



# Top Twelve Measures—Background Information, Evidence, and Clinical User Panel (CUP) Comments

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## DOMAIN 1: STRUCTURE AND PROCESS OF CARE (1 measure)

### MEASURE 1: HOSPICE AND PALLIATIVE CARE—COMPREHENSIVE ASSESSMENT

**Source:** PEACE subset (Hanson, 2012), <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

#### Measure Description

**Hospice:** Percentage of patients enrolled in hospice for longer than 7 days for whom a comprehensive assessment was completed within 5 days of admission. Components of comprehensive assessment include documentation of prognosis (can be prior to admission), functional assessment, screening for physical and psychological symptoms, and assessment of social and spiritual concerns.

**Palliative Care:** Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting for longer than 1 day for whom a comprehensive assessment was completed. Components of comprehensive assessment include screening for physical symptoms and discussion of the patient’s and family’s emotional or psychological needs. All physical screenings must be completed within 24 hours of admission (screening date – admission date ≤ 1). Discussions regarding emotional or psychological issues can take place at any time during the admission.

## Evidence/Rationale

Research on care of patients nearing the end of life shows they experience high rates of untreated pain and other physical, emotional, and spiritual causes of distress.<sup>1,2</sup> The National Priorities Partnership has identified palliative and end-of-life care as one of its national priorities. A goal of this priority is to ensure that all patients with life-limiting illness have access to effective symptom treatment as well as social, psychological, and spiritual support.<sup>3</sup>

In 2009, 1.56 million people with life-limiting illness received hospice care.<sup>4</sup> In 2008, 58.5% of US hospitals with 50 or more beds had some form of palliative care service.<sup>5</sup>

**Performance gap:** Pilot testing of the proposed measure revealed that only 25% of the 126 hospice patients and 19% of the 602 acute care hospital patients reviewed received a comprehensive assessment.

**Guideline citation:** The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for patient-family decision making. Family is defined by the patient.<sup>6(p14)</sup>

This measure also is relevant to the National Quality Forum-endorsed *A National Framework and Preferred Practices for Palliative and Hospice Care Quality* preferred practice #6: Formulate, utilize, and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated both internally and externally to all professionals involved in the patient's care.<sup>7</sup>

## References

1. Connors AF, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274(20):1591-1598.
2. Gade G, Venohr I, Conner D, et al. Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med*. 2008;11(2):180-190.
3. National Quality Forum. National Priorities Partnership and the National Quality Strategy. National Quality Forum website. [https://www.qualityforum.org/Setting\\_Priorities/NPP/Input\\_into\\_the\\_National\\_Quality\\_Strategy.aspx](https://www.qualityforum.org/Setting_Priorities/NPP/Input_into_the_National_Quality_Strategy.aspx). Accessed May 22, 2014.
4. National Hospice and Palliative Care Organization. *NHPCO Facts and Figures: Hospice Care in America*. Alexandria, VA: Author; 2010.
5. Palliative care programs continue rapid growth in US hospitals [press release]. New York, NY: Center to Advance Palliative Care; April 6, 2010. <http://www.capc.org/news-and-events/releases/04-05-10>
6. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*. 3rd ed. Pittsburgh, PA: Author; 2013. [http://www.nationalconsensusproject.org/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf)
7. National Quality Forum. *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*. Washington DC: Author; 2006.

## Comments from CUP

We cannot dictate who does the comprehensive assessment, but if a patient is referred to palliative care, a comprehensive assessment should be conducted regardless of who does it. The measure timeframe is 5 days because hospices get 5 days to do the whole comprehensive assessment.

## DOMAIN 2: PHYSICAL ASPECTS OF CARE (1 of 3 measures)

### MEASURE 2: PAIN TREATMENT (ANY)

Source: PEACE subset (Hanson 2012), <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

#### Measure Description

Seriously ill patients receiving specialty palliative care in an acute hospital setting for longer than 1 day or patients enrolled in hospice for longer than 7 days who screened positive for moderate to severe pain on admission, and the percent receiving medication versus nonmedication treatment, within 24 hours of screening.

#### Evidence/Rationale

Research on care of patients with serious illness and those nearing the end of life shows they experience high rates of untreated pain (40%-70% prevalence) and other physical, emotional, and spiritual causes of distress.<sup>1,2</sup> The National Priorities Partnership has identified palliative and end-of-life care as one of its national priorities. A goal of this priority is to ensure that all patients with life-limiting illness have access to effective treatment for symptoms such as pain and shortness of breath.<sup>3</sup>

In 2009, 1.56 million people with life-limiting illness received hospice care.<sup>4</sup> In 2008, 58.5% of US hospitals with 50 or more beds had some form of palliative care service.<sup>5</sup>

**Guideline citation:** The interdisciplinary team assesses and manages pain and other physical symptoms and their subsequent effects based on the best available evidence.<sup>6(p20)</sup>

- The goal of pain and symptom management is the safe and timely reduction of a physical symptom to a level acceptable to the patient or to the surrogate if the patient is unable to report distress.
- Symptoms include, but are not limited to, pain, shortness of breath, nausea, fatigue, anorexia, insomnia, restlessness, confusion, and constipation.
- The treatment of distressing symptoms and side effects includes the entire spectrum of pharmacological, interventional, behavioral, and complementary therapies and interventions, as supported by efficacy research, with referral to appropriate specialists.
- Symptom assessment, treatment, side effects, and treatment outcomes information is recorded in the medical record and transmitted across healthcare settings during transitions.<sup>6(p20)</sup>

#### References

1. Connors AF, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274(20):1591-1598.
2. Gade G, Venohr I, Conner D, et al. Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med*. 2008;11(2):180-190.
3. National Quality Forum. National Priorities Partnership and the National Quality Strategy. National Quality Forum website. [https://www.qualityforum.org/Setting\\_Priorities/NPP/Input\\_into\\_the\\_National\\_Quality\\_Strategy.aspx](https://www.qualityforum.org/Setting_Priorities/NPP/Input_into_the_National_Quality_Strategy.aspx). Accessed May 22, 2014.
4. National Hospice and Palliative Care Organization. *NHPCO Facts and Figures: Hospice Care in America*. Alexandria, VA: Author; 2010.
5. Palliative care programs continue rapid growth in US hospitals [press release]. New York, NY: Center to Advance Palliative Care; April 6, 2010. <http://www.capc.org/news-and-events/releases/04-05-10>
6. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*. 3rd ed. Pittsburgh, PA: Author; 2013. [http://www.nationalconsensusproject.org/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf)

**Data from other studies:** Pain is prevalent, underdiagnosed, and undertreated in patients with cancer and other life-limiting or serious illnesses. The prevalence of undetected and undertreated pain ranges from 40%-80% in seriously ill patient populations. As detailed in a systematic report from the Agency for Healthcare Research and Quality, pain screening and assessment are the essential steps required to ensure that pain is detected by clinicians and the appropriate treatment is implemented. Failure to screen, assess, and treat pain results in functional limitations, physiologic stress, and psychological harms such as social withdrawal and depression.<sup>1</sup>

**Data from the peace project:** Pilot testing of the PEACE proposed measure on pain assessment in the acute hospital sample revealed that although 99.5% of 562 acute care hospital patients were screened for pain, only 42% of seriously ill patients not receiving added specialty palliative care and only 67% of those receiving specialty palliative care who screened positive were given a comprehensive clinical assessment. Pilot testing in the hospice sample revealed that only 78% of 126 hospice patients were screened for pain, and 60% of those who screened positive were given a comprehensive clinical assessment.

Pain is underrecognized by clinicians and undertreated, resulting in excessive suffering for patients with serious illness. Pain screening and assessment are necessary to improve the patient-centered outcome of pain and its effects on the global outcomes of function and quality of life. Pain, like other symptoms, only can be understood through patient self-report and observation. Screening and assessment for pain are essential steps in pain management. Without initial screening to identify patients in pain and clinical assessment to determine the severity, etiology, and effect of this symptom on function, effective treatment cannot be administered.

## References

1. Wells N, McCaffery M, Pasero C. Improving the quality of care through pain assessment and management. In: Hughes RG, ed. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville, MD: Agency for Healthcare Research and Quality; 2008.

## Comments from CUP

Measure is not redundant with comprehensive assessment, they are just different measures. Having choices and the flexibility for different measures is a good thing. Anytime you have a nonmedication treatment option, you have to thoughtfully identify where it will be documented in the medical record. It's about developing a process for the data capture.

## DOMAIN 2: PHYSICAL ASPECTS OF CARE (2 of 3 measures)

### MEASURE 3: SCREENING FOR PHYSICAL SYMPTOMS

**Source:** PEACE subset (Hanson, 2012), <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

#### Measure Description

Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting for longer than 1 day or patients enrolled in hospice for longer than 7 days who had a screening for physical symptoms (pain, dyspnea, nausea, and constipation) during the admission visit.

## Evidence/Rationale

Research on the care of patients nearing the end of life shows they experience high rates of physical, emotional, and spiritual causes of distress.<sup>1,2</sup> The National Priorities Partnership has identified palliative and end-of-life care as one of its national priorities. A goal of this priority is to ensure that all patients with life-limiting illness have access to effective treatment for symptoms such as pain and shortness of breath.<sup>3</sup> In 2009, 1.56 million people with life-limiting illness received hospice care.<sup>4</sup> In 2008, 58.5% of US hospitals with 50 or more beds had some form of palliative care service.<sup>5</sup>

**Guideline citation:** The interdisciplinary team assesses and manages pain and other physical symptoms and their subsequent effects based on the best available evidence.<sup>6(p20)</sup>

- The goal of pain and symptom management is the safe and timely reduction of a physical symptom to a level acceptable to the patient or to the surrogate if the patient is unable to report distress.
- Symptoms include, but are not limited to, pain, shortness of breath, nausea, fatigue, anorexia, insomnia, restlessness, confusion, and constipation.
- The treatment of distressing symptoms and side effects includes the entire spectrum of pharmacological, interventional, behavioral, and complementary therapies and interventions, as supported by efficacy research, with referral to appropriate specialists.
- Symptom assessment, treatment, side effects, and treatment outcome information is recorded in the medical record and transmitted across healthcare settings during transitions.<sup>6(20)</sup>

## References

1. Connors AF, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274(20):1591-1598.
2. Gade G, Venohr I, Conner D, et al. Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med*. 2008;11(2):180-190.
3. National Quality Forum. National Priorities Partnership and the National Quality Strategy. National Quality Forum website. [https://www.qualityforum.org/Setting\\_Priorities/NPP/Input\\_into\\_the\\_National\\_Quality\\_Strategy.aspx](https://www.qualityforum.org/Setting_Priorities/NPP/Input_into_the_National_Quality_Strategy.aspx). Accessed May 22, 2014.
4. National Hospice and Palliative Care Organization. *NHPCO Facts and Figures: Hospice Care in America*. Alexandria, VA: Author; 2010.
5. Palliative care programs continue rapid growth in US hospitals [press release]. New York, NY: Center to Advance Palliative Care; April 6, 2010. <http://www.capc.org/news-and-events/releases/04-05-10>
6. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*. 3rd ed. Pittsburgh, PA: Author; 2013. [http://www.nationalconsensusproject.org/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf)

## Comments from CUP

Some panelists felt that screening is not enough, [and the measure] should include treatment. Others disagreed and reminded us that there's a gap in care for just the screening, so we're starting with the basics.

# DOMAIN 2: PHYSICAL ASPECTS OF CARE (3 of 3 measures)

## MEASURE 4: DYSPNEA SCREENING AND MANAGEMENT

**Source: National Committee for Quality Assurance/American Medical Association–Physician Consortium for Performance Improvement,** <http://www.ama-assn.org/apps/listserv/x-check/qmeasure.cgi?submit=PCPI>

## Measure Description

Percentage of patients with advanced chronic or serious life-threatening illnesses that are screened for dyspnea. For those who are diagnosed with moderate or severe dyspnea, a documented plan of care to manage dyspnea exists.

## Measure Details

A documented plan of care includes a plan for treatment of dyspnea, including but not limited to nonpharmacologic treatments (eg, repositioning, improving air circulation, relaxation techniques) and pharmacologic methods (eg, oxygen, opioids, anxiolytics) or a statement about why no intervention is undertaken and a plan for assessment including an indication of the reassessment time or interval.

**Denominator Details:** Patients with incurable cancer, organ system failure, or severe progressive neurological conditions (identified with ICD-9 code)

*and*

patients with a substantial risk of death within 1 year, based on the physician's clinical judgment, taking into account the patient's comorbidities, health status, and social and other factors (identified with CPT-II code)

*or*

patients with advanced disease whose goals of care prioritize comfort (identified with CPT-II code).

## Evidence/Rationale

Research on care of patients nearing the end of life shows they experience high rates of physical, emotional, and spiritual causes of distress.<sup>1,2</sup> The National Priorities Partnership has identified palliative and end-of-life care as one of its national priorities. A goal of this priority is to ensure that all patients with life-limiting illness have access to effective treatment for symptoms such as pain and shortness of breath.<sup>3</sup> In 2009, 1.56 million people with life-limiting illness received hospice care.<sup>4</sup> In 2008, 58.5% of US hospitals with 50 or more beds had some form of palliative care service.<sup>5</sup>

Dyspnea is a common symptom in serious illness, and is more common than pain in patients with chronic obstructive lung disease, lung cancer, cystic fibrosis, and restrictive lung diseases such as pulmonary fibrosis.<sup>6</sup> Between 50%-70% of patients with advanced lung cancer experience dyspnea near the end of life. As detailed in a systematic review, opioids, oxygen, and nonpharmacologic nursing interventions demonstrate efficacy in randomized controlled trials of treatment for dyspnea in cancer and in other serious illness.<sup>7,8</sup> Unfortunately, dyspnea often is persistent and undertreated in advanced cancer and other end-stage diseases.<sup>9</sup>

Guideline citation: The interdisciplinary team assesses and manages pain and other physical symptoms and their subsequent effects based on the best available evidence.<sup>10(p20)</sup>

- The goal of pain and symptom management is the safe and timely reduction of a physical symptom to a level acceptable to the patient or to the surrogate if the patient is unable to report distress.
- Symptoms include, but are not limited to, pain, shortness of breath, nausea, fatigue, anorexia, insomnia, restlessness, confusion, and constipation.
- The treatment of distressing symptoms and side effects includes the entire spectrum of pharmacological, interventional, behavioral, and complementary therapies and interventions, as supported by efficacy research, with referral to appropriate specialists.
- Symptom assessment, treatment, side effects, and treatment outcome information is recorded in the medical record and transmitted across healthcare settings during transitions.<sup>10(p20)</sup>

## References

1. Connors AF, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274(20):1591-1598.

2. Gade G, Venohr I, Conner D, et al. Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med*. 2008;11(2):180-190.
3. National Quality Forum. National Priorities Partnership and the National Quality Strategy. National Quality Forum website. [https://www.qualityforum.org/Setting\\_Priorities/NPP/Input\\_into\\_the\\_National\\_Quality\\_Strategy.aspx](https://www.qualityforum.org/Setting_Priorities/NPP/Input_into_the_National_Quality_Strategy.aspx). Accessed May 22, 2014.
4. National Hospice and Palliative Care Organization. *NHPCO Facts and Figures: Hospice Care in America*. Alexandria, VA: Author; 2010.
5. Palliative care programs continue rapid growth in US hospitals [press release]. New York, NY: Center to Advance Palliative Care; April 6, 2010. <http://www.capc.org/news-and-events/releases/04-05-10>
6. Luce JM, Luce JA. Perspectives on care at the close of life. Management of dyspnea in patients with far-advanced lung disease: “once I lose it, it’s kind of hard to catch it...”. *JAMA*. 2001;285(10):1331-1337.
7. Ben-Aharon I, Gafter-Gvili A, Paul M, Leibovici L, Stemmer SM. Interventions for alleviating cancer-related dyspnea: a systematic review. *J Clin Oncol*. 2008;26(14):2396-2404.
8. Lorenz KA, Lynn J, Dy SM, et al. Evidence for improving palliative care at the end of life: a systematic review. *Ann Intern Med*. 2008;148(2):147-159.
9. Roberts DK, Thorne SE, Pearson C. The experience of dyspnea in late-stage cancer. Patients’ and nurses’ perspectives. *Cancer Nurs*. 1993;16(4):310-320.
10. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*. 3rd ed. Pittsburgh, PA: Author; 2013. [http://www.nationalconsensusproject.org/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf)

**Data from other studies:** The prevalence of dyspnea in advanced cancer ranges from 50%-70%. Among patients with chronic obstructive pulmonary disease with advanced illness enrolled in the SUPPORT Study, dyspnea was present for at least 65% of patients throughout the 6 months preceding death and was moderate to severe at least half of the time.

## References

1. Luce JM, Luce JA. Perspectives on care at the close of life. Management of dyspnea in patients with far-advanced lung disease: “once I lose it, it’s kind of hard to catch it...”. *JAMA*. 2001;285(10):1331-1337.
- 2 Ben-Aharon I, Gafter-Gvili A, Paul M, Leibovici L, Stemmer SM. Interventions for alleviating cancer-related dyspnea: a systematic review. *J Clin Oncol*. 2008;26(14):2396-2404.
3. Roberts DK, Thorne SE, Pearson C. The experience of dyspnea in late-stage cancer. Patients’ and nurses’ perspectives. *Cancer Nurs*. 1993;16(4):310-320.

**From peace data:** Pilot testing of the related dyspnea measure from the PEACE project revealed that only 78% of 126 hospice patients were screened for dyspnea, and of these, only 45% of those who screened positive received treatment within 24 hours. Pilot testing in the seriously ill patient population in the hospital showed that 95% of 562 patients were screened for dyspnea and 94% of those who screened positive received treatment within 24 hours.

Dyspnea screening and assessment are necessary to detect the presence of dyspnea (for which physical signs such as hypoxia and tachypnea do not clearly correlate) and to understand its severity and underlying etiology. Evidence-based treatment of dyspnea will vary depending on the symptom’s severity and etiology, with treatment options differing for causes such as malignant pleural effusion, bulky tumor mass, congestive heart failure, anemia, and chronic obstructive pulmonary disease, among others. Additional guidelines from the American College of Physicians recommend dyspnea screening and assessment. Additional evidence includes numerous systematic reviews.

- (a) Dyspnea is a highly prevalent, distressing, and functionally limiting symptom common to many serious illness conditions, and its relief is an important priority for patients and families (per prospective observational studies).
- (b) Strong evidence supports the effectiveness of medical treatment for dyspnea in cases of cancer and other serious illnesses to improve dyspnea outcomes (per randomized clinical trials).

## Comments from CUP

“Dyspnea Screening and Management” is a better dyspnea measure because it includes the screening and the treatment. There’s a much broader denominator in the current “Dyspnea Screening and Management” measure, and could also be used in a physician’s office.

# DOMAIN 3: PSYCHOLOGICAL AND PSYCHIATRIC ASPECTS OF CARE (1 measure)

## MEASURE 5: DISCUSSION OF EMOTIONAL OR PSYCHOLOGICAL NEEDS

Source: PEACE subset (Hanson, 2012), <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

### Measure Description

Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting for longer than 1 day or patients enrolled in hospice for longer than 7 days with chart documentation of a discussion regarding emotional or psychological needs.

### Evidence/Rationale

Research on care of patients nearing the end of life shows they experience high rates of physical, emotional, and spiritual causes of distress.<sup>1,2</sup> The National Priorities Partnership has identified palliative and end-of-life care as one of its national priorities. A goal of this priority is to ensure that all patients with life-limiting illness have access to effective treatment for symptoms such as pain and shortness of breath.<sup>3</sup> In 2009, 1.56 million people with life-limiting illness received hospice care.<sup>4</sup> In 2008, 58.5% of US hospitals with 50 or more beds had some form of palliative care service.<sup>5</sup>

**Guideline citation:** The interdisciplinary team assesses and addresses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.<sup>6</sup>

- Based on the patient's and family's goals of care, interventions include assessing psychological needs, treating psychiatric diagnoses, and promoting adjustment to the physical condition or illness.
- Regular, ongoing assessment of psychological reactions related to the illness (including, but not limited to, stress, coping strategies, and anticipatory grieving) and psychiatric conditions is documented. Whenever possible and appropriate, a validated and context-specific assessment tool is used.
- Psychological assessment and treatment includes patient and family education about the disease or condition, symptoms, side effects, and treatments, as well as caregiving needs, decision-making capacity, and coping strategies.
- The interdisciplinary team effectively treats psychiatric diagnoses, such as depression, suicidal ideation, anxiety, and delirium, whether a consequence of the illness or occurring in patients with comorbid psychiatric illness in addition to other serious or life-threatening illness.<sup>7(p22)</sup>

### References

1. Connors AF, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274(20):1591-1598.
2. Gade G, Venohr I, Conner D, et al. Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med*. 2008;11(2):180-190.
3. National Quality Forum. National Priorities Partnership and the National Quality Strategy. National Quality Forum website. [https://www.qualityforum.org/Setting\\_Priorities/NPP/Input\\_into\\_the\\_National\\_Quality\\_Strategy.aspx](https://www.qualityforum.org/Setting_Priorities/NPP/Input_into_the_National_Quality_Strategy.aspx). Accessed May 22, 2014.
4. National Hospice and Palliative Care Organization. *NHPCO Facts and Figures: Hospice Care in America*. Alexandria, VA: Author; 2010.
5. Palliative care programs continue rapid growth in US hospitals [press release]. New York, NY: Center to Advance Palliative Care; April 6, 2010. <http://www.capc.org/news-and-events/releases/04-05-10>
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## Comments from CUP

Although this measure is somewhat low-bar, we have some domains with no measures at all, so we wouldn't want to lose measures if we have nothing to replace them. In addition, even though it's a low floor, it's still not being done; it's very hard to find chart documentation in these areas.

## DOMAIN 4: SOCIAL ASPECTS OF CARE (No measures in this domain)

## DOMAIN 5: SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE (1 measure)

### MEASURE 6: DISCUSSION OF SPIRITUAL/RELIGIOUS CONCERNS

**Source:** National Quality Forum #1647/Deyta, LLC, [http://www.qualityforum.org/Projects/Palliative\\_Care\\_and\\_End-of-Life\\_Care.aspx#t=2&s=&p=3%7C](http://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx#t=2&s=&p=3%7C)<sup>1</sup>

#### Measure Description

Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual and religious concerns or documentation that the patient or caregiver did not want to discuss these issues.

#### Measure Details

Examples of a discussion may include asking about the patient's need for spiritual or religious support or posing questions about the cause or meaning of illness or death. Other examples include a discussion about God or a higher power as they relate to the illness or offering a spiritual resource, including a chaplain. Discussion of spiritual or religious concerns may occur between the patient and family and a member of the clergy or a pastoral worker or between the patient and family and a member of the interdisciplinary team. Documentation of only the patient's religious or spiritual affiliation does not count for inclusion in numerator.

Data are collected via chart review. Criteria are

1. evidence of a discussion about spiritual and religious concerns, or
2. evidence that the patient or family declined to engage in a conversation on this topic.

Evidence may be found in the initial screening and assessment, comprehensive assessment, update assessments across the entire period of care, visit notes documented by any member of the team, or the spiritual care assessment. Note that these are examples and not a complete list.

#### Evidence/Rationale

Research on care of patients nearing the end of life shows they experience high rates of physical, emotional, and spiritual causes of distress.<sup>1,2</sup>

**Guideline citation:** The interdisciplinary team assesses and addresses the spiritual, religious, and existential dimensions of care.<sup>3(p26)</sup>

Hospice care is an increasingly important piece of the healthcare continuum, both in terms of the number of patients served and the financial benefits (eg, reducing costs associated with end-of-life care and rehospitalizations for home healthcare and hospitals). According to the National Hospice and Palliative Care Organization's *Facts and Figures* (2010), more than 1.5 million patients received services from approximately 5,000 hospices throughout the United States.

Spiritual care has been shown to be a critical element of quality of life at the end of life. This measure is in accordance with the *Clinical Practice Guidelines for Quality Palliative Care*, guideline 5.1, and the National Quality Forum-endorsed preferred practice #20.<sup>3,4</sup>

One of the unique aspects of hospice care involves a true interdisciplinary approach, providing care for the physical, psychosocial, and spiritual needs of the patient and caregiver. Discussion of spiritual concerns is the core of a rigorous assessment of spiritual care needs and is essential to ensuring that these needs are met. This measure will help agencies improve processes for addressing spiritual and religious concerns with patients receiving hospice care and their families.

Comparative data for this measure is limited throughout the industry. Data for this measure comes solely from participation in Deyta's proprietary system, Quality Navigator, but could be obtained from other sources. Participants include hospices with varied characteristics for a representative sample of the industry; characteristics included for-profit and not-for-profit status, single and large multilocation agencies, small (ADC < 50) to very large (> 1000) size, representation of multiple regions of the country, and the use of an electronic health record or paper documentation. Deyta, LLC, has been capturing data for this measure in the Quality Navigator since December 2008. In addition to enabling individual hospices to compare and trend their own performance, comparative benchmarking is available for the more than 100 hospice agencies participating in this measure. Patient-level data from 13,435 records were used for the testing for 2009 and 2010.

**Link to Outcomes:** In response to the National Quality Forum committee's questions about how this proposed measure may relate to measurable outcomes, we conducted some additional data analysis. In addition to the data described in this measure submission, Deyta's Quality Navigator also offers clients the ability to capture, track, and trend data on the intensity of spiritual distress—a measurable outcome related to spiritual care. We conducted an analysis of a subset of the 2009 and 2010 records that were used for this measure submission to determine whether patients who had documentation of a spiritual discussion were more likely to have improved spiritual distress scores (with distress scores measured as no distress, mild, moderate, or severe and improvement defined as a decrease of at least one level in the distress score) than patients who did not have documentation of a spiritual discussion. Data were retrospectively abstracted by trained personnel at each of the agencies and submitted to Deyta's system for trending and reporting. Patient records were abstracted from agencies that utilize both spiritual care measures. Records were excluded when patients reported that they were not experiencing any spiritual distress or because of missing data (ie, patient was unable to report at least one spiritual distress score while on service). A total of 652 records were included in the analysis.

The findings revealed that a greater proportion of patients who had documentation of a spiritual discussion (63%) showed improvement in their spiritual distress scores than patients who did not have a documented spiritual discussion (48%). These findings help support the importance of the spiritual discussion and the existence of a relationship between the occurrence of the spiritual discussion and reduction in spiritual distress scores.

Documentation of spiritual discussion; improvement in spiritual distress score: 330 (63%)

Documentation of discussion; no improvement in distress score: 194 (37%)

No documentation of discussion; improvement in distress score: 62 (48%)

No documentation of discussion; no improvement in distress score: 62 (52%)

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## Comments from CUP

Eventually, we'd like to broaden the denominators of measures limited to only hospice, but for now, we're recommending the measures as they're specified.

## DOMAIN 6: CULTURAL ASPECTS OF CARE (no measures in this domain)

## DOMAIN 7: CARE OF THE PATIENT AT THE END OF LIFE (1 of 2 measures)

### MEASURE 7: PROPORTION ADMITTED TO HOSPICE FOR LESS THAN 3 DAYS

**Source:** National Quality Forum #0216/American Society of Clinical Oncology, [http://www.qualityforum.org/Projects/Cancer\\_Endorsement\\_Maintenance\\_2011.aspx#t=2&s=&p=2%7C3%7C](http://www.qualityforum.org/Projects/Cancer_Endorsement_Maintenance_2011.aspx#t=2&s=&p=2%7C3%7C)

#### Measure Description

Percentage of patients who died from cancer and who were admitted to and spent fewer than 3 days in hospice.

#### Measure Details

Numerator—Patients who died from cancer and spent fewer than 3 days in hospice

Denominator—Patients who died from cancer who were admitted to hospice

#### Evidence/Rationale

Earlier referral and admission to hospice allows patients to derive maximal benefit from it.

A structural feature: Regional availability of hospice has been shown to correlate with a composite measure of the aggressiveness of cancer care near the end of life that contains this measure. Mostly it is a process measure indicating a possible, inadequate focus on palliation and supportive care that can affect quality of life.

The process-outcome link is that early admission to hospice, which focuses on improving quality of life, is not associated with a detriment to survival.<sup>1</sup>

In the National Institutes of Health-funded Cancer Care Outcomes Research and Surveillance Consortium, bereaved family members of 706 patients with lung and colorectal cancer rated the quality of the end-of-life care their loved one had received. Adjusted for age, sex, marital status, income, education, stage, comorbidity, health system type, census region, and the respondent's relationship to the patient, respondents were significantly more likely to rate the end-of-life care to have been very good or excellent (86.1% vs 75.4%), having no unmet need for help with anxiety or depression (86.4% vs 78.1%), and that the patient died in his or her preferred location (77.3% vs 56.3%) if they had spent longer than 3 days in hospice before death (Landrum MB, et al, under review).

Because the studies are observational and use administrative data, there are limitations to the quality of the data. Still, the sensitivity in claims is 0.97, specificity 1.00, accuracy 0.97 and variability 2.39 (95% CI, 1.99-2.95).<sup>2</sup>

The argument is made that because providers cannot predict the future, measures based on decedent cohorts are unfair. However, as described above, the idea is for the measure to be seen as an overall indication of practice style or available palliative resources. An individual patient experiencing this process of care has not necessarily received poor-quality care. If explanations other than practice style and resource availability, such as unusually poor prognostic ability on the part of the provider or unexpected toxic deaths (whether unavoidable or from overly aggressive treatment or poor patient selection) are enough to influence the overall aggregate rates, it is still justifiable to consider it a red flag that should prompt examination of the care provided.

The underlying evidence was obtained by expert consensus, as described by Earle, Park, and colleagues.<sup>3</sup> The panel consisted of oncologists, nurses, palliative care specialists, and others, and used a modified Delphi process to evaluate the measures.

Although this does not take patient preferences into account when operationalized as a claims-based measure, the idea is for the measure to be seen as an overall indication of practice style or available palliative resources. An individual patient experiencing this process of care has not necessarily received poor-quality care, but unless there is a reason to think that the patient population in one setting has a significantly greater proportion of individuals with differing preferences, aggregate rates of the measure justifiably can be compared across settings. In this way, it is a reflection of the quality of end-of-life care.

Results from the National Hospice and Palliative Care Organization's Family Evaluation of Hospice Care survey, reported in 2005, show that 10.8% of 29,292 surveys reported lengths of stay of 2 or fewer days after admission to hospice. Other sources have shown that up to 28% of patients stay fewer than 7 days. The US Government Accountability Office has noted that with Medicare, more beneficiaries use hospice, but use it for fewer days of care.<sup>4</sup> When surveyed, most family and staff stated that patients are not being admitted to hospice with enough time for care to be most effective.<sup>5</sup> Short admissions to hospice amount to simply managing death without allowing for the full palliative benefit of hospice care. It is interesting to note that oncology medical textbooks have been found to be more likely to have no coverage of end-of-life issues than other specialties.<sup>6</sup>

**NOTE:** This measure is not intended to identify a "never" event. Rather, if this is happening more frequently than in comparable practices, it may indicate a quality problem related to such things as communication, patient-centered decision making, or the availability of supportive end-of-life services in the practice setting.

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## Comments from CUP

When we talk about utilization, we need to stress that this matters to patients and families and also to payers. (Does it matter if patients spend extra time in the intensive care unit? Yes it matters to patients and to payers.) The “3 Days in Hospice” measure speaks to utilization review (UR)—if patients spend more time in hospice, they’re using fewer hospital and intensive care unit resources. What we hope is that this measure would be used at the system level. What we would hope for, from the patient perspective, is shared accountability.

# DOMAIN 7: CARE OF THE PATIENT AT THE END OF LIFE (2 of 2 measures)

## MEASURE 8: PROPORTION WITH MORE THAN ONE EMERGENCY ROOM VISIT IN THE LAST DAYS OF LIFE

**Source:** National Quality Forum #0211/American Society of Clinical Oncology, [http://www.qualityforum.org/Projects/Cancer\\_Endorsement\\_Maintenance\\_2011.aspx#t=2&s=&p=2%7C3%7C](http://www.qualityforum.org/Projects/Cancer_Endorsement_Maintenance_2011.aspx#t=2&s=&p=2%7C3%7C)

### Measure Description

Percentage of patients who died from cancer having more than one emergency room visit in the last 30 days of life.

### Measure Details

Numerator—patients who died from cancer and had more than one emergency room visit in the last 30 days of life

Denominator—patients who died from cancer

### Evidence/Rationale

Decreases in the number of emergency room visits would improve quality of life and save resources. Less emergency room utilization can indicate a better quality of life, advance care planning, and result in resource savings. Multiple emergency room visits near the end of life may indicate inadequate attention to symptoms.

A structural feature: Regional availability of hospice has been shown to correlate with a composite measure of the aggressiveness of cancer care near the end of life that contains this measure. Mostly it is a process measure indicating a possible, inadequate focus on palliation and supportive care that can affect quality of life.

The argument is made that because providers cannot predict the future, measures based on decedent cohorts are unfair. However, as described above, the idea is for the measure to be seen as an overall indication of practice style or available palliative resources. An individual patient experiencing this process of care has not necessarily received poor-quality care. If explanations other than practice style and resource availability, such as unusually poor prognostic ability on the part of the provider or unexpected toxic deaths (whether unavoidable or from overly aggressive treatment or poor patient selection) are enough to influence the overall aggregate rates, it is still justifiable to consider it a red flag that should prompt

examination of the care provided.

The underlying evidence was obtained by expert consensus, as described by Earle CC et al.<sup>1</sup> The panel consisted of oncologists, nurses, palliative care specialists, and others, and used a modified Delphi process to evaluate measures.

Although this does not take patient preferences into account when operationalized as a claims-based measure, the idea is for the measure to be seen as an overall indication of practice style and available palliative resources. An individual patient experiencing this process of care has not necessarily received poor-quality care, but unless there is a reason to think that the patient population in one setting has a significantly greater proportion of individuals with differing preferences, aggregate rates of the measure justifiably can be compared across settings. In this way it is a reflection of the quality of end-of-life care.

**NOTE:** This measure is not intended to identify a “never” event. Rather, if this is happening more frequently than in comparable practices, it may indicate a quality problem related to such things as communication, patient-centered decision making, or the availability of supportive end-of-life services in the practice setting.

## Reference

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## Comments from CUP

Important measure.

# DOMAIN 8: ETHICAL AND LEGAL ASPECTS OF CARE (1 of 3 measures)

## MEASURE 9: DOCUMENTATION OF SURROGATE

**Source:** PEACE subset (Hanson, 2012), <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

### Measure Description

The percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting for longer than 1 day or patients enrolled in hospice for longer than 7 days with the name and contact information for the patient’s surrogate decision maker in the chart or documentation that there is no surrogate.

### Evidence/Rationale

This measure addresses patient autonomy for patients with a high severity of illness and risk of death, including seriously and incurably ill patients enrolled in hospice or hospital-based palliative care. The National Priorities Partnership has identified palliative and end-of-life care as one of its national priorities. A goal of this priority is to ensure that all patients with life-limiting illness have the right to express preferences that guide the use of invasive or life-sustaining forms of treatment.<sup>1</sup> Patients who are unable to articulate their treatment preferences need an identified surrogate to act on their behalf to fulfill this objective. The affected populations are large; in 2009, 1.56 million people with life-limiting illness received hospice care.<sup>2</sup> In 2008, 58.5% of US hospitals with 50 or more beds had some form of palliative care service, and national trends show steady expansion of these services.<sup>3</sup>

Patients and family caregivers rate control over treatment decisions as a high priority when living with serious and

life-limiting illnesses.<sup>4</sup> The findings of systematic review of clinical trials provide moderate evidence supporting multicomponent interventions to increase advance directives and “care planning through engaging values, involving skilled facilitators, and focusing on key decision makers.” These studies found improved outcomes of patient-physician communication, improved satisfaction with care, and increased hospice enrollment.<sup>5</sup> The Coping with Cancer Study, a prospective observational study of more than 300 patients with advanced cancer, found that communication of patient treatment preferences was associated with the use of treatments honoring those preferences and less use of aggressive, high-cost treatments.<sup>6,7</sup> Patients who are unable to articulate their treatment preferences need an identified surrogate to act on their behalf to fulfill this objective.

**Guideline citation:** The patient’s or surrogate’s goals, preferences, and choices are respected within the limits of applicable state and federal laws, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.<sup>8(p32)</sup>

## References

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5. Lorenz KA, Lynn J, Dy SM, et al. Evidence for improving palliative care at the end of life: a systematic review. *Ann Intern Med*. 2008;148(2):147-159.
6. Wright AA, Mack JW, Kritek PA, et al. Influence of patients’ preferences and treatment site on cancer patients’ end of life care. *Cancer*. 2010;116(19):4656-4663.
7. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673.
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Seriously ill and dying patients who are given the opportunity to express life-sustaining treatment preferences are more likely to receive care consistent with their values; this practice also improves patient and family satisfaction outcomes. Patients who are unable to articulate their treatment preferences need an identified surrogate to act on their behalf to fulfill this objective. Patients and physicians alike hesitate to initiate discussions, although acknowledging their value and desirability. Use of the “Documentation of Surrogate” quality measure will improve attention to this important practice to enhance patient autonomy, facilitate patient-centered decision making, and allow for the communication of patient preferences via documentation to other treating providers.

## Comments from CUP

The “Documentation of Surrogate” measure would not be applicable for pediatric patients because the surrogate is always the parent or legal guardian. Pediatric programs do take care of adults age 18 years and older, but this measure may not be important to children under 18.

# DOMAIN 8: ETHICAL AND LEGAL ASPECTS OF CARE

## (2 of 3 measures)

### MEASURE 10: TREATMENT PREFERENCES

**Source:** National Quality Forum # 1641/PEACE Measure Set/Hospice Item Set, <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

#### Measure Description

The percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting for longer than 1 day or patients enrolled in hospice for longer than 7 days with chart documentation of preferences for life-sustaining treatments. Documentation should reflect patient self-report; if not available, a discussion with the surrogate decision maker or review of the patient's advance directive documents is acceptable. This item is meant to capture evidence of discussion and communication. Therefore, "full code" (FC) or "do not resuscitate/do not intubate" (DNR/DNI) do not count by themselves.

#### Measure Details

This quality measure is intended for patients with serious illness who are enrolled in hospice care or who are receiving specialty palliative care in an acute hospital setting. Conditions may include, but are not limited to, cancer, heart disease, pulmonary disease, dementia and other progressive neurodegenerative diseases, stroke, HIV/AIDS, and advanced renal or hepatic failure.

#### Evidence/Rationale

This measure addresses patient autonomy for patients with a high severity of illness and risk of death, including seriously and incurably ill patients enrolled in hospice or hospital-based palliative care. The National Priorities Partnership has identified palliative and end-of-life care as one of its national priorities. A goal of this priority is to ensure that all patients with life-limiting illness have the right to express preferences that guide the use of invasive or life-sustaining forms of treatment.<sup>1</sup> The affected populations are large; in 2009, 1.56 million people with life-limiting illness received hospice care.<sup>2</sup> In 2008, 58.5% of US hospitals with 50 or more beds had some form of palliative care service, and national trends show steady expansion of these services.<sup>3</sup>

Patients and family caregivers rate control over treatment decisions as a high priority when living with serious and life-limiting illnesses.<sup>4</sup> From a systematic review of clinical trials, moderate evidence supports multicomponent interventions to increase advance directives and "care planning through engaging values, involving skilled facilitators, and focusing on key decision makers." These studies found improved outcomes of patient-physician communication, improved satisfaction with care, and increased hospice enrollment.<sup>5</sup> The Coping with Cancer Study, a prospective observational study of more than 300 patients with advanced cancer, found that communication of patient treatment preferences was associated with the use of treatments honoring those preferences and with less use of aggressive, high-cost treatments.<sup>6,7</sup>

**Guideline citation:** The patient's or surrogate's goals, preferences, and choices are respected within the limits of applicable state and federal laws, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.<sup>8(p32)</sup>

#### References

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Seriously ill and dying patients who are given the opportunity to express life-sustaining treatment preferences are more likely to receive care consistent with their values; this practice also improves patient and family satisfaction outcomes. Patients and physicians alike hesitate to initiate discussions, although acknowledging their value and desirability. Use of the “Treatment Preferences” quality measure will improve attention to this important practice to enhance patient autonomy, facilitate patient-centered decision making, and allow for the communication of patient preferences via documentation to other treating providers.

**Performance gap:** Poor communication about patient preferences has been identified as a major quality concern in palliative and end-of-life care since a comprehensive Institute of Medicine report.<sup>1</sup> The SUPPORT Study found marked discrepancies between patients' reports of treatment preferences and providers' awareness of and use of these preferences to guide treatment.<sup>2</sup> Patients and families prioritize communication with providers and control over treatment choices when faced with serious or life-threatening illness.<sup>3</sup> However, physicians and other providers fail to open the door to these discussions at critical time points in illness progression.<sup>4</sup> A systematic review of communication research found a consistent discrepancy between the quality and content of communication providers believed they provided and the quality and content of communication experienced by seriously ill patients and their families.<sup>5</sup>

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**Link to Outcome:** The “Treatment Preferences” quality measure addresses a key process—eliciting and documenting patient treatment preferences—with evidence linking it to outcomes of patient autonomy and control over treatments, patient and family satisfaction with care, improved transitions to hospice and palliative care, and reduced emotional distress for surviving family members. There is broad legal and ethical consensus that the treatment of seriously ill and dying patients should be guided by their values and preferences regarding life-sustaining treatments.<sup>1</sup> Failure to elicit and communicate these preferences can result in an intermediate outcome of treatment that is contradictory to patients' and families' values, in turn decreasing patient and family satisfaction. If patients die without adequate opportunities for treatment guided by their own preferences, families report markedly greater emotional distress following the death.

A systematic review found evidence of poor-quality communication but limited evidence for its relationship to outcomes.<sup>2</sup> However, an updated systematic review by the same investigators found moderate evidence to support multicomponent

interventions to increase advance directives and for care planning through engaging values, with improved rates of hospice use, reduced numbers of intensive care unit days, and enhanced quality of patient-provider communication.<sup>3</sup> More targeted trials that enhance the frequency and quality of communication have positive effects, including treatment consistent with preferences, reduced family distress, and improved comprehension as well as decreased use of intensive treatments without adverse effects on mortality.<sup>4,5</sup>

In addition to this direct evidence, some indirect evidence supports the link between enhanced communication about treatment preferences in palliative care interventions and improved patient and family outcomes. One systematic review of specialized palliative care covering heterogeneous complex clinical interventions, which included communication of treatment preferences, found a small number of interventions resulted in improved quality of life and family satisfaction with care, but concluded that future trials needed improved methodological rigor.<sup>6</sup> Several subsequent palliative care clinical trials and two observational studies have added evidence that these complex interventions, which included enhanced clinical communication about treatment preferences as a key component, are associated with enhanced attention to patient autonomy, improved satisfaction with care, and fewer high-cost life-sustaining treatments, and these benefits accrued without adverse effects on mortality.<sup>7-12</sup>

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## Comments from CUP

Important measure.

# DOMAIN 8: ETHICAL AND LEGAL ASPECTS OF CARE

## (3 of 3 measures)

### MEASURE 11: TREATMENT PREFERENCES FOLLOWED

Source: ACOVE Measure Set, <http://www.rand.org/health/projects/acove/acove3.html>

#### Measure Description

If a vulnerable elder has documented treatment preferences to withhold or withdraw life-sustaining treatment (eg, a do-not-resuscitate order, no tube feeding, no hospital transfer), then these treatment preferences should be followed.

#### Measure Details

The Assessing Care of Vulnerable Elders (ACOVE) project is a collaboration between RAND Health and Pfizer Inc. to develop a living set of quality indicators (QIs) for the medical care provided to vulnerable older persons. The ACOVE QIs aim to measure care for ill older patients, conceptualized as “vulnerable elders.” These are community dwelling individuals age 65 years and older who are at greater risk of death or functional decline over a 2-year period.

#### Evidence/Rationale

Patients and family caregivers rate control over treatment decisions as a high priority when living with serious and life-limiting illnesses.<sup>1</sup> A systematic review of clinical trials found moderate evidence supporting multicomponent interventions to increase advance directives and “care planning through engaging values, involving skilled facilitators, and focusing on key decision makers.” These studies found improved outcomes of patient-physician communication, improved satisfaction with care, and increased hospice enrollment.<sup>2</sup> The Coping with Cancer Study, a prospective observational study of more than 300 patients with advanced cancer, found that communication of patient treatment preferences was associated with the use of treatments honoring those preferences and with less use of aggressive, high-cost treatments.<sup>3,4</sup>

**Guideline citation:** The patient or surrogate’s goals, preferences, and choices are respected within the limits of applicable state and federal laws, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.<sup>5(p32)</sup>

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Seriously ill and dying patients who are given the opportunity to express life-sustaining treatment preferences are more likely to receive care consistent with their values; this practice also improves patient and family satisfaction outcomes. Patients and physicians alike hesitate to initiate discussions, although acknowledging their value and desirability. Use of the “Treatment Preferences Followed” quality measure will improve attention to this important practice to help enhance patient autonomy, facilitate patient-centered decision making, and allow for the communication of patient preferences via documentation to other treating providers.

**Performance gap:** Poor communication about patient preferences has been identified as a major quality concern in palliative and end-of-life care since a comprehensive Institute of Medicine report.<sup>1</sup> The SUPPORT Study found marked discrepancies between patients' reports of treatment preferences and providers' awareness of and use of these preferences to guide treatment.<sup>2</sup> Patients and families prioritize communication with providers and control over treatment choices when faced with serious or life-threatening illness.<sup>3</sup> However, physicians and other providers fail to open the door to these discussions at critical time points in illness progression.<sup>4</sup> A systematic review of communication research found a consistent discrepancy between the quality and content of communication providers believed they provided and the quality and content of communication experienced by seriously ill patients and their families.<sup>5</sup>

## References

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## Comments from CUP

Outcome measure.

## GLOBAL MEASURE (1 measure)

### MEASURE 12: THE FAMILY EVALUATION OF PALLIATIVE CARE (FEPC)

**Source:** National Hospice and Palliative Care Organization, <http://www.nhpc.org/performance-measures/family-evaluation-palliative-care-fepc>

#### Measure Description

The Family Evaluation of Palliative Care (FEPC) is a post-death survey that captures family members' perceptions about the quality of the palliative care their loved ones received—whether that care was provided by a hospital-based consult service or by a hospice program offering palliative care. The questions on the FEPC survey are based on those in the Family Evaluation of Hospice Care (FEHC) survey, with wording modifications appropriate to palliative care service delivery.

#### Measure Details

The FEPC survey provides two basic categories of information. The first is descriptive in nature and includes demographic information such as the patient's age and primary diagnosis and whether the patient experienced symptoms such as pain, difficulty breathing, and anxiety. The second category encompasses aspects of the quality of care delivery in areas such as care coordination, symptom management, and the provision of information. These results are indicators for how well the palliative care program is performing and reflect areas that can be used for quality assessment and improvement activities.

The surveys are mailed to family members of deceased patients. The National Hospice and Palliative Care Organization recommends mailing the survey 1 to 3 months following the patient's death. When surveys are returned, data submission can begin.

## Evidence/Rationale

Opportunities to improve the effectiveness, efficiency, and accountability of programs providing palliative care should be considered as a vehicle to improve outcomes and access, increase satisfaction, and reduce administrative and clinical inefficiencies. The FEPC offers programs a valuable opportunity to receive feedback and compare their performance with nationally representative data. The FEPC survey provides useful, meaningful, and actionable data, thereby furnishing palliative care programs with a valid means of ensuring quality of care.

About the FEHC, upon which the FEPC is based: Measure focus is a health outcome that reflects the patient's and family caregiver's experience of hospice care. Because the measure is a composite/global measure of hospice care, multiple intermediate clinical outcomes and hospice care processes are linked in the areas of symptom management, communication, the provision of information, emotional support, and care coordination. The survey that serves as the data source for the measure is based on a conceptual model of patient-focused, family-centered medical care. This model was developed based on expert advice, a structured review of guidelines, and focus groups with bereaved family members.

More about the FEHC, upon which the FEPC is based: The model was developed by Dr. Joan Teno and colleagues at Brown University as part of a larger research project and mortality follow back study that examined the quality of end-of-life care in multiple care settings. The model posits that high-quality care at the end of life is obtained when healthcare institutions a) provide the desired level of symptom palliation and emotional support, b) treat the patient with respect, c) promote shared decision making, d) attend to the needs of caregivers for information and skills in providing care for the patient, e) provide emotional support to the family before and after the patient's death, and e) coordinate care across settings of care and healthcare providers. The model was developed based on advice from a panel of experts in end-of-life care, a structured review of existing guidelines for the provision of end-of-life care, and analysis of data from focus groups conducted with bereaved family members. This model serves as the conceptual framework for the FEHC survey, which is the data source for the measure. The measure also is consistent with the domains delineated in the National Quality Forum consensus report titled *A National Framework and Preferred Practices for Palliative and Hospice Care Quality*, endorsed by the National Quality Forum in 2006.

## Comments from CUP

FEPC seems a better, more inclusive instrument for the global surveys we reviewed. Anything we recommend in this domain is ultimately a placeholder until something better comes along. The more important thing is to use a survey of any kind. Therefore, we're strongly endorsing the concept, but the tool may change.