

ENDORSEMENT SUMMARY:

Palliative Care and End-of-Life Care Measures

FEBRUARY 2012

Purpose of the Project

Estimates show that by 2030, there will be 72 million older persons in the United States, more than twice the number in 2000. Accordingly, the healthcare community has in recent years increasingly focused its attention on the quality and availability of palliative and end-of-life care services – both for acutely ill patients and older adults with life-limiting diseases. This number of palliative care programs in hospitals, for example, has more than doubled in the last decade.

Palliative and end-of-life care programs help improve care quality throughout the course of a patient's illness. Specifically, patients tend to be more satisfied with their overall care and communication with their providers, and they are less likely to end up in intensive care units and emergency departments. Furthermore, providers are increasingly referring patients to hospice care to ease suffering and better manage pain at the end of life.

Despite the evidence for and support around palliative and end-of-life care, these services are still underused. More than one million people each year who, studies indicate, could have benefited from hospice care die without receiving it. Palliative and end-of-life care performance measures that can assess the quality of care for older adults and acutely ill patients are needed to track improvement in this critical area.

NQF has previously endorsed performance measures related to symptom management and end-of-life care, focused solely on cancer patients. In April 2011, NQF – at the request of the Department of Health and Human Services – began a project focused on identifying, endorsing, and updating a broader set of palliative and end-of-life care performance measures. Specifically, the project sought to endorse measures that addressed:

- Assessment and management of conditions and symptoms in patients, including pain, dyspnea, weight loss, weakness, nausea, serious bowel problems, delirium, and depression;
- Patient- and family-centered palliative and hospice care focused on psychosocial needs and care transitions; and
- Patient, caregiver, and family experiences of care.

The resulting endorsed measures begin to further address palliative and end-of-life care delivery, and will help providers ensure older adults and acutely ill patients receive the high quality care they deserve.

What Was Endorsed

Table 1: Summary of Palliative Care and End-of-Life Care Endorsement Maintenance Measures Project

Measure submitted for consideration	22
Measures withdrawn by the developer for more testing and further refinement	7
Measures recommended for endorsement	14
Measures not recommended for endorsement	1

Under the palliative and end-of-life care endorsement project, NQF endorsed 14 measures suitable for accountability and quality improvement. Of the 14 measures, two were previously endorsed and granted continued endorsement status, and 12 were newly submitted measures.

Measure stewards included a range of healthcare stakeholders, including the National Hospice and Palliative Care Organization; the



University of North Carolina-Chapel Hill; RAND Corporation; the Center for Gerontology and Health Care Research; Deyta; and PROMISE Center. A full list of measures is available at the end of this report.

The Need these Measures Fill

This project sought to identify and endorse measures that specifically address palliative and end-of-life care services for accountability and quality improvement. The resulting measures focus on a wide range of care processes, including pain screening and management for patients in hospital and palliative care settings; documenting treatment preferences for patients admitted to intensive care units; documenting patient preferences for life sustaining treatments in hospice and palliative care settings; and evaluating family satisfaction with the quality of care provided following a patient's death.

As the number of palliative and end-of-life care programs continue to grow across the country, it is critical that providers have the right measurement tools to help ensure patients receive safe, high-quality, and compassionate care. Considering that palliative and end-of-life care is a relatively new field of measurement, these measures provide a solid foundation for measuring and improving care quality.

Potential Use

These measures are applicable for use in a range of clinical settings and providers, which will help improve quality across the healthcare spectrum. Settings include acute care hospitals, hospices, and intensive care units.

Project Perspectives

As the number of older adults in the United States continues to increase, palliative and end-of-life care services – not to mention metrics for evaluating the quality of such care – are more important than ever. Measuring palliative and end-of-life care quality is relatively new territory; in fact, healthcare stakeholders are just now beginning to define what end-of-life care quality really means, and palliative care units in hospitals didn't even exist until a few years ago. With this set of endorsed measures, NQF has taken significant strides towards advancing higher-quality care for gravely ill patients and people at the end of life.

Throughout the course of the project, NQF identified several areas where further work is needed to more fully address care quality concerns for palliative and end-of-life care patients. Notably, more outcomes measures – measures that evaluate actual results of care – are needed; these are considered most relevant to providers looking to improve care delivery and families looking to choose the best programs to meet the needs of their loved ones. Additionally, measures that evaluate patient care across the continuum, as well as measures that assess how well providers address and integrate patient preferences into treatment plans, are needed to ensure patients receive and are satisfied with higher-quality care. Finally, a significant measure gap exists around measures specifically focused on children receiving palliative or end-of-life care services.

Endorsed Measures

1634: Hospice and Palliative Care- Pain Screening (UNC) (paired with measure 1637)

Description: Percentage of hospice or palliative care patients who were screened for pain during the hospice admission evaluation/palliative care initial encounter.

1637: Hospice and Palliative Care – Pain Assessment (UNC) (paired with measure 1634)

Description: Percentage of hospice or palliative care patients who screened positive for pain and who received a clinical assessment of pain within 24 hours of screening.

1617: Patients treated with an Opioid who are given a bowel regimen (RAND)

Description: Percentage of vulnerable adults treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed.

1628: Patients with advanced cancer assessed for pain at outpatient visits (RAND)

Description: Adult patients with advanced cancer who have an assessment of pain with a standardized quantitative tool at each outpatient visit.

1638: Hospice and Palliative Care- Dyspnea Treatment (UNC) (paired with measure 1639)

Description: Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening.

1639: Hospice and Palliative Care – Dyspnea Screening (UNC) (paired with measure 1638)

Description: Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation / palliative care initial encounter.

1626: Patients admitted to the ICU who have care preferences documented (RAND)

Description: Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done.

1641: Hospice and Palliative Care- Treatment Preferences (UNC)

Description: Percentage of patients with chart documentation of preferences for life sustaining treatments.

1647: Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss (Deyta)

Description: Percentage of hospice patients with documentation of a discussion of spiritual/religious concerns or documentation that the patient/caregiver/family did not want to discuss.

0209: Comfortable dying (NHPCO) (maintenance)

Description: Number of patients who report being uncomfortable because of pain at the initial assessment (after admission to hospice services) who report pain was brought to a comfortable level within 48 hours.

1625: Hospitalized patients who die an expected death with an ICD that has been deactivated (RAND)

Description: Percentage of hospitalized patients who die an expected death from cancer or other terminal illness and who have an implantable cardioverter-defibrillator (ICD) in place at the

time of death that was deactivated prior to death, or there is documentation why it was not deactivated

0208: Family Evaluation of Hospice Care (NHPCO) (maintenance)

Description: Composite Score: Derived from responses to 17 items on the Family Evaluation of Hospice Care (FEHC) survey presented as a single score ranging from 0 to 100. Global Score: Percentage of best possible response (Excellent) to the overall rating question on the FEHC survey. Target Population: The FEHC survey is an after-death survey administered to bereaved family caregivers of individuals who died while enrolled in hospice. Timeframe: The survey measures family members perception of the quality of hospice care for the entire enrollment period, regardless of length of service.

1632: CARE- Consumer Assessments and Reports of End of Life (Center for Gerontology and Health Care Research)

Description: The CARE survey is a mortality follow-back survey that is administered to the bereaved family members of adult persons (age 18 and older) who died of a chronic progressive illness receiving services for at least 48 hours from a home health agency, nursing homes, hospice, or acute care hospital. The survey measures perceptions of the quality of care either in terms of unmet needs, family reports of concerns with the quality of care, and overall rating of the quality of care. The time frame is the last 2 days of life up to last week of life spent in a hospice, home health agency, hospital, or nursing home.

1623: Bereaved Family Survey (PROMISE Center)

Description: The purpose of this measure is to assess families' perceptions of the quality of care that Veterans received from the Veteran's Administration in the last month of life. The BFS consists of 19 items (17 structured and 2 open-ended). The BFS items were selected from a longer survey that was developed and validated with the support of a VA HSR&D Merit Award and have been approved for use by the Office of Management and Budget.



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