power of attorney, DNR orders, hospice preference, resource management/social support concerning caregivers, family, financial, community, cultural, spiritual, religious needs, and the benefits and risks of anticancer therapy) to identify patient and family goals and expectations, wishes for referral for complex palliative care, discussion of palliative care options (including hospice), documentation of the personal values and preferences of the patient and family for end of life care, communication of wishes between patient and family, and encourage the designation of a health care proxy.	Mixed cancer	Adult	Hospice Ambulatory/outpatient care Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported

**Potential Indicators  
Application**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
4	Clinical practice guidelines for quality palliative care <sup>16</sup>  Standards and Quality Committee <sup>17</sup>	A plan of care for dying patients should be developed for the patient based on 1) a comprehensive interdisciplinary medical, psycho-social, spiritual/existential, cultural assessment of the patient and family; 2) the identified and expressed values, goals, and needs of the patient and family developed with professional guidance and support for decision making; the plan is regularly reviewed and is responsive to the patient's changing illness and the family's changing needs; 4) where identified, the patient/family should be referred to external specialist services; and 5) the services provided by the Palliative Care Team are consistent with the care plan and the patient's and family wishes.	All patients admitted to any health care setting and determined to need palliative care.	Number of dying patients admitted to any health care setting and needing palliative care with documentation in the patient's medical record of: 1) a comprehensive interdisciplinary medical, psycho-social, spiritual/existential, cultural assessment of the patient and family; 2) documentation that the expressed values, goals, and needs of the patient and family were developed with professional guidance and support for decision making; 3) the plan was regularly reviewed and was responsive to the patient's changing illness and the family's changing needs; 4) the patient/family were referred to external specialist services when appropriate; and 5) the services provided by the Palliative Care Team were consistent with the care plan and the patient's and family wishes.	Not Reported	Adult	Home care Hospice Ambulatory/outpatient care Hospital (non-ICU) Hospital (ICU)	Chart  Reliability / Validity not reported

**Potential Indicators  
Application**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
5	Standards and Quality Committee <sup>17</sup>	All patients, in any health care setting, determined to be dying or whose death is expected, THEN the patient and family should have their psychological, emotional, social, cultural, and spiritual needs assessed on an ongoing basis by an interdisciplinary health care team, and where psychological, emotional, and/or spiritual needs are identified or expressed, should be referred to internal and external specialist services, including bereavement services and these assessments and referral/receipt of supportive services should be documented in the patient's medical record or why these needs were not assessed and/or addressed.	All patients, in any health care setting, who died with an expected death.	Number of deceased patients, in any health care setting, who died an expected death with documentation in the patient's medical record of ongoing assessment of the patient and family's psychological, emotional, social, cultural, and spiritual needs by an interdisciplinary health care team, and where psychological, emotional, and/or spiritual needs are identified or expressed, documentation of referral to internal and external specialist services, including bereavement services, and receipt of supportive services or why these needs were not assessed and/or addressed.	Mixed disease	Adult	Other	Data Collection specified Reliability / Validity not reported
6	Clarke, E.B. <sup>18</sup>	IF a vulnerable elder's care, in any health care setting, will be transferred to another health care provider (individual, team, setting), THEN the current provider should maximize continuity of care across clinicians, consultants, and settings by orienting new clinicians regarding the patient and family health care preferences and plan of care and prepare patient and family for a change of clinician(s) and introduce new clinicians.	All vulnerable elders, in any health care setting, who were transferred to new clinician(s) or settings.	% of vulnerable elder's care, in any health care setting, who were transferred to another health care provider (individual, team, setting), with documentation in the patient's medical record that the current provider oriented new clinicians regarding the patient and family's treatment preferences and plan of care, prepared the patient and family for a change of clinician(s), and introduced new clinicians to the patient and family.	Mixed disease	Adult	Hospital (ICU)	Chart Reliability / Validity not reported
7	Masera, G. <sup>19</sup> American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children <sup>20</sup>	IF a child with life threatening illness is admitted to any health care setting, THEN a discussion of an advance directive discussion should be conducted within 48 hours of admission to ensure that treatments that have become burdensome are not used.	All children with life threatening illness admitted to any health care setting.	% of children with life threatening illness admitted to any health care setting with documentation in the medical record of a discussion with the child's parents of advance directives with LST decisions documented within 48 hours of admission.	Mixed cancer	Adult/Children	Home care Hospital (ICU)	Chart Reliability / Validity not reported

**Potential Indicators  
Application**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
8	Masera, G. <sup>19</sup>  American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children <sup>20</sup>	IF a child with cancer cannot be successfully treated by presently available therapies, and the child needs specific treatments identified to be palliative and not curative for mental or physical distress, THEN the focus of care should be on key issues, including communication, social, psychological, emotional support, symptom control, etc. and a advance directive discussion should be conducted with the child's parents within 48 hours of admission.	All children with life threatening illness admitted to any health care setting.	% of children with cancer that cannot be successfully treated by presently available therapies needing specific treatments identified to be palliative and not curative for mental or physical distress with documentation in their medical record that the focus of care is on key issues, including communication, social, psychological, emotional support, symptom control, etc. and a advance directive discussion should be conducted with the child's parents within 48 hours of admission.	Mixed cancer	Children	Home care  Hospital (ICU)	Chart  Reliability / Validity not reported
9	Mitchell, S.L. <sup>21</sup>	IF a patient entering any health care facility is determined to have dementia and has a feeding tube inserted and there is no accompanying documentation of the patient's advance directive or treatment preferences, THEN the medical record should document that the health care team has conferred with the patient's family members and/or proxy regarding sustaining or withdrawing the feeding tube (including a discussion of the evidence regarding the lack of benefit, improved survival, or prevention of aspiration of feeding tubes) within 48 hours of admission.	Total number of patients entering any health care facility with dementia, a feeding tube, and no accompanying documentation of the patient's advance directive or treatment preferences with LOS > 24 hours.	Number of patients entering any health care facility with dementia, a feeding tube, and no accompanying documentation of the patient's advance directive or treatment preferences with documentation in the medical record that the health care team conferred with the patient's family members and/or proxy regarding sustaining or withdrawing the feeding tube (including a discussion of the evidence regarding the lack of benefit, improved survival, or prevention of aspiration of feeding tubes) within 48 hours of admission.	Mixed disease	Adult  Lower boundary  for age is 65	Hospital (non-ICU)  Hospital (ICU)	Chart  Reliability / Validity not reported

**Potential Indicators  
Application**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
10	Dokken, D.L. <sup>13</sup>	IF a child with life threatening illness is admitted to any health care facility, THEN the child and his/her family should be regarded as the unit of care and 1) any concerns raised by the family about the child's condition should be acknowledged and addressed in a timely and respectful manner, 2) the family's cultural values, beliefs, views about quality of life and customary modes of interaction among family and community should be respected by health care providers, 3) the family is present with the child and involved in his/her care to the extent they desire and degree feasible based on the child's condition and health care setting, and 4) the impact of the child's illness on the parental relationship, siblings, and family coping strategies and finances should be routinely assessed, and a range of practical (including financial), emotional, and spiritual supports should be made available to meet family-identified needs by the health care institution and/or through the community.	All children with a life threatening illness admitted to any health care facility.	Number of children with life threatening illness is admitted to any health care facility with documentation in the patient's medical record that the child and his/her family were regarded as the unit of care and 1) any concerns raised by the family about the child's condition were acknowledged and addressed in a timely and respectful manner by the health care team, 2) the family's cultural values, beliefs, views about quality of life and customary modes of interaction among family and community were respected by health care providers, 3) the family was present with the child and involved in his/her care to the extent they desired and degree feasible based on the child's condition and health care setting, and 4) the impact of the child's illness on the parental relationship, siblings, and family coping strategies and finances was routinely assessed and a range of practical (including financial), emotional, and spiritual supports were made available to meet family-identified needs by the health care institution and/or through the community.	Not Reported	Children	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported

***Potential Indicators  
Application***

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
11	Widger, K.A. <sup>22</sup>	Key components of quality care for children include information transmission, preparation for death and care at death, bereavement care, interpersonal aspects and competence of health professionals, clarity and honesty of communication, parent role, support for the family, pain and symptom management, decision making, psychosocial and spiritual needs of the child, availability and accessibility of services, coordination and integration of services, respite care for families, and financial support.	All children with a life threatening illness admitted to any health care facility.	Number of children with a life-threatening illness admitted to any health care facility with documentation in the patient's medical record that the key components of quality terminal care for children with cancer and their families.	Mixed cancer	Children	Not Reported	Not Reported

**Potential Indicators  
Application**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
12	Dokken, D.L. <sup>13</sup>	IF a child with life threatening illness is admitted to any health care setting, THEN each child should have a designated individual, a physician or other health care providers, identified as responsible for coordinating the child's overall care and who should 1)should be involved in care planning and decision-making with the child, family, and other health care providers, 2) is responsible for ongoing communication among the designated health care provider, the child and family, and the child's other health care providers, and the health care setting should develop and implement a process for the child and family to articulate concerns about the choice of designated health care provider and to explore the possibility of changing providers.	All children with a life threatening illness admitted to any health care facility.	Number of children with life threatening illness admitted to any health care setting with documentation in the medical record that a designated individual, a physician or other health care providers, was identified and was identified as being responsible for the coordinating the child's overall care and who was involved in care planning and decision-making with the child, family, and other health care providers, 2) was identified to the child and family as responsible for ongoing communication among the designated health care provider, the child and family, and the child's other health care providers, and there is documentation in the medical record that the child and family were informed about the health care setting's process for the child and family to articulate concerns about the choice of designated health care provider and to the method established for the child and family to change designated providers if they chose to do so.	Not Reported	Children	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported



**Potential Indicators  
Application**

No.	Measure or Indicator Set/ Reference / Year	Description / Original Source Wording	Numerator	Denominator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
13	Dokken, D.L. <sup>13</sup>	IF a child with life threatening illness is admitted to any health care setting, THEN each child should have a comprehensive and appropriate written plan of care documented in their medical record and should be developed with the child's (to the extent appropriate), the family, and their health care providers involvement and that is 1) periodically reviewed, 2) that outlines the roles of family caregivers and the relationships between them, and 3) that includes discharging and receiving health care providers, within and across care settings, and 4) that is communicated in a timely manner across all care settings.	Number of children with life threatening illness admitted to any health care setting with documentation in their medical record of a comprehensive and appropriate written plan of care developed with the child's (to the extent appropriate), the family, and their health care providers involvement that is 1) periodically reviewed, 2) that outlines the roles of family caregivers and the relationships between them, and that is communicated in a timely manner across all care settings, including discharging and receiving health care providers and within and across care settings.	All children with a life threatening illness admitted to any health care facility.	Not Reported	Children	Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported
14	National Comprehensive Cancer Network (NCCN) <sup>15</sup>	All families and next of kin of cancer patients who have died SHOULD receive culturally sensitive and respectful after death care, including respectful treatment of the patient's body, family time with the body, address concerns about organ donation or autopsy, facilitate funeral arrangements, inform insurance companies, and the offer and referral of family/next of kin to grief and bereavement services.	Number of families and next of kin of cancer patients who died with documentation of receiving culturally sensitive and respectful after death care, including respectful treatment of the patient's body, family time with the body, address concerns about organ donation or autopsy, facilitate funeral arrangements, inform insurance companies, and the offer and referral of family/next of kin to grief and bereavement services.	All families and next of kin of patients who died in any health care setting.	Mixed cancer	Adult	Home care Hospice Ambulatory/outpatient care Hospital (non-ICU) Hospital (ICU)	Chart Reliability / Validity not reported

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## Appendix F5. Quality Measures for Cancer Palliation: Measures That Cross All Domains

### *Pain, Depression, Dyspnea, and Advance Care Planning*

No.	Measure or Indicator Set/ Reference / Year	Description of measure or indicator	Denominator	Numerator	Disease	Patient Characteristics	Setting	Data Source, Reliability, and Validity
1	Connor, S. R. <sup>1</sup>	<b>(Measure)</b> Family evaluation of hospice care	Family members of hospice decedents	Percentage of respondents reporting opportunity for improvement in attention to family needs for support, attending to family needs for information, provision of desired physical comfort and emotional support; and mean overall satisfaction	Mixed hospice population	Adult/Children White African American Hispanic Asian	Hospice	Family interview / survey Reliability / Validity not reported

## Reference List

1. Connor SR, Teno J, Spence C, Smith N. Family evaluation of hospice care: results from voluntary submission of data over website.

## Appendix G. Peer Reviewer Comments

<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
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1	Adalsteinn Brown, AB, D.Phil	University of Toronto	Reviewer	2	Introduction	When we review performance measures with complex continuing (chronic) care hospitals and rehabilitation hospitals in Ontario they often ask us to think about measures of caregiver burden and health status. When I read your comments about depression on page 2 and how both patients and care-givers maintain hope, I thought it might be important to point out that measures of how care-givers are doing might be important (at least as predictors of patients' capacities) but that they would be difficult to incorporate into the assessment, treatment, and follow-up paradigm and might be also be subject to a lot of exclusions in measurement.	We agree that measures of caregiver burden are important elements of palliative cancer care not addressed within the scope of the current task order. However, we have been reminded to stress the need to consider these in future work in the Discussion.
2	Adalsteinn Brown, AB, D.Phil	University of Toronto	Reviewer			We have just completed an assessment of recall or reliability in complex continuing care hospital patients in relation to their ability to report on their perceptions of care. It was awful. But the important thing out of the study was the fact that repeated assessment, in this case by a trained interviewer, actually caused some of the patients anxiety as they worried that they "hadn't gotten it right the first time" or wouldn't be able to answer the same again. I think it might be useful to point out some of the issues associated with repeated measurement that might happen in some surveying programs in chronically ill patients.	Your comment raises the caution that application of measures that require patient report will have to be tested carefully as there are unique challenges given the frailty of the population. We have now emphasized this in our Discussion.

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3	Adalsteinn Brown, AB, D.Phil	University of Toronto	Reviewer	30	CCO-Measure	CCO patient satisfaction survey. All the NRC surveys go through a very primitive form of psychometric validation (alpha) before they go into widespread use. I don't know whether you believe the Picker surveys are reflexive surveys or not, but you might want to note that there has been some validation. Also, we have used a cut-off of 100 responses for a long time in Ontario for virtually all our other surveys (for no better reason than that the confidence intervals were reasonable at that point). I wouldn't be surprised that CCO (you note 300 surveys) goes that route shortly as well. We will be publishing two papers on oncology satisfaction shortly (one has been accepted at Annals of Oncology and the other is under revision) but I do not believe they will be of much use to you. Let me know if you want to see them confidentially regardless.	We have now noted this in the text discussion of the measure-thank you.
6	Ellen Stovall, PhD/ Mark Gorman	National Coalition for Cancer Survivorship (NCCS)	Reviewer		Stage of Illness	Evidence discussed is derived from end of life, hospice or a narrowly defined "palliative" stage of a cancer patient's illness. Numerous IOM evidence-based findings point out, cancer patients need comprehensive symptom management at all phases of their treatment beginning with their diagnosis and continuing throughout the remainder of their lives.	We raise this concern in the introduction, although it is true that many measures do not speak to earlier stages of illness explicitly. We have emphasized this shortcoming in the Discussion.
7	Ellen Stovall, PhD/ Mark Gorman	National Coalition for Cancer Survivorship (NCCS)	Reviewer		Settings of Care	Many measures discussed in this report are derived from an inpatient setting and some are derived from the highly specialized setting of an ICU. A majority of US cancer patients are treated in ambulatory settings, and most of those are treated completely outside a hospital setting in private community oncology practices. Therefore, there is a need for development of measures and indicators relevant to physician office settings where most of cancer care is provided.	We now raise this issue in the Discussion.

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8	Ellen Stovall, PhD/ Mark Gorman	National Coalition for Cancer Survivorship (NCCS)	Reviewer		Sources	One source of data that does not appear, namely information from the 60 NCI designated cancer centers. Most if not all of these centers have formal guidelines pertaining to at least some of the domains dealt with in this report.	While we reviewed the NCCN guidelines, these recommendations unfortunately did not meet our standard of being able to be operationalized.
9	Ellen Stovall, PhD/ Mark Gorman	National Coalition for Cancer Survivorship (NCCS)	Reviewer		Task Order	Processes vs. Outcomes: Task order for this study directed a focus on processes, from the patient's perspective outcomes are more important. While it is useful that the study has included some outcome measures for "completeness," assigning such secondary importance to outcomes measures represents a misplacement of priorities. Particularly in the domains of symptom management, which so dramatically impact a cancer patient's quality of life, having good measures of whether particular interventions are resulting in better patient outcomes is vital.	We agree that the process-outcome link is a critical assumption. We have not commented directly on that issue here, although you have reminded us to raise it in our conceptual discussion.
10	Ellen Stovall, PhD/ Mark Gorman	National Coalition for Cancer Survivorship (NCCS)	Reviewer		Overall	Progress in setting quality measures for cancer will need to focus on both process and patient outcomes, be based on the real world settings where most of cancer care is provided, and be applicable to all stages of patient's treatment.	We acknowledge that evaluation of process measurement implementation should include validation of the effects on patient and caregiver outcomes.
11	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer	10	Methods	Search strategy: what was the rationale for starting the search in 1995? Some justification is warranted.	Our prior experience with the topic of palliative care and quality indicators suggested that relevant literature would be found in the past decade. Empirically, Shekelle et.al., have found that the lifetime of guidelines in general is ~3 years.

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12	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer	16	Results	re statement on ORYX, JCAHO, NCQA – should you at least include them in Table 1?	We decided not to include them since we did not abstract these measures or indicators.
13	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer	18	Table 1	Description of CCNS qualitative phase – the most important component of this phase is the focus groups with patients with metastatic cancer and bereaved caregivers, and the modified Delphi process with health care providers (oncologists, palliative care physicians, cancer nurses, social workers, community family physicians) to determine their views on the 19 quality indicators being measured in the quantitative component of the study. You may want to add this to your description of the qualitative phase of this project. (NB: These have now all been conducted and analysis is nearing completion.)	Thank you - we have amended this description.
14	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer	28	Pain	re: treatment for painful bony metastases. We have now examined this indicator both in terms of its acceptability to stakeholders (i.e., through the Delphi with health care providers) and through attempting to calculate it using administrative datasets. Based on these two processes, it is now clear that we will not adopt this as a useful QI despite the evidence that it is an effective treatment. The primary difficulty is that we are not able to measure when the pain is no longer controlled by medications and requires radiotherapy. The one week window was considered appropriate by the stakeholder group but they did not agree with our denominator for the same reason given above.	Thank you - we have amended information about this indicator.



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15	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer	46-50	ACP	the measures included here (those used by Dana Farber and CCNS) do not appropriately fit under ACP since they do not measure when these aspects of care are in keeping with the patients'/caregivers' preferences. In fact, in our Delphi process the principal objection was that measuring these indicators in isolation of knowledge of patients' preferences does not necessarily reflect good quality of care.	You have pointed out an important limitation of these indicators and we have noted it. At the same time, it is not clear that they should not be included for completeness sake. We felt that it was reasonable to consider treatments or healthcare utilization under care planning since much of the literature on care planning focuses on utilization outcomes and their avoidance (e.g., resuscitation) or facilitation (e.g., hospice use) through care planning. Indeed, others might have made a reasonable decision to exclude them.
16	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer	54, Para1	ACP	I think this is a very important point. Where are these indicators being used to actually improve quality of care?	We agree that this is important. Unfortunately, we found little evidence related to actual current use of these indicators. Where we did find such information it is discussed in the Results.
17	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer	Appendix	Reviewer list	Please note the correction to your reviewer list: Dr. Grunfeld, MD, DPhil	Done
18	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer		Depression	Consideration might be given to include an indicator for screening/treatment of depression in caregivers	See response to Item #1

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19	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer		Title	I find the title not sufficiently specific. Suggest either end-of-life cancer measures (as originally termed) or measures of cancer symptom management.	We changed the title to reflect the task order.
20	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer			In some instances you discuss the issue of benchmarking which essentially aims to define how one concludes whether an institution/organization/region is doing a good job. When is it enough, when is it too much, or too little? A general discussion about this point and potential approaches to benchmarking would enhance the usefulness of the report.	Unless it is used in reference to a specific project or title, we have eliminated use of the term 'benchmarking' since our report is spherically addressing quality performance and we find more specific terminology more helpful, in general.
21	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer		Suggestions	Perhaps a table summarizing those indicators you conclude are most helpful could be added.	While it was out of scope for us to make specific recommendations about preferred measures or indicators, we did try to provide similar information about their attributes for the comparability of readers.
22	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer		Evidence Tables	Tables – description of CCNS indicators: For all indicators - Patient characteristics should read “all patients in the population with cancer”. The data sources are: cancer registry, administrative claims data, hospital discharge abstracts.	We have amended these descriptions.
23	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer		Chapter 4	The major gap is raised by your statement in the first paragraph of Chapter 4: where is the evidence that quality measures are actually being used to measure and promote quality of care. Two possible examples are the National Comprehensive Cancer Network (Weeks et al) which uses a measurement and feedback system with the goal of improving adherence to guidelines (as a process measure of quality of care); and the Cancer Care Ontario quality initiative (your references 54, 113 and 114)..	We highlight these examples in the Discussion.

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24	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer		Measurement tools and data capture methods.	The principal point of QIs is that they are measurable. The report does not specifically discuss the issue of measurement instruments (for example, is asking the patient if they have pain equal in value to using a validated pain assessment tool?) or data capture methods (chart abstraction vs prospective data capture using validate instruments vs administrative datasets). There is a general discussion within the text of some of the QIs but no overarching discussion. The validity, reliability and feasibility of measuring QIs will vary with each of the different data capture techniques and their useful is contingent on how the data is captured and how accessible it is to use. Just to give one example, the QI 'effective treatment of pain' (p.81). The denominator for this indicator is "number of cancer patients who are not comatose". The rationale for this definition is self-evident. However, precisely how an institution would capture the information is questionable. Institutions may be able to know precisely how many cancer patients they see in a given period of time. They are much less likely to be able to subtract from the denominator the number that are comatose (or, at least not without a detailed chart review). Hence the value of the intended precision of this QI is reduced by the difficulty of actually capturing the data.	We have amended the Discussion to include these limitations of the descriptions. Unfortunately, a higher level of description was not possible for these indicators - either because it was unpublished and / or it was not provided by developers.
25	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer		Scope of the report	The questions posed in the task order indicate that the scope of the report is <b>at any point</b> of the cancer trajectory (i.e., not just end-of-life). This is a very wide scope. However, the review seems to focus on end-of-life/palliative care (EOL/PC). For example the majority of the indicator sets you have identified relate to EOL/PC. This raises some confusion in my mind whether the broader scope is being adequately addressed or whether, in fact, it is the narrower scope that is really intended for the report. If EOL/PC really is the focus, it should be specified clearly (for example, in the title of the report). If it is intended to be the entire cancer trajectory then the other periods (e.g., diagnosis, treatment, and survivorship) have not be adequately addressed or a statement should be made that no quality indicators (QIs) were identified for these periods.	See response to Item #6

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26	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer			While a comprehensive discussion about measurement is probably beyond the scope of the task order, you do touch on it in a general way on pages 54-55. I think the usefulness of the report would be enhanced by a slightly more detailed discussion about measurement within each of the domains.	We have expanded on generic challenges related to measurement as suggested.
27	Eva Grunfeld, MD, Dphil	Cancer Care Nova Scotia	Reviewer		Suggestions	You identify many of the indicators as 'not in current use'. A separate table listing those indicators that are currently being used would be helpful	For brevity's sake, we decided not to provide an additional table, although we have provided this information in the report.
28	Joanne Wolfe, MD, MPH	Harvard University-Pediatrics	Reviewer	11	Methods	With regard to the Grey Literature - Internet Search the following sites could have also been included: American Society of Pediatric Hematology/Oncology <a href="http://www.aspho.org">www.aspho.org</a> The Association for Children with Life-Threatening or Terminal Conditions and Their Families (ACT) <a href="http://www.act.org.uk">www.act.org.uk</a> Children's Oncology Group <a href="http://www.childrensoncologygroup.org/">http://www.childrensoncologygroup.org/</a> Children's Hospice International <a href="http://www.chionline.org/">www.chionline.org/</a> <a href="http://www.apon.org/files/public/last_acts_precepts.pdf">http://www.apon.org/files/public/last_acts_precepts.pdf</a> <a href="http://www.aps-spr.org">http://www.aps-spr.org</a>	We did review the APON guidelines but they did not meet our definitions as indicators or measures. We requested a reviewer from ASPHO but there was no response from several inquiries with the organization. We acknowledge that we did not access some of the other sources, although we should have identified published information about indicators or measures promulgated by these organizations.
29	Joanne Wolfe, MD, MPH	Harvard University-Pediatrics	Reviewer	13, para 4	Methods	I suspect you intended to include "Canada" inside parentheses.	Corrected
30	Joanne Wolfe, MD, MPH	Harvard University-Pediatrics	Reviewer		Gaps/articles	Consider including the attached article (Beal A. Quality Measures for Children's Health Care. Pediatrics 2004;113(1) 199-209	We reviewed this article, however, it did not meet our criteria (disease not cancer)

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31	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	3	Summary/ Conclusion	The sentence: "Palliative care is a term that is sometimes used interchangeably, except that it is focused on <u>living with the more advanced stages of illness.</u> " I would question this description of palliative care- is a component of care from diagnosis and increasing in focus.	We agree that these distinctions and definitions are inexact, and therefore we have not attempted to define them more precisely.
32	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	19	Table 1	VHA- Spell out VHA, no reference found	VHA is the actual name of the system.
33	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	30	First paragraph	"...PE.1.4; and the National Consensus <b>Project</b> for Quality Palliative..." add Project	Corrected
34	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	32	Under Treatment, second paragraph, last sentence	"...the reviewers concluded that improved adherence with long-acting drugs in clinical practice improved outcomes." is an incomplete sentence	The sentence beginning with "Although..." is complete.
35	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	35	Dyspnea QA Tools	end of paragraph, " ...Association of Palliative Medicine." Reference country here- could be confused with AAHPM.	It is true, but these are distinct organizations.
36	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	36	Dyspnea-PI- Assessment	ACCP, spell out somewhere, found on page 37 but should also be reference here, should also be listed on page 11.	Corrected
37	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	48	ACP- Chemo in last 14 days measure	"A high proportion (> 10%) of cancer patients receiving chemotherapy in the last 14 days of life <u>indicates poor quality care.</u> This is the indicator?"	Yes, that is the implications of the measure according to the developers.

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38	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	50	ACP- safe dying in hospice measure	"This indicator is based on the assumption that <u>caregivers who lack confidence or...</u> " consider adding this to your sentence. This is also an indicator of caregiver competence.	Corrected
39	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer	52	ACP - PI	What about POLST (Physicians Order for Life Sustaining Treatment) In use in Oregon and West Virginia, close to being used in NY. Nationwide rollout in 2006+. Probably should have some mention.	The team is familiar with the POLST, but not its use as an indicator or measure.
40	Judi L. Person, MPH	National Hospice and Palliative Care Organization	Reviewer		Reviewer list	Organization incorrect, change to National Hospice and Palliative Care Organization. Also, Kaiser is spelled incorrectly.	Done
43	Lindsey Bramwell, MPH, RN, CDR, USPHS	CMS (Fed Reviewer)	Reviewer		Symptom Management	Symptom management measures for pain, dyspnea, and depression disappoint in their failure to adequately examine patients freed from these symptoms, as well as the other processes of care such as assessment, treatment, and follow-up.	We agree and have modified our discussion of the limitations of the measures to point out that indicators or measures of follow-up are particularly lacking.
44	Lindsey Bramwell, MPH, RN, CDR, USPHS	CMS (Fed Reviewer)	Reviewer		General	The Report identifies gaps in the research--- the majority of the measures and indicators which are mentioned in this report have not specified the reliability and/or validity of these measures and have only been tested, not implemented.	Thank you.
45	Lindsey Bramwell, MPH, RN, CDR, USPHS	CMS (Fed Reviewer)	Reviewer		Dyspnea Measures	Your innovative approach of using dyspnea measures developed for chronic obstructive pulmonary disease in view of the lack of specific cancer population dyspnea research is to be commended. You have identified the need for new Cancer Care measurement research, but in the meanwhile, you have promoted the concept of cross-cutting measures which apply to multiple diseases to move towards broadening the applicability and aligning Cancer Care measures with measurement research projects and guidelines.	Thank you.

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46	Anna M. Lythgoe, RN, MSN	VHACO	Reviewer			The review of the literature for quality indicators related to cancer care was broad enough to capture relevant information but stringent enough to focus on particular areas of interest: pain, depression, dyspnea, and advance care planning/patient as decision-maker. It was surprising that there were not more quality of care indicators related to cancer care noted in the literature.	Thank you.
47	Anna M. Lythgoe, RN, MSN	VHACO	Reviewer	8		Symptom management included assessment of “frequency, severity, and bother or functional impact” (pg 8). Recently reviewed studies for development of home care indicators indicate patients feel that loss of independence/function is critical to their perceptions of the quality of their lives. Clinical review of functional impact of symptoms (pain, depression, dyspnea) would potentially improve symptom assessment and impact of treatment for those with cancer. The VHA “pain management workgroup” is currently discussing how to measure improvement in function as pain management improves. It would seem that this would also be relevant for the cancer patient.	We agree that it is relevant, although no indicators account for functional status at the present time in measuring clinical improvement.
48	Anna M. Lythgoe, RN, MSN	VHACO	Reviewer			Potential indicators discussed that could be used to address the gaps in the literature were fairly global as currently stated. However, with refinement, they may be well utilized to drive ongoing assessment and treatment of symptoms related to cancer care. Many could be readily operationalized (almost) as written (e.g. physician documentation of pain assessment, patient education regarding pain management, routine assessment for dyspnea) while others may require clinical evidence to support change in practice (e.g. use of long acting opiates with as-needed opiates, indicators supporting specific interventional modalities). In summary, the suggested indicators based on the literature reviewed were more hopeful than the indicators currently in place.	We agree that there are many gaps in current knowledge not addressed by the available measure or indicator sets.

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49	Anna M. Lythgoe, RN, MSN	VHACO	Reviewer			Mention is made of the burden of cancer on patients and caregivers (pg 1) but the caregivers are not addressed in the review. The significant fiscal impact of (unpaid) family caregivers on the healthcare system begs their inclusion in the quality of care review. Also, the clinical responsibility to ensure that the family caregiver has the education, support, and resources needed to successfully provide this care is heavy and must be addressed at some level.	We agree, and it is unfortunate that caregiver concerns were out of the scope of this report.
50	Anna M. Lythgoe, RN, MSN	VHACO	Reviewer			Table 2 (Processes potentially relevant to symptom care and advance care planning) – Assessment – Advance Care Planning: If a family caregiver will be providing care, assessing his/her ability and willingness to provide care, educational needs, support systems, and identifying the limitations of their abilities may need to be assessed.	Thank you. This issue is addressed in the actual indicators under NHPCO client and caregiver assessment for unmet needs and care preferences. No need to add to potential indicators, except perhaps as a supplemental citation and reference.
53	Phil Madvig, MD(Paul Feigenbaum and Jann Dorman)	Kaiser Permanente	Reviewer			For those metrics where the denominator is a population associated with an institution or delivery system, e.g., "all deceased cancer patients" at Dana Farber there may be a concern that the metric would be driven by the unique characteristics of the institutional population in addition to the practice patterns applied to the numerator population. For example, the patient population attracted to an academic medical center with a reputation for clinical trials may be different than the patient population at a regional medical center. How would these 2 institutions compare their performance on a single metric?	We agree and have broadened our discussion of limitations to suggest that the populations tested may need to account for or examine differences in institutional bias with this difference in mind.
54	Phil Madvig, MD (Paul Feigenbaum and Jann Dorman)	Kaiser Permanente	Reviewer			The listings of measures and indicators appeared relatively complete to us. We are not aware of additional sources of measures or indicators which you have not included.	Thank you.



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55	Phil Madvig, MD (Paul Feigenbaum and Jann Dorman)	Kaiser Permanente	Reviewer		Comment	<p>We face several challenges in developing quality metrics at Kaiser Permanente. We need metrics that are:</p> <ul style="list-style-type: none"> <li>*Feasible to collect on a scale basis. Metrics which are dependent upon chart review present tremendous resource challenges to measure in a large population.</li> <li>*Low risk for perverse incentives. For example, the percentage of patients referred to hospice in the last 3 days of life can be decreased by not referring patients to hospice in the last 3 days of life.</li> <li>*Timely. We need performance feedback that can be used to manage operations. The metric must be reported within a time frame that is meaningful to make operational improvements.</li> </ul> <p>These dimensions represent the major gaps and priorities we face.</p>	This is helpful and we have highlighted these needs in our Discussion.
56	Phil Madvig, MD (Paul Feigenbaum and Jann Dorman)	Kaiser Permanente	Reviewer		ACP	<p>We question if the logic of the conceptual framework for the processes of care used for symptom management holds up for advance care planning. As an example, you have labeled the second step in the conceptual framework "application", but refer to "application of preferences..." in the third step for ACP. Given the well known challenges in operationalizing advance care planning on a scale basis, an accurate framework for the processes of advance care planning would be a great asset in understanding how to be successful.</p>	We agree that this is somewhat awkward, and we have changed 'application' to 'implementation' .
59	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	2	Last paragraph	<p>"...varies significantly among <u>elderly</u> cancer patients.." only among elderly, or all cancer patients?</p>	The citations for this statement are from the work of Fisher et.al. in the Medicare population. We are unaware of analyses that have addressed this directly in younger populations, although we would not be surprised if variation were found here as well.

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60	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	2	Last paragraph	"Cancer treatment at any stage commonly requires potentially <b>difficult</b> interventions such as chemotherapy or surgery." Not sure what "difficult means.	We have clarified this language.
61	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	2	Last paragraph	"Now, quality practice endorses advance care planning for a number of reasons: to allow patients to shape care to their preferences, to avoid imposition of <b>[unwanted?]</b> treatment in urgent situations, to relieve patient and family anxiety..."	Corrected
62	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	3	Summary/ Conclusion	"...that is sometimes used <b>interchangeably</b> , except that it is focused..." Interchangeably with what? Supportive care?	Clarified
63	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	5	Overview	Staff conducted an extensive <b>grey literature</b> and Web search..." Will the readers know what "grey literature" is?	This is a standard systematic review term, but we have added some descriptive language to clarify it for readers unfamiliar with it.
64	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	6	Third paragraph	"Concerns were related relative to the feasibility of conducting a systematic review of distress." Consider "Concerns were <b>expressed</b> relative to the feasibility of conducting a systematic review of distress."	Clarified
65	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	9	Last paragraph	"Elements of care planning include <b>prediction of the clinical situation</b> ..." Not sure what this means? Prognostication?	Yes. Clarified

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66	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	10	Table 2, first row under Symptom Management	"...preferences for evaluation and treatment;..." Does this include patients desired level of relief?	Yes, among other considerations. Clarified in Table 2.
67	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	17	Table 1, Dana Farber	The Dana-Farber Cancer Center at Harvard University has pursued an effort to develop a set of administrative data-based indicators for palliative cancer care as part of its recent research agenda.- Are these intended as <u>quality</u> measures, or for some other <u>purpose</u> ?	We are not certain if there are other intended uses besides quality assessment, although they have been reported as quality measures.
68	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	19	Table 1, GCC	1. Pain assessment and management. 2. Use of hospice care. Why only mention these 2 of the 80 measures? Are none other relevant to this project?	Yes that is correct. Our discussion of the indicator and measure sets highlights how we selectively used these sets to identify indicators or measures relevant to this project.
69	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	19	Table 1, CCO	Measures relevant to palliative [ <u>cancer?</u> ] care include those that address:	Corrected
70	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	20	Table 1, VHA	o Assess pain regularly o Manage pain optimally Do these not continue across the ICU stay/measurement period? Are they only measured at day 1?	The VHA bundle is designed so that each measure is targeted to a day of admission. The pain measures are targeted to day 1 and are only measured for that period.
71	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	21	Literature flow	"...we found 389 articles from the database..." Unique from the 4580?	Yes, and we have clarified this description.

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72	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	21	Table 1, NHPCO	Quality measures included: 1. Comfortable dying 2. Self-determined life closure 3. Safe dying 4. Effective grieving 5. Family evaluation of hospice care Any need to define any of these?	Corrected-We have provided a reference so that readers can explore these definitions themselves.
73	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	24	Pain, Introduction-	Two last paragraphs of the introduction, Can this be presented as a table instead? Somewhat difficult to follow in text?	Corrected-We embedded a reference to the Evidence Tables which essentially present this in tabular form.
74	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	25	Measures and Indicators	Section is somewhat difficult to follow in text but is a nice description of these measures.	Thank you.
75	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	25	Measures and Indicators	Suggest add, Measures and Indicators: <b>Pain</b> as the section header. Did I miss somewhere a statement of the <u>structure</u> for this section (re measures/indicators in italics)	We have changed our Chapter and section headings for smoother reading of the report.
76	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	31	Potential Indicators and Measurement Gaps	Any data that physician documentation actually translates into improved pain management?	This is addressed in a limited fashion in the Discussion.

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77	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	31	Potential Indicators and Measurement Gaps	Suggest add Potential Indicators and Measurement Gaps: <b>Pain</b> as section title	We have changed our Chapter and section headings for smoother reading of the report.
78	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	32	Potential Indicators and Measurement Gaps	First paragraph "Disparities in pain assessment" What about age related differences/disparities? Are also data that geriatrics population (especially in [illegible]) receives inadequate pain control.	This is addressed in a limited fashion in the Discussion.
79	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	32	Treatment-Measurement gap	Treatment. "Procedure-related pain in children paragraph." Should this one be limited to children? Is it not a relevant issue for adults?	We agree that such an indicator would be reasonable to consider for adults by analogy and have suggested so.
80	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	32	Treatment	Treatment. Education. "The numerator is patients who are <b>educated</b> about pain management.." Does this need to be defined any more (e.g.. Person is printed materials)	We agree this is ambiguous and this would be required as part of trying to operationalize these potential indicators.
81	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	33	Dyspnea-Introduction	First paragraph. Again, can this be formatted differently for ease of following?	We embedded a reference to the Evidence Tables which essentially present this in tabular form.
82	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	33	Measures and Indicators	Measures and Indicators: <b>Dyspnea</b> . Suggest adding Dysnea to section title	We have changed our Chapter and section headings for smoother reading of the report.

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83	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	34	Treatment-Measurement gap	Treatment: Pain. Suggest adding Dysnea to section title	We have changed our Chapter and section headings for smoother reading of the report.
84	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	35	Follow-up	Follow-up: <b>Dysnea</b> . Suggest adding Dyspnea to section title.	We have changed our Chapter and section headings for smoother reading of the report.
85	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	36	Potential Indicators and Measurement Gaps	"Assessment for treatable causes of dyspnea" I like the measure, but am concerned that there are sufficient data to support a list of defined "treatable" causes.	Agree that this would require further clarification. The potential indicators are meant to suggest informed opinion, not definitive evidence in that regard.
86	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	36	Potential Indicators and Measurement Gaps	footnote 1, Nice summary and important to include	Thank you.
87	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	36	Potential Indicators and Measurement Gaps	Suggest adding Dyspnea to section title	We have changed our Chapter and section headings for smoother reading of the report.
88	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	37	Treatment	"Treatment for malignant pleural effusions. The numerator is patients <b>who have ...</b> " "Bronchoscopic therapy: The numerator is patients <b>who have had...</b> " "Palliative radiation and chemotherapy. The numerator is patients who have <b>received...</b> " Would it be "who have been <b>offered</b> " to respect patients choice?	We agree that it is correct to consider patients who were 'offered' a treatment as part of an indicator or measure. Making this suggested indicator into a measure would require resolving that consideration.

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89	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	37	Treatment	Treatment: Dyspnea. Suggest adding Dyspnea to title section	We have changed our Chapter and section headings for smoother reading of the report.
90	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	39	Measures and Indicators	Suggest adding Depression to title section.	We have changed our Chapter and section headings for smoother reading of the report.
91	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	41	Measures and Indicators	Suggest adding Advance Care Planning to title section.	We have changed our Chapter and section headings for smoother reading of the report.
92	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	45	Application	Suggest adding Advance Care Planning to title section.	We have changed our Chapter and section headings for smoother reading of the report.
93	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	46	Follow-up	Suggest adding Advance Care Planning to title section.	We have changed our Chapter and section headings for smoother reading of the report.
94	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	50	First paragraph	(Measure- site of death) paragraph. "... (greater than 4%)... Is this number correct?	The paper actually states that high performing systems will have less than 4% with multiple hospitalizations or emergency room visits or are admitted to the ICU in the last month of life (p.11 in Earle) and sentence clarified in Report.

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95	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	51	Potential Indicators	Not ruse what is being addressed here- is this the "gaps" section? Where are the actual potential indicators? Did I miss something?	This section has been completed in the final draft.
96	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	51	Potential Indicators	Suggest adding Advance Care Planning to title section.	We have changed our Chapter and section headings for smoother reading of the report.
97	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	54	Chapter 4	Last paragraph. " Symptom assessment requires efficient indicators that can become part of the <b>dashboard</b> of quality monitors for care settings. Is this a comment enough terminology?	The language has been clarified
98	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	55	Chapter 4	Second Paragraph. Consider the following revision: Pediatric [cancer] <del>cases</del> represent the second leading cause of death among children ages 5-15 in the United States.	Clarified
99	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	55	Chapter 4, Last paragraph	there is an extra closing parenthesis after dying that need not be there.	No error found in current draft.
100	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	56	Chapter 4, Second to last paragraph	It is important to define subgroups of cancer by stage of illness and to understand the performance of indicators among major subgroups. Issues such as timeliness of care and how side effects are tolerated or managed may vary in importance across groups distinguished by type or severity of illness. This seems to be a separate issue than the disparities addressed above, \$	We modified the language to unify these considerations.



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101	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	56	Chapter 4	Third paragraph, first sentence. "We found insufficient evidence to comment on important difference by gender, race/ethnicity..." Age, should geriatric population have separate consideration? What about <u>language</u> issues? If measures that require patients report are only available in <u>English</u> , are less useful?	We agree and have added language as a consideration in the Discussion.
102	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP	57	Chapter 4	Last paragraph. Starting with the sentence "However, unlike other tools..." Should this be separate paragraph? Is really a distinct issue from measurement availability.	Agree and we separated these issues
103	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP			Conceptual Issues and processes of care? Quite complete. One area that I did not see mentioned (expect in an ACOVE measure related to advance care planning) is the coordination of these symptom management and advance care planning areas across specialty and primary care. This may be beyond the scope of this project, but perhaps worth addressing or at least acknowledging.	We agree that coordination is an important element of care that was not addressed within the scope of the current project.
104	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP			How complete is the listing of relevant measures or indicators? Quite complete. Appropriate attention is paid to the need for pediatric-specific measures and those that address potential racial, ethnic disparities. I question whether specific attention needs to e paid to geriatric-specific issues as well.	We agree and have added some language to our discussion of population differences in the Discussion to highlight the need for further information on this topic.
105	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP			The "take home" message being that there are sufficient measures to begin assessment/monitoring in these areas, but that additional research is necessary to fill in the gaps.	Thanks for highlighting this important conclusion, and we have underscored it more strongly in our Discussion.
106	Jean Kutner, MD, MSPH	University of Colorado Health Sciences Center	TEP		Overall	The Evidence tables are especially well-constructed and useful	Thank you.

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107	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	32		Proposed indicator for patient education regarding pain management - how would "education" be operationalized? Would this be based upon physician/nurse documentation in the chart? Or would patients' and or their caregivers be assessed for their knowledge?	See response to Item #78.
108	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	32		Why is the procedure-related pain indicator limited to children? Seems like it should apply to adults also.	See response to Item #77.
109	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	36		Routine dyspnea assessment in cancer - the denominator "all cancer encounters" is too broad - many patients with a diagnosis of cancer will not have active disease (i.e. routine follow-up of early stage breast cancer treated 5 years ago). Even limiting this indicator to "all encounters in patients with metastatic disease" is probably too broad. Perhaps "all encounters in patients with lung involvement with cancer or a prior complaint of dyspnea" would be a reasonable starting place for routine assessment of dyspnea. What would constitute assessment? Is recording of a respiratory rate in the chart assessment? Does the clinician need to question the patient regarding the presence or absence of dyspnea?	We did not intend to resolve these ambiguities in posing this as a 'potential indicator' We did clarify language around these ambiguities somewhat in the discussion of this particular item. We also added further description of potential indicators in our Methods so that readers would understand our intent of offering only reasoned suggestions in this section of potential indicators.
110	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	36		Assessment for treatable causes of dyspnea - consider making this numerator more specific - perhaps # of patients who have had all of the following performed within xx weeks of the complaint of dyspnea: vital signs, lung exam, O2 saturation, Hb, chest imaging, DVT/PE assessment (documentation of physical exam of legs or Doppler/UTZ lower extremities or CT angio or VQ or D-dimer). The other challenge here is longitudinal assessment - what if patient has dyspnea in July and is evaluated and treated for pneumonia with resolution of symptoms and then in September has dyspnea again?	See response to #107.

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111	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	37		Treatment of malignant pleural effusions. I would urge you to consider being more cautious in the recommendation of pleurodesis as a quality indicator. In my own experience, there tends to be overuse not underuse of pleurodesis - use in patients who are not symptomatic or where the production of malignant fluid is occurring at such a rapid rate that pleurodesis cannot be successful. Many of the published reports tend to overstate the effectiveness observed in actual practice and rarely provide the rates of continued success 1-2 months later. I'm attaching a survey of pulmonologists regarding their views of the procedure which I think echoes the uncertainty regarding its effectiveness.	Treatment of malignant effusions were taken from ACCP and are the state-of-the-art and most current recommendations - limitations are noted and we only propose this as a potential indicator supported by available data. The limitations will need to be addressed in subsequent work
112	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	37		Bronchoschopic therapy - other treatment modalities for central airway obstruction are not mentioned. Brachytherapy and external beam radiation can often be quite effective and may be more widely available than bronchoscopic therapy. In selected cancers (small cell lung cancer, lymphoma), chemotherapy is the most effective approach. Also, steroids may provide significant relief of symptoms and if patients are in a terminal phase of their disease, this may be enough to provide them palliation until death.	These other modalities are briefly mentioned proportionate to the available data identified in the systematic review.
113	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	37		Patient education - same comment as pain indicator regarding education.	See response to Item #78.

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114	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	46		<p>Late life hospital use - it may be worth explaining under what circumstances this may or may not be a good quality measure. It likely reflects structural as much if not more than process quality - without high quality in home care or inpatient hospices or nursing homes that really address the needs of the dying, hospitalization may actually provide patients with a more comfortable death experience and more support for families. Given the daily capitation rate for hospice, current home hospice provides very little in the way of support - and is really not viable for patients who do not have informal caregivers or the resources to pay for round the clock care.</p> <p>In addition, there is a catch-22 that as not been fully addressed by the work of the proponents of this and other similar measures: patients hospitalized late in life and/or who die in the hospital is asked may have had a preference for hospitalization at that time. Those same patients may also have had a preference to die at home. However, at the time of hospitalization, they may not yet accepted that death was imminent even if this was communicated to them. I cannot tell you how many times in my own practice, I have talked with patients and or family of members of patients at home receiving hospice care while the paramedics were waiting to take them to ER (even after making a home visit earlier in the day...).</p> <p>The issue of the limitations posed by the retrospective "look back" of a number of these quality measures should also be addressed (see article by Bach et al.). Research efforts should focus on developing quality measures that allow prospective identification of the denominator, for example by using performance status or some other predictor of death. My own experience caring for patients at the end-of-life has been limited to patients with breast cancer. And, except in a rare case, I have been struck by how patients have lived with good quality of life and excellent performance status for several years before having quite a precipitous decline over 3-6 weeks prior to dying. I imagine that different cancers have different trajectories and that for our quality measures to improve the care of patients we need to be able to account for these differences in disease trajectory -- as well as patient preferences - neither of which can be accomplished with these global "look back" measures.</p> <p>Finally, there may be cultural differences regarding preferences for place of death that have yet to be fully explored.</p>	<p>Thank you - we agree that it is important to stress these limitations and we have added language to make that clear to readers (P41) Also, see response to Item # 17.</p>

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115	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	8	para 2	"Self report" may be jargon and not readily understood by all readers - it may be worth explaining a few more words the first time you use it.	Clarified
116	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	11	para 2	We also searched for 'related articles' for citations that described measures..." -- I found this sentence confusing. I was not sure what 'related articles' were or how they pertained to ACOVE.	Clarified
117	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	12	Last paragraph	It might be clearer to state "We searched the database of the End of Life Care and Outcomes Project, a systematic review recently completed by this report's authors, for articles coded as 'cancer."	Clarified
118	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	23		Figure only mentions indicators and potential indicators not measures	Corrected
119	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	25		Consider reminding reader of the distinction between measure and indicator. Also I found the use of the parentheses in the headings somewhat distracting - consider using heading and subheadings: Measures Identified Regular Assessment of Pain: Quality Assessment Tools proposed	We have changed our Chapter and section headings for smoother reading of the report.
120	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	25		last paragraph refers to the second UHC "pain assessment indicator" but this appears to be a measure?	Corrected
121	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	26	para 3	"As with other pain outcome measures..." - Is the proposed measure "regular pain assessment," which would be a process measure, or the score (average, final, change in?), which would be an outcome measure?	More information on the specification of the measure is not available.

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122	Jennifer Malin, MD	UCLA School of Medicine, RAND	TEP	31	para 2	Have the numerator and denominator been reversed?	No error found in current draft.
124	Joan Teno, MD, MS	Brown Medical School	TEP		Indicators	You need to move away chart based indicators	Agree that this is a consideration that should affect the use of the current set and implications for future research. We have stressed that chart-based and administrative data based indicators may not provide adequate information for quality assessment and improvement, and that these limitations should be understood as part of better population studies. Obviously, the merits of specific indicators and data sources must be understood individually.
125	Joan Teno, MD, MS	Brown Medical School	TEP		Literature Search	The literature searching strategy that restricted everything to cancer was unneeded for symptoms, pain, and cancer. They do not need to be cancer specific processes. There is nothing that is inherent to the disease trajectory that warrant a different process of care. So you indicators that could go forward that has been used in other research and quality improvement efforts.	While we went beyond the scope of our task order in searching dyspnea and ACP, we agree this would have been a consideration had resources permitted it. We have tried to acknowledge this as a limitation and have suggested how that might be mitigated by the NQF process.

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126	Joan Teno, MD, MS	Brown Medical School	TEP		Measurement Set	My overall assessment is that the current measurement set is very weak and potentially, should not go forward - information on reliability and validity is missing. Even more important, I did not see information on responsiveness, discriminate validity.. all things that are very important prior to the use of accountability.	We have stressed the need for additional evaluation in populations to address these attributes and that the use of measures should be concordant with the strength of information on their applicability within clinical settings and across systems.
127	June Dahl, PhD	University of Wisconsin-Madison	TEP	31	Pain	I found the comment at the end of page 31: "improvements in pain assessment by non-physician staff may not lead to improved outcomes because the physician may not attend to the report of pain." I need to explore that reference source because if that statement is true, we are in deep trouble. Physicians rarely see patients in LTC and in the post-op period it is obviously non-physician clinicians who have the responsibility to assess and document pain.	It is true that assessment must be linked to clinically meaningful outcomes to assure relevance to patients.
128	June Dahl, PhD	University of Wisconsin-Madison	TEP	32	Pain	there is a statement: "the reviewers concluded that improved adherence with long-acting drugs in clinical practice improved outcomes." Is there any rationale for this conclusion? What outcomes are the reviewers referring to?	They are referring to pain and the application of expert opinion. We have clarified the statement.
129	June Dahl, PhD	University of Wisconsin-Madison	TEP	43	General Edits	Data is a plural noun and yet sometimes use as a singular noun, e.g., line 2 page 43 ...."validity data is available."	The final report has been reviewed by a medical editor.

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130	June Dahl, PhD	University of Wisconsin-Madison	TEP		General Edits	Dangling participles are another issue. I am a purist about those, but only mention two. On page 26, line 5: what or who is "using an appropriate rating scale?" On page 49, 10th line from bottom, who is "using the highest performing decile of this measure?" I am certain you will catch the others as you edit.	The final report has been reviewed by a medical editor.
131	June Dahl, PhD	University of Wisconsin-Madison	TEP		Pain	An important measure identified: how many patients being treated with opioids are on a bowel regimen was also identified by the JCAHO-NCQA-AMA Task Force. I think JACHO's field trial showed there was lots of room for improvement.	In our discussion with JCAHO about this project, they felt that these were not yet ready to be measures since they still needed further development. This information has been added to this section: " A similar potential measure has also undergone some field testing in a population including cancer patients as part of the JCAHO-AMA-NCQA pain management performance measure development project {#8404}."
132	June Dahl, PhD	University of Wisconsin-Madison	TEP		Dana Farber Guidelines	I was very interested in measures developed at Dana Farber: of new chemotherapy in the last 30 days of life, of patients receiving chemotherapy in the last 14 days of life, and late referral to hospice. Unfortunately, in our area, some of the more recently developed chemotherapies are being offered to patients with very advanced disease which results in a delay in their admission to hospice. My comment adds nothing to your review - it is just a reflection of our realities and makes me question how implementing these measures could improve quality given the forces in the oncology profession that are pushing for more therapy.	Agree these might be useful, although we have added some caveats about the use of utilization outcomes as measures in Discussion and introduction to ACP measures.



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133	June Dahl, PhD	University of Wisconsin-Madison	TEP		General Edits	Inconsistency in use of terms related to opioid analgesics. Opioid would be preferred, but narcotic appears (e.g., page 27) as does the term opiate (e.g., page 32).	We have changed all opiate(s) to opioid(s).
134	June Dahl, PhD	University of Wisconsin-Madison	TEP		Numeric rating scales	Is it intended that numeric rating scales be 1-10 (page 26)? The numeric pain rating scale is 0-10. On page 33, there is reference to a 10-point dyspnea scale. Is it indeed a 10 point scale or an 11 point scale?	Corrected VHA lists this as a 1-10 rating scale so that is what is reported here.
135	June Dahl, PhD	University of Wisconsin-Madison	TEP		Pain	It is interesting that none of the studies you cited used pharmacy department data. If pain is the symptom of interest, one could measure the percentage of patients with a diagnosis of cancer and moderate to severe pain who are/were being treated with opioids.	We agree that there are additional data sources and indicators that should be considered.
136	June Dahl, PhD	University of Wisconsin-Madison	TEP		Future research	Obviously data collection is a huge challenge. The data have to be easy to obtain. The advent of electronic medical records, should enable collection of accurate data so as to make measurement possible.	We do now provide some additional discussion of measurement issues in the Discussion
137	June Dahl, PhD	University of Wisconsin-Madison	TEP		Pain	The cognitively impaired are a special assessment challenge. We need to develop measures that don't rely on self reports if we are to assess pain in that population. We are working on a scale based on items in MDS 2.0; certain behaviors suggest the presence of pain.	Agree and we have highlighted the challenge of those who cannot self-report in our Discussion.

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138	June Dahl, PhD	University of Wisconsin-Madison	TEP		Pain	<p>The critical first step is assessment. And as your report emphasizes, waiting 48 hours to do the assessment makes no sense. I would prefer the JCAHO standard: ask about pain on admission: All patients with a diagnosis of cancer who are admitted to hospital should be screened for pain on admission regardless of the reason for their admission. If pain is present, the intensity and quality of the pain should be assessed. The focus in all of the literature available is on assessment of pain intensity. Quality should be assessed as well so as to determine whether the patient has neuropathic pain. A measure of the presence of neuropathic pain is critical to development of an effective treatment plan. Krause and Backonja (Clinical J of Pain, 2003) have developed a short form of a neuropathic pain questionnaire which involves rating of numbness, tingling, increased pain due to touch. A comprehensive pain assessment involves asking questions about quality; should be possible to add two or three boxes to check or numbers to circle to provide data for this assessment. We haven't made an effort to create appropriate forms to make this additional component of assessment a practical reality.</p>	<p>We agree that symptom assessment is a complex task. We have added some language to address other aspects of assessment that are not covered in the existing indicators and measures to the potential pain indicators discussion.</p>
139	June Dahl, PhD	University of Wisconsin-Madison	TEP		Sources	<p>The recent recommendations from the American Pain Society (Archives Int Med 2005; 165: 1574-1580) were published after you finished your intensive review. They deal with acute and cancer pain; the recommendations for acute pain reflect what was in reference #87 of your draft.</p>	<p>The updated information from this new article has been added in several places in the report to update reference #87, for example: "A related outcome potential measure, that patients should be adequately informed and knowledgeable about pain management, is included in the 2005 American Pain Society Recommendations for Improving the Quality of Acute and Cancer Pain Management (#8404) based on an expert review of the measurement tools used in 20 quality improvement studies in pain management.87"</p>

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140	Laura Hanson, MD, MPH	University of North Carolina at Chapel Hill	TEP		Process vs. Outcome Measures	Consider adding to the report whether a measure is a process measure which primarily addresses quality of care, vs. an outcome measure which directly addresses the patient experience.	These are sometimes hard to qualify or categorize exactly. There is also the concern that some measures may reflect structure (see Item # ). We agree that it is important to stress that measures should ideally reflect the patient experience. We have added additional language to highlight these issues in the Discussion.
141	Laura Hanson, MD, MPH	University of North Carolina at Chapel Hill	TEP			I would encourage addition of the absence of reliable and valid measures for cognitively impaired patients to your lists of gaps in quality measurement.	Thank you and this is discussed in the current version (as those who cannot self report).
142	Laura Hanson, MD, MPH	University of North Carolina at Chapel Hill	TEP			In addition to reporting reliability and validity of individual measures, it would be very valuable to report on the responsiveness of these measures. It will not be true for all measures, but for any that have repeated measures over time and/or in relations to interventions, adding evidence that a measure has dynamic properties adds its relevance to clinical quality improvement.	We agree and have highlighted the need for more research on this as an issue in the Discussion.

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143	Laura Hanson, MD, MPH	University of North Carolina at Chapel Hill	TEP		Pain	<p>The text would benefit from an introduction to measurement issues from pain, the best studied of all these symptoms, so that the measures are in a broader context of certain limitations. I would include the following aspects:</p> <p>Measurement systems need to specify exclusion or use of alternative measures for patients unable to self-rate symptoms due to cognitive impairment</p> <p>Effect of depression, symptom interpretation and addiction history may modify treatment approaches; settings may vary in the frequency with which these effects influence measurement</p> <p>Pain literature shows a discrepancy between pain severity scores and patient satisfaction with pain treatment- perhaps due to low expectations for relief, OR due to positive responses to attention to pain even when it is not fully relieved. You might want to address the dilemma of symptom scores as measures vs. satisfaction with care.</p>	We agree that it might be helpful to illustrate these challenges in the context of pain care. We have added some language to highlight these considerations in the conceptual discussion.
144	Marilyn Bookbinder, RN, PhD	Beth Israel Medical Center	TEP		Future research	<p>If benchmarks are to represent best practice and serve as the “gold standard” for practitioners to emulate – more rigorous research designs and larger homogeneous samples are needed to strengthen the evidence base and persuade those allocating funds to increase “quality” care research dollars.</p>	This is a helpful point and we have stressed the need for testing of the measures in cancer populations in our Discussion.
145	Marilyn Bookbinder, RN, PhD	Beth Israel Medical Center	TEP		Sources	<p>Revised indicators for measuring outcomes of pain management have recently been published (Arch Intern Med. 2005 Jul 25;165(14):1574-80) by the American Pain Society Task Force on Quality. They include items such as how often the patient had moderate to severe pain in the last 24 hours; how much interference did pain have with their function (able to do what they needed to do) interference with sleep, interference with mood. No data has been published to date, although we at Beth Israel and colleagues at University of Wisconsin have data on selected indicators.</p>	We have included this in our review.

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146	Marilyn Bookbinder, RN, PhD	Beth Israel Medical Center	TEP		Potential Indicators	The potential indicators lists are relevant and are an excellent approach to using data available (not meeting the criteria). The indicators selected and approach used to target vulnerable populations (DRG, LOS, Adm) is excellent and I think will give others the guidance and tools needed to measure and improve symptom management and ACP in problem- prone high risk groups.	Thank you.
147	Molla Donaldson, DrPH, MS	National Cancer Institute (Fed Reviewer)	TEP	0	Title	Make the title more specific as there are two other EPC reports on cancer measures - perhaps along the line of Cancer Quality of Care Measures for Supportive care and End of Life	See Response to Item # 19
148	Molla Donaldson, DrPH, MS	National Cancer Institute (Fed Reviewer)	TEP	3	Introduction	The term "utilization outcomes" is a little strange without explanation - I think of utilization as just that (e.g., admissions, length of stay, hospice use), so that sentence could be clarified.	We have added additional discussion to explain our inclusion of these items and why we placed them in Advance Care Planning. We also modified the description in the Introduction.
149	Molla Donaldson, DrPH, MS	National Cancer Institute (Fed Reviewer)	TEP	5	Chapter 2	Under the 1. RFTO question, you might explain that after further discussion distress was dropped in favor of dyspnea - something along those lines so that it is clear you were responsive to the task order.	We have clarified this under the task order questions.

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150	Patricia Ganz, MD	UCLA Schools of Medicine and Public Health	TEP			It looks like you have found quite a few measures, but overall, I was very disappointed to see that so few had been implemented or tested. Have you contacted the measure developers in follow-up to see if they can give you any information on their use? For that reason, I worry that many of the measures may look good from an academic or measurement perspective, but may not be ready for prime time. I see this as a real limitation.	Yes, we contacted measure developers for all measure sets except the Georgia Cancer Coalition.
151	Patricia Ganz, MD	UCLA Schools of Medicine and Public Health	TEP			Did you find any references to the pain thermometer scales that are being widely used in hospitals as required for hospital accreditation? We also use them in our outpatient department. I don't know how reliable and valid they are as measures, but they are now in wide use and seem practical.	No, we did not.
152	Patricia Ganz, MD	UCLA Schools of Medicine and Public Health	TEP			I think Chapter 4 does a good job talking about the limitations of the measures and indeed the issue of obtaining self-report data from seriously ill patients is a real challenge.	Thank you.
153	Patricia Ganz, MD	UCLA Schools of Medicine and Public Health	TEP			In summary, I think you have done a fine job, but I have concerns about how practical a lot of these measures will be for implementation.	We agree that further testing is of the highest priority before the potential of these measures can be fully realized.

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154	Perry Fine, MD	University of Utah	TEP	11	Internet Search	Under the section listing "Studies or Internet documents....", the first bullet point omits Canadian references. Was this purposeful or an unintended omission?	Unintended, now corrected
155	Perry Fine, MD	University of Utah	TEP	32	Treatment-Measurement gap	Might I suggest that a more broadly applicable potential indicator (measurement gap) would be (numerator) patients with moderate-severe pain who receive prescriptions for opioid analgesics (denominator = all patients with moderate-severe pain scores). This might be simplified further to the % of all cancer patients in a given practice who are prescribed opioids, with a benchmark extrapolated from exigent literature on the prevalence of moderate-severe pain in cancer patients.	Thank you. Our pain reviewers concur and we have added it to the list of potential indicators. This is also a potential indicator from a project including JCAHO, AMA, & NCQA.
156	Perry Fine, MD	University of Utah	TEP	40	Depression	I was very surprised to see that there were no potential indicators/ measurement gaps enumerated for depression. Is there really no basis to elaborate upon this section (assessment, treatment and follow-up)?	This section has been completed in the final draft.
157	Perry Fine, MD	University of Utah	TEP		Chapter 4	You rightly elaborate upon the clinically significant and problematic area of pain assessment in non-self-reporting patients. There may be the opportunity to round out the pain assessment section with additional potential indicators from (non-cancer) dementia studies. I would refer you to Dr. Keela Herr, who chairs the gerontological nursing division in the U. of Iowa College of Nursing, whose area of focus is pain assessment in cognitively impaired older patients. She may be able to point quickly to a rich little vein of literature that was not easily uncovered in your search. Her email address is keela-herr@uiowa.edu	Corrected-Thanks you - we were unable to expound upon this information for the draft report, but we have cited it for readers so that they can avail themselves of it

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158	Roger Winn, PhD	National Quality Forum	TEP		Overall	I think the reviewers have done an admirable job of collecting available measures and analyzing them in a well conceptualized framework. I found the division between measures, indicators, and potential indicators useful and operationally sound. The analyses of the specific measures appears to be balanced and to target the major strengths and weaknesses. The conclusions of the report are justified by the body of evidence reported.	Thank you.
159	Roger Winn, PhD	National Quality Forum	TEP	1	1	Mention scope: limited to pain, dyspnea, depression, advanced directives	The scope is covered in the introduction
160	Roger Winn, PhD	National Quality Forum	TEP	3	para 2, line 13	toxic instead of taxing	Changed to 'difficult'
161	Roger Winn, PhD	National Quality Forum	TEP	7	para 2, line 2-3	I think this statement is a little too strong, For example the number of trained social workers or psychologists might have an impact on depression. I think it's more the case that it's difficult to directly establish the linkages between structure and outcomes.	Modified



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162	Roger Winn, PhD	National Quality Forum	TEP	7	para 2	Although I think it's implied, you might want to point out that for symptom-related measures, the data collection is usually a patient response instrument, which from a measure perspective is much harder than trying to capture data from administrative sources or even the medical record. {I see you make the point later in the report}	Thank you.
163	Roger Winn, PhD	National Quality Forum	TEP	16	1	I don't understand the decision not to abstract JCAHO, ORYX, or NCQA measures of relevance	This decision was made because these are widely available measure sets and in light of resources, it was felt to be more helpful for NQF's purposes to enumerate less visible indicator and measure sets. This decision was made in consultation with our task order officer.
164	Roger Winn, PhD	National Quality Forum	TEP	34		ACOVE effective dyspnea measure: I'm confused about the numerator: shouldn't the denominator be all patients with dyspnea?	No, the specifications are correct as described
165	Roger Winn, PhD	National Quality Forum	TEP	39		ACOVE spiritual assessment: Numerator and denominator definitions are reversed	Corrected

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166	Roger Winn, PhD	National Quality Forum	TEP	41		ACOVE surrogates for poor cognition measure: how does the measure operationalize “dementia and altered mental state” to determine the denominator? How is impairment assessed, i.e standard tests, etc? Similar consideration for regular assessment of inpatients with severe dementia (p 42).	We have now included a definition.
167	Roger Winn, PhD	National Quality Forum	TEP	46		ACOVE documentation of specific life sustaining preferences. Why is the denominator restricted to those who state they do not want life-prolonging measures? Shouldn't the preference of those who do want aggressive therapy also be documented?	Since the default of providing these treatments is typical in clinical practice, documentation is not typically required to assure these interventions. Certainly, effective communication should be the standard for patients and families whether or not they elect specific treatments. However, the specification reflects the actual indicator.
168	Roger Winn, PhD	National Quality Forum	TEP	46		ACOVE consistency of preferences and mechanical ventilation. 1) As stated, the numerator doesn't seem to get at the consistency (concordance) issue: isn't the measure all those who are receiving ventilation in the denominator and all those who stated they did not want it in the numerator? 2) The discussion appears to be about withdrawal of ventilation not its institution.	In this case, the numerator reflects a discussion of preferences having occurred in patients who qualify for mechanical ventilation, regardless of whether or not they declined it.
169	Roger Winn, PhD	National Quality Forum	TEP	47		Dana Farber hospital use and ICU use measures: both discussions quote the norm in terms of use of emergency visits. This applies only to the ER measure.	The paper actually states that high performing systems will have less than 4% with multiple hospitalizations or emergency room visits or are admitted to the ICU in the last month of life (p.11 in Earle) and sentence clarified in Report.

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170	Roger Winn, PhD	National Quality Forum	TEP	48		Dana Farber new chemo measure: does it exclude acute leukemias (10-15%) die from drug toxicity and hospitals with large leukemia practices might therefore suffer from this measure.	This information was not available, but we have addressed the concern that institutional variation and care mix adjustment needs to be strongly considered with these measures. See response to Item # 51
171	Roger Winn, PhD	National Quality Forum	TEP	49		Dana Farber admission to hospice measure: the Earle paper gives reasons for the low sensitivity (24%) and this should probably be included.	Agree and this is now included.
172	Roger Winn, PhD	National Quality Forum	TEP	49		Site of death Dana Farber late referral to hospice: does this need to be a composite measure with the % hospice admission? If two hospitals both have 9% late admissions of all the patients who die, i.e. poor quality, is this the same measure of quality for hospital A who has a 50% hospice admission rate and hospital B who has a (% admission rate (all late)?	While this measure does not address it, we agree that this measure has to be interpreted in light of the total hospice referrals of an organization.
173	Roger Winn, PhD	National Quality Forum	TEP	50		Dana Farber site of death , line 7 should be "(greater than 17%)" not 4%	Corrected
174	Roger Winn, PhD	National Quality Forum	TEP	51		Need NEJM reference for Danis.	Corrected

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175	Roger Winn, PhD	National Quality Forum	TEP	54	para 4 line 1:	I really have trouble understanding: "Symptom assessment requires efficient indicators that can become part of the dashboard of quality monitors for care settings". What are efficient indicators?	We have clarified this sentence.
176	Steve Asch, MD, MPH	VAGLHS	TEP			No comments received.	N/A
177	William Lawrence, MD	AHRQ	TOO	5	Task Order questions	I think this would read easier to start with the final key questions in the task order questions section (if you'd like, you can even change the subhead to final questions). I'd rather the emphasis for the report were placed on the questions you actually answer in the report, not the ones that you were originally asked. If you'd like, I think it would be quite reasonable to put the initial questions (unbolded) in the approach to the report section, if you want to detail how we arrived at the final questions. At the moment, the only stand-alone key questions section lists questions that you only answer some of.	We agree and have presented the final, modified task order questions in the introduction - with a note that they were modified. We decided not to include all of the original questions since they are largely duplicative and we thought this presentation would be clearer for readers.
178	William Lawrence, MD	AHRQ	TOO	24	Pain	the mention of an XRT measure in relation to pain was a bit confusing – I presume this was palliative XRT specifically?	Yes, XRT for symptom management.
179	William Lawrence, MD	AHRQ	TOO	25	Pain	First measure (as general comment). "The measure is not in use" – I appreciate having this bit of data, but this means not in use anywhere? Not in use by the organization that has proposed it?	That is correct - to our knowledge.

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180	William Lawrence, MD	AHRQ	TOO	37	Dyspnea	treatment of malignant pleural effusions. Despite having worked in a cancer center, I don't have enough clinical experience here to judge, so I'll ask you – does this happen with enough frequency that you think it will be usable as a quality measure (i.e. will the rates be made from enough cases for a particular entity, be it practice, hospital, health plan, that the rate is stable enough to judge quality from the number)? This would get at the importance of the measure.	See our response to item #113
181	William Lawrence, MD	AHRQ	TOO	39	Depression	assessment of psychosocial well-being. Is "formal assessment" defined? Is a screening survey sufficient? Must it be an assessment by a psychologic specialist?	We have clarified that this generally meant an assessment by a social worker.
182	William Lawrence, MD	AHRQ	TOO	39	Depression	Spiritual assessment. Looks like you have your numerator and denominator backward. Also, I presume the numerator is specifically those with a spiritual assessment and have died? Otherwise, numerator is not a subset of the denominator.	Corrected
183	William Lawrence, MD	AHRQ	TOO	40	ACP	first measure. Watch the measure/indicator terminology – you refer to this first as a measure, then as an indicator.	Corrected
184	William Lawrence, MD	AHRQ	TOO	40	Gaps	Would appreciate this section sooner or later, preferably sooner. While I'm thinking about it, I thought your gaps sections (at least the ones that exist) were excellent in both content and writing.	Thank you,.

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185	William Lawrence, MD	AHRQ	TOO	41	ACP	regular identification of surrogate. Numerator is “vulnerable” elderly. How do we define vulnerable? This section in general seems to have a several terms with a similar degree of vagueness.	Vulnerable elders are conceptually defined as those persons 65 years or older who are at increased risk of death or functional decline in the next 2 years. Vulnerable elders are specifically defined as those scoring 3 or greater on the VE-13 scale, a self-report that gives points for age, self-reported general health and activity limitations( Saliba et al. JAGS 49:1691-1699, 2001). In practice the VE-13 identifies about 20-30% of community-dwelling older adults as vulnerable and they have a 4 fold increase in the odds of death or function decline.
186	William Lawrence, MD	AHRQ	TOO	42	ACP	2 <sup>nd</sup> regular identification of surrogate. Is the numerator a subset of the denominator here?	Yes, but we tried to clarify the description to make that clearer (42)

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187	William Lawrence, MD	AHRQ	TOO	42	ACP	last measure – how do we assess that a patient had care consistent with expressed preferences?	The assumption in the ACOVE measures is that the patient's preferences, surrogate will be elucidated and documented within the patient's medical record, usually within a specified timeframe depending on site within the hospital, or why surrogate and preferences were not able to be obtained. Thus, the documentation in the patient's record of their preferences would provide the standard by which care consistency will be evaluated. Clarification text inserted in final report.
188	William Lawrence, MD	AHRQ	TOO	46	ACP	documentation of specific life sustaining preferences. Not sure why the denominator is only those who don't want therapies (although, if this is what the measure says, we go with it, but might deserve comment). Also, numerator and denominator could be from different sets.	See response to Item #162

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189	William Lawrence, MD	AHRQ	TOO	47	ACP	DFCC measure set – you refer to ER visits for discussions of hospitalizations and ICU episodes. Also, while I could grasp your ratio of the 5 <sup>th</sup> percentile/95 <sup>th</sup> percentile for a measure of variability of the measure, I think it would be helpful to put in the raw rates here also.	Raw rates are not included in the paper from which these data were derived {#0742} or in the published article used as supporting evidence {#0142}. Accuracy data and the range for the 95% CI have been added to the text of the final report.
190	William Lawrence, MD	AHRQ	TOO	48	ACP	chemotherapy in last 30 days of life. Does this include Phase I trials? Should it? Is palliative chemotherapy used this late?	This is not addressed in the available information we have on the measure. Presumably it would not capture Phase 1 trials, unless they are covered (and recorded) in Medicare administrative records.
191	William Lawrence, MD	AHRQ	TOO	49	ACP	admission to hospice and others. Is there a definition of “deceased cancer patients”? Is a breast cancer survivor NED for 5 years who dies of a heart attack a deceased cancer patient?	This is not addressed in the available information we have on the measure.
192	William Lawrence, MD	AHRQ	TOO	51	ACP	potential indicators – a reference to the appendix would be nice here.	Corrected-We embedded a reference to the Evidence Tables which essentially present this in tabular form.



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193	William Lawrence, MD	AHRQ	TOO	54	Chapter 4, 3rd paragraph	Can we say anything from the extensive amount of data that you reviewed concerning the frequency with which pain is assessed and appropriately treated? I realize that by virtue of the settings being quality measure testing settings, they might not be generalizable, but presumably they could at least be considered an upper bound of what happens in reality.	We have added this information: "Some information is available on measure for pain assessment, but we identified no measures with this type of information for appropriate pain treatment. The UHC measure of any pain assessment within 48 hours of admission to the hospital, which was met in almost 100% of patients and showed little variation among facilities, would not be useful for any of these purposes. The more rigorous UHC measure, requiring assessment with a numeric pain scale(mean 76%, range 13-100%) and the QOPI measure for pain assessment on the last oncology visit prior to death (mean 56%, range, 30-90%) show more variation and therefore more promise, but would need evaluation for responsiveness and association with outcomes. The VHA measure for regular pain assessment in the ICU shows a low level of initial performance in 1 institution (42%), responsiveness to an intervention (94%), and a relationship with improved outcomes (a decrease in pain scores $\geq 3$ from 41 to 6%).60) "
194	William Lawrence, MD	AHRQ	TOO	55	Chapter 4, second paragraph	Agree with the issue of no measures in pediatric cancer. It might be worthwhile echoing this in some of the gaps sections in the prior paragraphs.	We have added this additional language.

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195	William Lawrence, MD	AHRQ	TOO	56	Chapter 4, 1st paragraph	Also agreed on the issue of the measures not providing guidance. My question for you is whether this is a downside of the measure. Ideally, a quality measure is linked to a leverage point that clinicians, health systems, or someone else should be able to impact upon both to change the measure but ultimately to improve outcomes. For me as a clinician, it would be much easier to implement change if I have parameters with which to act in accordance with the quality measure and presumably in accordance with quality care. If the trigger is that I should take action 3 weeks prior to the person dying, it is somewhat hard to operationalize in my practice. I agree that the ACOVE measures have a better conceptual basis here, although again it would be helpful to understand what defines a vulnerable elder (if a definition has been specified in the measure).	We do agree that this is a downside of some of these measures.
196	William Lawrence, MD	AHRQ	TOO	56	Chapter 4, 3rd paragraph	The lack of information on race, gender, etc, is not particularly surprising, but does anyone at all publish rates on their measures by these categories? If so, it would be worth mentioning.	We found no published differences in rates of these indicators by race / ethnicity or gender.
197	William Lawrence, MD	AHRQ	TOO	25 and on		Minor editorial comment – could you reference the appropriate appendix containing the evidence tables at the intro of the sections, simply to note that there is more detailed info on the discussed measures. That way, if people want a formal definition of numerator, denominator, or want to know how data are abstracted, they'll know where to look.	Corrected-We embedded a reference to the Evidence Tables which essentially present this in tabular form.
198	William Lawrence, MD	AHRQ	TOO	Front Matter		Don't forget abstract, executive summary, etc. Would also appreciate an acknowledgement of the Federal Partners – in addition to AHRQ, they include NCI, CMS, and CDC.	We have acknowledged the Partners in the Introduction.

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199	William Lawrence, MD	AHRQ	TOO		Measures	Also, general issue on the reports of measures – at times, you put in rates for the measures (e.g. second measure on page 25), which is an issue in testing (has someone actually put the measure out in the field and tested it enough to be able to get a rate?). It might be reasonable to consistently comment on rates, or might want to put up front that if you don't comment on rates, there aren't any (or whatever the conditions are for your not including these data). Also, should they appear in the evidence tables?	We have clarified this in our Methods. This information was provided only when it was available.
200	William Lawrence, MD	AHRQ	TOO		Evidence Tables	could you spell out Advanced Care Planning in the title? To me, ACP is American College of Physicians	Clarified
201	William Lawrence, MD	AHRQ	TOO		Organization	I liked the organization of the measures/indicators by Assessment/Treatment/Follow-up – that seems a very intuitive approach to dividing the measures.	Thank you.
202	William Lawrence, MD	AHRQ	TOO		Defining difference between measures and indicators	In the results section, you divide things into measures and indicators, but I haven't found where you define the difference between the two. Could you make this clear in text? Similarly, you have in your abstraction sheets a working definition of a quality measure, which I didn't see in text in the intro – might be worth adding.	We added a sentence referring readers back to the Methods sections for the definitions.
203	William Lawrence, MD	AHRQ	TOO		Evidence Tables	Incidental note after comparing page 39 text to evidence tables – it would be helpful if you could have the order of measures in the evidence table match the order in text – much easier to find a measure in the appendix that way.	We have now corrected this.

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				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
204	William Lawrence, MD	AHRQ	TOO		Table 1	Table 1. I like this table. Having just finished commenting on the draft of colorectal measures report recently, they found a lot of literature reports on one or two measures (e.g. percent of stage III colorectal cancer patients receiving adjuvant chemotherapy) in a report. In yours, it appears that most or all of the measures/indicators are individual items from much broader measure sets. Is this true? Don't necessarily need to comment on this in the report, but I found the difference quite interesting	Yes, that is true.
205	William Lawrence, MD	AHRQ	TOO		Evidence Tables	While it is out of chronologic order, would suggest for the evidence tables that you list denominator first, then numerator, since typically the numerator should be a subset of the denominator. This will a) save you repeating the denominator in the numerator cell in the tables, and b) help make it easier to spot when the numerator isn't a subset (happened at least once – I'll find it in my notes), which should at least raise a red flag.	Thank you, and we have reversed the order of the columns in the final tables.
206	Castillo, DonnaRae	AHRQ			Title	The title is not descriptive enough. Suggest a change to "Quality Measures for Supportive Cancer Care" or something very similar as you mention in your text.	We changed the title to reflect the task order.
207	Castillo, DonnaRae	AHRQ			Title page	It is unclear who the actual authors are. I am assuming the two PIs and the two directors. This needs to be clear (for reference purposes).	Done
208	Castillo, DonnaRae	AHRQ			Contents	This needs to be restructured. List the chapters in order, then References, Figures, Tables, Appendixes. (The last are merely listed with their titles; no page numbers for Appendixes (note it is "Appendixes" not Appendices) as these are only online.) Note also figures and tables are <u>not</u> listed within chapters.	Done

<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
209	Castillo, DonnaRae	AHRQ			Contents	We normally only use the first and, if necessary, second level of headings. Otherwise it becomes too unwieldy (see reworking of Chapter 3 contents, below).	We have corrected our chapter and section headings.
210	Castillo, DonnaRae	AHRQ			Contents	<p>Remove the line "Areas of Study" from the Contents for Chapter 3. It is not in text and is superfluous. Here is Chapter 3 using 1st and 2nd level heads:</p> <p>Chapter 3: Results.....</p> <p>    Overview.....</p> <p>    Literature Flow.....</p> <p>    Pain.....</p> <p>        Introduction.....</p> <p>        Measures and Indicators.....</p> <p>        Potential Indicators and Measurement Gaps..</p> <p>    Dyspnea.....</p> <p>        Introduction.....</p> <p>        Measures and Indicators.....</p> <p>        Potential Indicators and Measurement Gaps..</p> <p>    Depression.....</p> <p>        Introduction.....</p> <p>        Measures and Indicators.....</p> <p>        Potential Indicators and Measurement Gaps..</p> <p>    Advance Care Planning.....</p> <p>        Introduction.....</p> <p>        Measures and Indicators.....</p> <p>        Potential Indicators and Measurement Gaps..</p> <p>    Summary.....</p> <p>You may want to only use the chapter title and 1st level since the sections are short.</p>	Done

Item	Name	Institution	Role	-	-	-	-
				Page	Section	Comment	Response
211	Castillo, DonnaRae	AHRQ			General Format and Style	Report proper begins on page 1 (arabic not roman). All chapters open on a right hand page	This reviewer received a different version of the report directly from AHRQ.
212	Castillo, DonnaRae	AHRQ			General Format and Style	First level headings (next level down from the chapter title) are centered	Corrected
213	Castillo, DonnaRae	AHRQ			General Format and Style	Appendixes, tables and figures are numbered <u>in the order they are cited</u> in the text.	Corrected
214	Castillo, DonnaRae	AHRQ			General Format and Style	Please do not leave space between paragraphs. The indentation is enough to mark the beginning of new paragraph. The extra leading wastes space.	Corrected
215	Castillo, DonnaRae	AHRQ			General Format and Style	Do <b>not</b> use bold to emphasize a word in text; <i>italics</i> is sufficient and it should only be used when defining a term e.g., "An <i>indicator</i> was defined as a descriptive statement..."). Italics should not be used repeatedly. For example, ACOVE or Dana Farber should not be emphasized whenever they are noted as the measure source and so forth.	Corrected
216	Castillo, DonnaRae	AHRQ			General Format and Style	Titles of published books listed in running text should be in italics. (See for example p. xxxi, 1 <sup>st</sup> full paragraph and p. xv, 2 <sup>nd</sup> full paragraph.) This includes the title of your evidence report/summary in the run-on sentence at the bottom of p. xv; suggest you rewrite as: The authors had recently conducted a systematic review, <i>End-of-Life Care and Outcomes</i> . <sup>21</sup> The project's database was searched for articles coded as "cancer"—regardless of type—by our topics of interest.)	Corrected.
217	Castillo, DonnaRae	AHRQ			General Format and Style	First word of a bulleted item is capitalized. Generally, periods end each bulleted item (this is mainly a Web convention for compliance and readability).	Corrected

<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
218	Castillo, DonnaRae	AHRQ			General Format and Style	If quotations are necessary they should be double, not single marks (e.g., "living wills" on p. vi). Often, however, these marks are not needed.	Corrected
219	Castillo, DonnaRae	AHRQ			General Format and Style	As a courtesy to the reader, spell out any acronym when it is introduced in the report (e.g., SCEPC on p. viii, DNR and DNI on p. xv). Do not, however, spell out acronyms in every chapter or in every section within chapters.	Done
220	Castillo, DonnaRae	AHRQ			General Format and Style	The following are printed solid: <b>followup</b> (used as a noun or adjective), <b>contraindicated</b> , <b>decisionmaking</b>	Corrected
221	Castillo, DonnaRae	AHRQ			General Format and Style	When used as a reflexive pronoun, <b>self</b> is hyphenated (e.g., self-expression, self-reported, etc.)	Done
222	Castillo, DonnaRae	AHRQ			General Format and Style	Health care is two words (e.g. "health care measurement" or "health care system") unless used as an established title (e.g., "Agency for Healthcare Research and Quality").	Corrected
223	Castillo, DonnaRae	AHRQ			General Format and Style	There is no space on either side of the solidus mark; i.e., <b>Summary/Conclusion</b> and <b>5/95</b> are correct (not Summary / Conclusion or 5 / 95).	Corrected
224	Castillo, DonnaRae	AHRQ			General Format and Style	Use the <sup>™</sup> and <sup>®</sup> symbols when required; for example, Google <sup>™</sup> CINAHL <sup>®</sup> PsychINFO <sup>®</sup> HEDIS <sup>®</sup>	Corrected
225	Castillo, DonnaRae	AHRQ			General Format and Style	If two or more numerals are used in conjunction and at least 1 of them is 10 or more, make them all numerals (as in this sentence). Thus we would not say "In nine of 10 trials..."	Corrected

<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
226	Castillo, DonnaRae	AHRQ			General Format and Style	The word <b>State</b> is initial cap when referring to a U.S. State (this is U.S. govt. style).	Done
227	Castillo, DonnaRae	AHRQ			General Format and Style	It is not necessary to name books or articles if you are providing reference citations (see p. xxxi for example; you already cite the reference #71.)	Corrected
228	Castillo, DonnaRae	AHRQ			Chapter 1	I suggest that either here (or alternatively at the beginning of the next chapter), you distinguish between measure and indicator as you are using them. This is not totally clear.	We discuss this in our Methods chapter.
229	Castillo, DonnaRae	AHRQ			Chapter 2	On current p. viii where you list your two key questions, I suggest you either put the a/b/c of question 1 with the main part of the question or break out the two parts of question 2 after the word "including" as "a" and "b" in order to be consistent in format with question 1. In other words, question 2 formatted like question 1 would read:2. What gaps in knowledge about quality measurement are evident from the currently available literature, including: a. Absence of measures or b. Measures lacking evidence of their scientific soundness, whether for the population of cancer patients as a whole or for specific populations.	These were the key questions assigned to us.
230	Castillo, DonnaRae	AHRQ			Chapter 1	Table 1 is mentioned at top of current p. x as a list of organizations. I am assuming this is the Table 1, now in Chapter 3, that lists the organizations and the measures they are supplying. thus this table should be moved to Chapter 2. Table 1 and Table 2 can be placed at the end of this chapter so as not to interfere with the running text. If this current Table 1 is not the one you reference on p. x, that table needs to be supplied.	We changed the order in which we describe them in the text. We decided to leave Table 2 in the Results section rather than Methods because it reflects findings of the review.



<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
231	Castillo, DonnaRae	AHRQ			Chapter 2	As noted above, appendixes are numbered in the order cited. As cited in the text of Chapter 2, the order should be: A. Technical Expert Panel and Peer Reviewers B. TEP Worksheet C. Literature Search Strategies (NOTE: This is one appendix, Appendix C, not Appendixes C; the individual databases are not C-1, C-2 etc.). D. Contact Form E. Article Screener	Corrected
232	Castillo, DonnaRae	AHRQ			Chapter 2	At the top of p. xiv, to make more typographically consistent, I suggest you reformat as the end of the sentence just before the bulleted items as follows: The main search strategy included an extensive list of terms intended to identify research publications associated with all of the following: · Each of the domains of interest (pain, dyspnea, depression, advance care planning). · Quality assessment or improvement. · Quality measurement.	Done
233	Castillo, DonnaRae	AHRQ			Chapter 2	The hyperlinks on pp. xiv and xv should be removed. (okay to leave the underlining).	Corrected
234	Castillo, DonnaRae	AHRQ			Chapter 3	Headings should be consistent in wording and format. For example, in the Pain section, one of the headings is "Potential Measures & Measurement Gaps"; in the Dyspnea section, the equivalent heading reads "Potential Measures / Measurement Gaps"; and in the Advance Care section it is just "Potential Measures." They should all read <b>Potential Measures and Measurement Gaps</b>	Corrected

<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
235	Castillo, DonnaRae	AHRQ			Chapter 3	As noted above, if the reference to Table 1 is to the Table 1 mentioned in Chapter 2, it needs to be moved and the title should reflect the measure source; for example: <b>Table 1. Sources and attributes of identified measures and indicators</b>	We corrected the names and titles of Table 1 and 2 as suggested.
236	Castillo, DonnaRae	AHRQ			Chapter 3	Run-in headings should be bold, not italics or parenthesized, and followed by a period. Do not make the beginning of the sentence bold. For example, in the Pain section, the first paragraph under “Measures and Indicators” in Chapter 3, p. xxviii, begins with the following heading and 1st sentence:(Measure - regular assessment of pain) Quality Assessment Tools (QA Tools), proposed in 200062 includes one measure relevant to pain assessment.This is awkward and not according to our required style. It should read:Measure: Regular assessment of pain. Quality Assessment Tools (QA Tools), proposed in 2000,62 includes one measure relevant to pain assessment.All the measure or indicator names would be set up the same way.	Corrected
237	Castillo, DonnaRae	AHRQ			Chapter 3	Move the name of the second UHC measure on p. xxviii to make it a heading, for typographical consistency. For example: Measure: Routine inpatient pain assessment. (for the first measure) Measure: Routine inpatient pain assessment with a numeric scale. (for the second measure) This would apply also on p. xliii to the second ACOVE measure under Treatment of Depression.	Corrected
238	Castillo, DonnaRae	AHRQ			Chapter 3	Under the “Treatment” section on p. xxx, the text mentions “3 measures and 1 indicator”; however the text in that section (see pp. xxx and xxxi) presents 2 measures and 2 indicators. This discrepancy must be reconciled; either the intro sentence or a run-in heading is wrong.	Corrected

<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
239	Castillo, DonnaRae	AHRQ			Chapter 3	Under the “Followup” section of Advance Care Planning, the intro sentence mentions 14 measures in 10 categories and 7 indicators in 8 categories. The 10 general measure categories are easily seen; the indicators are not. For those measures that also that include a similar indicator, we should modify the run-in heading to include the notation. For example the measure noted as “Measure: late life hospital use” includes a similar indicator. Let’s change the heading to: <b>Measure/Indicator: Late life hospital use.</b> (or alternatively, but less preferable, <b>Measure and indicator: Late life hospital use.</b> )	Corrected
240	Castillo, DonnaRae	AHRQ			Chapter 3	In addition, I count 8, not 7, indicators listed within this section as follows (page nos. in parens): 1) late life hospital use (p. xlix) 2) late life ICU use (p. l) 3) late life rate of emergency care (also p. l) 4) new chemotherapy regimen in last 30 days of life (p. li) 5) chemotherapy in last 14 days of life (also p. li) 6) admission to hospice (p. lii) 7) site of death (p. liii) The above 7 are within the “measure” paragraphs; but there is also 8) care consistency with documented care preferences (p liii) If this is correct, please change the intro paragraph to read 8 indicators in 8 categories.	Corrected
241	Castillo, DonnaRae	AHRQ			Chapter 4	This should include <b>Discussion</b> as part of the chapter title.	Corrected
242	Castillo, DonnaRae	AHRQ			References	<b>References</b> is the correct title of this section	Corrected

<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
243	Castillo, DonnaRae	AHRQ			Excluded Studies	Since this is one of the last reports under the “old” style guide, it is appropriate to list alphabetically the excluded studies (your current Appendix J as listed in the Contents could fill this need here.)	The excluded studies will be a separate appendix.
244	Castillo, DonnaRae	AHRQ			Appendixes	As noted these should be reordered and numbered in the order of their citation in text. As of now, this is the order of their call-out in the text: A. Technical Expert Panel and Peer Reviewers B. TEP Worksheet C. Literature Search Strategies (NOTE: This is one appendix, Appendix C, not Appendixes C; the individual databases are not C-1, C-2 etc.). D. Contact Form E. Article Screener F. Evidence Tables	Corrected
245	Castillo, DonnaRae	AHRQ			Appendix A:	Please make sure you have permission from the individuals to be listed to include their names in the report.	Permissions granted.
246	Castillo, DonnaRae	AHRQ			Appendix B:	Title should be Appendix C: Literature Search Strategies.	Corrected
247	Castillo, DonnaRae	AHRQ			Evidence Tables	Title should be Appendix F. Evidence Tables. Table titles should be where the distinctions are made. For example: Evidence Table F.1. Quality Measures and Indicators for Supportive Cancer Care: Pain.	Corrected

<u>Item</u>	<u>Name</u>	<u>Institution</u>	<u>Role</u>	-	-	-	-
				<u>Page</u>	<u>Section</u>	<u>Comment</u>	<u>Response</u>
248	Castillo, DonnaRae	AHRQ			Other Appendixes	<ul style="list-style-type: none"> <li>· Perhaps I overlooked them but I could not find any text reference to several appendixes (G-L) currently listed in your Contents table. These appendixes are not here.</li> <li>· Is the “Cambridge Ballot” necessary?</li> <li>· I have already mentioned Appendix J above which can become the List of Excluded Studies.</li> <li>· What is the purpose of separating observational evidence tables currently noted as Appendix L from the others currently noted as Appendix E (which will become App F)? Can these be combined? Why are the “Observational Studies” necessary anyway if they are not discussed?</li> <li>· Appendix H should be one appendix, not two, entitled Appendix H: Methodological Issues in Measurement or, if you prefer, Appendix H: Reliability, Validity, and Other Measurement Issues. Include the table within the appendix.</li> <li>· Delete Appendix K. Including peer review comments is unnecessary. This is prepublication information. They belong in your file, not with a published report.</li> </ul>	This reviewer received a different version of the report /appendixes from AHRQ.

# Appendix H. Excluded Studies

## Rejected: Duplicate Data

1. Appendix A: panel rating sheets by condition. Kerr, E. A.; Asch, S. M.; Hamilton, E. G., and McGlynn, E. A. Quality of care for cardiopulmonary conditions: a review of the literature and quality indicators. RAND; 2000; pp. 251-84.  
Rec #: 739
2. Appendix B: crosswalk table to original and final indicators. Kerr, E. A.; Asch, S. M.; Hamilton, E. G., and McGlynn, E. A. Quality of care for cardiopulmonary conditions: a review of the literature and quality indicators . RAND; 2000; pp. 285-327.  
Rec #: 740

## Rejected: Non-Western Location

1. Auchus, A. P. and Chen, C. P. Asia-Pacific Consensus Statement on dementia. *Alzheimer Dis Assoc Disord.* 2001 Apr-2001 Jun 30; 15(2):63-5.  
Rec #: 635
2. Howland SC. Managing the Alzheimer's patient. *Emerg Med Serv.* 2000 Sep; 29(9):89-92.  
Rec #: 32435
3. Ministry of Health, Singapore. Cancer pain. 2003 Mar(Clinical Practice Guildelines).  
Rec #: 207
4. National Comprehensive Cancer Network (NCCN). Colon cancer. *Clinical Practice Guidelines in Oncology.* 2005; (2).  
Rec #: 128
5. Palliative Care and Critical Care Committees. Removal of mechanical ventilation in the dying patient. *Guidelines for Physician Staff Froedtert Hospital, Milwaukee, Wisconsin* :1-4.  
Rec #: 136
6. Tomita T and Kitamura T. Clinical and research measures of grief: a reconsideration. *Compr Psychiatry.* 2002 Mar-2002 Apr 30; 43(2):95-102.  
Rec #: 15879

## Rejected: No Domain of Interest

1. American Academy of Hospice and Palliative Medicine (AAHPM). Position statements: comprehensive end-of-life care and physician-assisted suicide [Web Page]. 1997 Jun 25; Accessed 2005 Jan 24.  
Rec #: 483
2. American Academy of Hospice and Palliative Medicine (AAHPM). Position statements: statement on the ethics of palliative care research [Web Page]. 2002 Jan 30; Accessed 2005 Jan 24.  
Rec #: 482
3. American Academy of Hospice and Palliative Medicine (AAHPM). Position statements: statement on the use of nutrition and hydration [Web Page]. 2001 Nov 16; Accessed 2005 Jan 24.  
Rec #: 481
4. American Academy of Hospice and Palliative Medicine (AAHPM). Positions statements: statement on sedation at the end-of-life [Web Page]. 2002 Sep 13; Accessed 2005 Jan 24.  
Rec #: 480
5. American Board of Family Practice. Carcinoma of the breast. Reference Guide. 2001.  
Rec #: 465
6. Bast, R. C. Jr; Ravdin, P.; Hayes, D. F.; Bates, S.; Fritsche, H. Jr; Jessup, J. M.; Kemeny, N.; Locker, G. Y.; Mennel, R. G., and Somerfield, M. R. 2000 update of recommendations for the use of tumor markers in breast and colorectal cancer: clinical practice guidelines of the American Society of Clinical Oncology. *J Clin Oncol*. 2001 Mar 15; 19(6):1865-78.  
Rec #: 174
7. Benson, A. B. 3rd; Schrag, D.; Somerfield, M. R.; Cohen, A. M.; Figueredo, A. T.; Flynn, P. J.; Krzyzanowska, M. K.; Maroun, J.; McAllister, P.; Van Cutsem, E.; Brouwers, M.; Charette, M., and Haller, D. G. American Society of Clinical Oncology recommendations on adjuvant chemotherapy for stage II colon cancer. *J Clin Oncol*. 2004 Aug 15; 22(16):3408-19.  
Rec #: 170
8. Bramwell, V. H. C.; Anderson, D.; Charette, M. L., and Sarcoma Disease Site Group. Doxorubicin-based chemotherapy for the palliative treatment of adult patients with locally advanced or metastatic soft tissue sarcoma. Practice Guideline Report #11-1. 1999(Program in Evidence-Based Care).  
Rec #: 152
9. Browning, D. M. and Solomon, M. Z. The initiative for pediatric palliative care: an interdisciplinary educational approach for health care professionals.  
Rec #: 755
10. Burt, R. A. The limitations of protocols for end-of-life care. *Respir Care*. 2000 Dec; 45(12):1523-9; discussion 1529-33.  
Rec #: 223
11. Byock, I.; Norris, K.; Curtis, J. R., and Patrick, D. L. Improving end-of-life experience and care in the community: a conceptual framework. *J Pain Symptom Manage*. 2001 Sep; 22(3):759-72.  
Rec #: 642
12. Cherny, N. I.; Catane, R.; Kosmidis, P. A., and Members of the ESMO Palliative Care Working Group. ESMO policy on supportive and palliative care. *European Society for Medical Oncology (ESMO)*. 2003:1-5.  
Rec #: 139



13. Chow, T. W. and MacLean, C. H. Quality indicators for dementia in vulnerable community-dwelling and hospitalized elders. *Ann Intern Med.* 2001 Oct 16; 135(8 Pt 2):668-76.  
Rec #: 645
14. Cluzeau, F. A.; Littlejohns, P.; Grimshaw, J. M.; Feder, G., and Moran, S. E. Development and application of a generic methodology to assess the quality of clinical guidelines. *Int J Qual Health Care.* 1999 Feb; 11(1):21-8.  
Rec #: 432
15. Cummings, J. L.; Frank, J. C.; Cherry, D.; Kohatsu, N. D.; Kemp, B.; Hewett, L., and Mittman, B. Guidelines for managing Alzheimer's disease: part I. Assessment. *Am Fam Physician.* 2002 Jun 1; 65(11):2263-72.  
Rec #: 633
16. Daly, B. J. Organizational change and delivery of multidisciplinary palliative care. *Respir Care.* 2000 Dec; 45(12):1501-10; discussion 1510-2.  
Rec #: 221
17. Davidson, K. Family bereavement support before and after the death of a nursing home resident. University of Iowa Gerontological Nursing Interventions Research Center (RDC); 2002.  
Rec #: 713
18. Dudley, R. A.; Bowers, L. V., and Luft, H. S. Reconciling quality measurement with financial risk adjustment in health plans. *Jt Comm J Qual Improv.* 2000 Mar; 26(3):137-46.  
Rec #: 427
19. European Society for Medical Oncology (ESMO). Minimum clinical recommendations for diagnosis, adjuvant treatment and follow-up of primary breast cancer. ESMO Guidelines Task Force; 2003.  
Rec #: 117
20. --. Minimum clinical recommendations for diagnosis, treatment and follow-up of advanced colorectal cancer. ESMO Guidelines Task Force; 2002.  
Rec #: 115
21. European Society for Medical Oncology (ESMO). Minimum clinical recommendations for diagnosis, treatment and follow-up of Ewing's sarcoma of bone. ESMO Guidelines Task Force; 2002.  
Rec #: 118
22. European Society for Medical Oncology (ESMO). Minimum clinical recommendations for diagnosis, treatment and follow-up of locally recurrent or metastatic breast cancer (MBC): ESMO Guidelines Task Force; 2003.  
Rec #: 114
23. --. Minimum clinical recommendations for diagnosis, treatment and follow-up of non-small-cell lung cancer (NSCLC). ESMO Guidelines Task Force; 2003.  
Rec #: 116
24. --. Minimum clinical recommendations for diagnosis, treatment and follow-up of osteosarcoma : ESMO Guidelines Task Force; 2002.  
Rec #: 111
25. European Society for Medical Oncology (ESMO). Minimum clinical recommendations for diagnosis, treatment and follow-up of small-cell lung cancer (SCLC): ESMO Guidelines Task Force; 2003.  
Rec #: 112

26. European Society for Medical Oncology (ESMO). Minimum clinical recommendations for the diagnosis, treatment and follow-up of prostate cancer: ESMO Guidelines Task Force; 2003.  
Rec #: 113
27. Fahey, T.; Montgomery, A. A.; Barnes, J., and Protheroe, J. Quality of care for elderly residents in nursing homes and elderly people living at home: controlled observational study. *BMJ*. 2003 Mar 15; 326(7389):580.  
Rec #: 631
28. Fowler, F. J. Jr.; Coppola, K. M., and Teno, J. M. (Center for Survey Research, University of Massachusetts at Boston, 100 Morrissey Boulevard, Boston, MA 02125-3393.). Methodological challenges for measuring quality of care at the end of life. *Journal of Pain and Symptom Management*. 1999 Feb; 17(2):114-9.  
Rec #: 343
29. Gagliardi, A. R.; Fung, M. F. K.; Langer, B.; Stern, H., and Brown, A. D. Development of ovarian cancer surgery quality indicators using a modified delphi approach. Ottawa, Ontario, Canada.  
Rec #: 726
30. Giordano, M. The respiratory therapist and palliative care. *Respir Care*. 2000 Dec; 45(12):1468-74; discussion 1475-7.  
Rec #: 218
31. Gralla, R. J.; Osoba, D.; Kris, M. G.; Kirkbride, P.; Hesketh, P. J.; Chinnery, L. W.; Clark-Snow, R.; Gill, D. P.; Groshen, S.; Grunberg, S.; Koeller, J. M.; Morrow, G. R.; Perez, E. A.; Silber, J. H., and Pfister, D. G. Recommendations for the use of antiemetics: evidence-based, clinical practice guidelines. American Society of Clinical Oncology. *J Clin Oncol*. 1999 Sep; 17(9):2971-94.  
Rec #: 162
32. Hillner, B. E.; Ingle, J. N.; Chlebowski, R. T.; Gralow, J.; Yee, G. C.; Janjan, N. A.; Cauley, J. A.; Blumenstein, B. A.; Albain, K. S.; Lipton, A., and Brown, S. American Society of Clinical Oncology 2003 update on the role of bisphosphonates and bone health issues in women with breast cancer. *J Clin Oncol*. 2003 Nov 1; 21(21):4042-57.  
Rec #: 462
33. Holtzman, J.; Degelau, J.; Meyers, R.; Christianson, C., and Lurie, N. (Institute of Health Services Research, School of Public Health, Box 197 Mayo, 420 Delaware Street S.E., Minneapolis, MN 55455.). Development and testing of a process measure of nursing home quality of care. *Journal of the American Geriatrics Society*. 1997 Oct; 45(10):1203-7.  
Rec #: 397
34. Hunt et al. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: a report of the American College of Cardiology/American Heart Association task force on practice guidelines (Committee to revise the 1995 guidelines for the evaluation and management of heart failure). ACC/AHA Practice Guidelines. 2001:1-55.  
Rec #: 120
35. Jacobsen, P. B.; Donovan, K. A.; Trask, P. C.; Fleishman, S. B.; Zabora, J.; Baker, F., and Holland, J. C. Screening for psychological distress in ambulatory cancer patients: a multi-center evaluation of the distress thermometer.  
Rec #: 487
36. Jennings, B. M.; Loan, L. A.; DePaul, D.; Brosch, L. R., and Hildreth, P. Lessons learned while collecting ANA indicator data. *J Nurs Adm*. 2001 Mar; 31(3):121-9.  
Rec #: 554

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