



Building Additional Serious Illness Measures into Medicare Programs

March 14, 2017

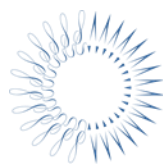


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Significant changes to the healthcare delivery system are necessary for patients with serious illness to consistently receive high-quality, affordable, and person-centered care that is tied to their documented goals and preferences. However, such changes are unlikely to result in better care without metrics that assess the quality provided across the various settings in which patients receive care. While quality metrics have proliferated in nearly all areas of medicine over the last several decades, serious illness and end-of-life care continue to lack sufficient tools to effectively evaluate and improve care.

The Gordon and Betty Moore Foundation and The Pew Charitable Trusts, with support from Discern Health, sought to identify a small number of setting-specific quality measures applicable to various types of serious illness that could be immediately implemented by the Centers for Medicare & Medicaid Services (CMS) for relevant Medicare quality programs. To do this, Discern and Pew—working closely with a multi stakeholder panel of 16 experts and building on previous measurement initiatives—identified and prioritized gaps among current Medicare measures for the home health, hospice, hospital, and nursing home settings and recommended measures that could fill these gaps. The panel also identified areas where new measures need to be developed, validated, and implemented in order to drive improvements in the care of seriously ill patients.

Taken together, the following five recommendations outline a path to transforming the care that seriously ill people receive, especially near the end of life.

1. Implement Existing Quality Measures Applicable to the Seriously Ill in Medicare Quality Programs

- a. CMS should add the Advance Care Plan measure ([NQF #0326](#)) to the Medicare Hospital Inpatient Quality Reporting Program, the Hospital Outpatient Quality Reporting Program, and the Long-Term Care Hospital Quality Reporting Program; and
- b. CMS should add the Patients Admitted to the ICU Who Have Care Preferences Documented measure ([NQF #1626](#)) to the Medicare Hospital Inpatient Quality Reporting Program.

2. Improve Collection of Patient and Caregiver Feedback

- a. CMS should implement in all Medicare settings a supplemental set of questions to the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys, with the goal of capturing the experiences of patients who have died and/or who cannot speak for themselves; or
- b. CMS should implement the Veterans Health Administration's (VA's) Bereaved Family Survey across all Medicare settings of care.

3. Standardize Data Collection to Help Identify Vulnerable Individuals

- a. CMS should require that all facilities, particularly hospitals, collect standardized functional and cognitive data at both admission and discharge.

4. Create New Tools to Ensure Patients Are in Control of Their Care

- a. CMS should allocate a portion of funding from the bipartisan Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) to develop measures that ensure that patients' goals, preferences, and values are honored.

5. Develop and Implement Measures that Align with New Payment Models

- a. CMS should implement meaningful quality measures that can be used to assess the care seriously ill patients are receiving in new payment models.

Although setting-specific measures for Medicare programs were the focus of this project, such measures are only a starting place. As the healthcare system shifts away from setting-based, fee-for-service payments to payments based on outcomes and value, measures are needed to encourage movement toward more comprehensive, community-based care and to ensure that the needs of individuals with serious illnesses are met. Accordingly, serious illness care measures are needed not only at the setting level, where care is delivered, but also at the community and program levels.

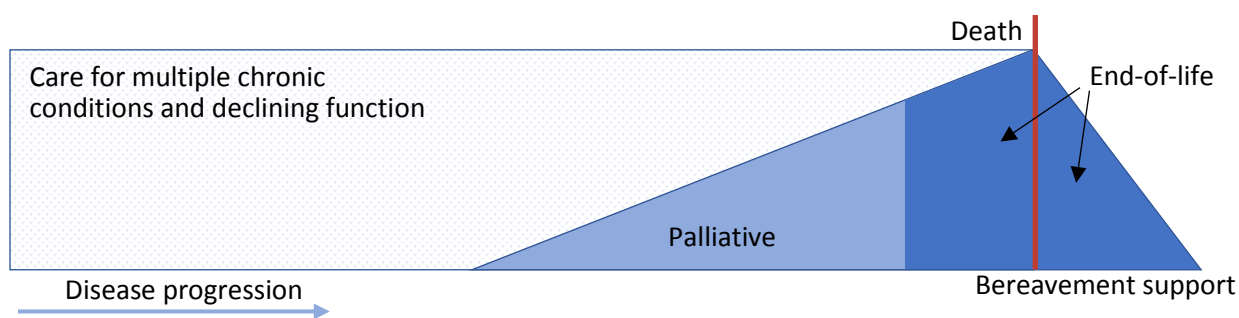
Background and Context

Defining Serious Illness

Serious illness has been described as “a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments or caregiver stress.”¹ The Coalition to Transform Advanced Care (C-TAC) describes serious illness as occurring when one or more conditions lead to a general decline in health and function and treatments begin to lose their impact; the decline in health leads to the end of life for the patient. Examples of serious illness include cancer, congestive heart failure, chronic obstructive pulmonary disease, kidney failure, Alzheimer’s disease, Parkinson’s disease, and amyotrophic lateral sclerosis. These illnesses are responsible for the highest-cost and highest-need patients in the health system.

Models for delivering healthcare services to people with serious illness generally include patients who are two to three years from their expected end of life.² As figure 1 (adapted from the National Quality Forum [NQF]) shows, the progression to serious illness care includes curative care for chronic conditions, treatment to address declining function, and palliative care to address both advancing disease and end-of-life care.³

Figure 1. Serious Illness Care Progression



Adapted from National Quality Forum, “National Framework and Preferred Practices for Palliative and Hospice Care Quality.”

Serious illness disproportionately affects frail older adults. Medicare beneficiaries with four or more chronic conditions account for more than three-quarters of all Medicare spending.⁴ It is projected that by 2030, there will be over nine million Americans age 85 or older with multiple chronic conditions. This will increase hospitalizations and use of intensive care treatments that are often not necessary or in alignment with patient care preferences.⁵

¹ Amy S. Kelley, “Defining ‘Serious Illness,’” *Journal of Palliative Medicine* 17, no. 9 (2014): 985, doi:10.1089/jpm.2014.0164.

² The C-TAC and AHIP Foundation, “The Advanced Care Project,” 2015. <http://www.thectac.org/wp-content/uploads/2015/06/ACP-Report-6-18-15-FINAL.pdf>.

³ National Quality Forum, “A National Framework and Preferred Practices for Palliative and Hospice Care Quality,” 2006. http://www.qualityforum.org/publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx.

⁴ “Chartbook and Charts,” Centers for Medicare & Medicaid Services, last modified Jan. 7, 2016. https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Chartbook_Charts.html.

⁵ The C-TAC, “Advanced Illness Care: Key Statistics,” 2012. <http://www.thectac.org/wp-content/uploads/2014/10/Advanced-Illness-Key-Statistics-12-22-2012.pdf>.

Needed Improvements in Serious Illness Care

There is widespread agreement on the need to improve the care provided to the seriously ill. According to the National Academy of Medicine's (NAM) report, *Dying in America*, "Despite considerable progress, significant problems remain in providing end-of-life care for Americans that is high quality and compassionate and preserves their choice while being affordable and sustainable."⁶ Among the challenges are the:

- Increasing number of elderly Americans;
- Growing cultural diversity of the U.S. population;
- Structural barriers in access to care;
- Mismatch between the services patients and families need most and the services they can readily obtain;
- Inability of palliative care services to keep pace with the growing demand;
- Wasteful and costly systemic problems, perverse financial incentives, a fragmented care delivery system, time pressures that limit communication, and a lack of service coordination across programs; and
- Unsustainable growth in costs of the current healthcare delivery system over the past several decades.⁷

Other literature on serious illness care reports similar findings. The current system can be particularly burdensome for patients and families; according to one survey, a majority of caregivers of patients whose last place of care was a hospital reported that end-of-life care was poor.⁸ This is particularly true for patients who cannot communicate for themselves and have a serious illness that results in one or more functional impairments; these people often receive less than optimal care.⁹

Additionally, the current healthcare system does not do a good job in ensuring that the care patients receive is consistent with their goals and preferences. For example, although the majority of Americans say they would prefer to die at home, national data indicates that nearly 75 percent die elsewhere, such as in hospital intensive care units or nursing homes.¹⁰ Recent trends showed that from 2000 to 2009, the use of intensive-care units and the rate of healthcare transitions increased in the last month of life.¹¹

Research indicates that patients with serious illness typically want to be at home with loved ones with their symptoms managed and spiritual needs honored, while avoiding emotional and financial

⁶ Committee on Approaching Death, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Washington, D.C.: Institute of Medicine, 2014).

⁷ Ibid.

⁸ Joan M. Teno et al., "Family Perspectives on End-of-Life Care at the Last Place of Care," *JAMA* 291, no.1 (2004): 88-93, doi:10.1001/jama.291.1.88.

⁹ Center to Advance Palliative Care, "America's Care of Serious Illness," 2015. <https://reportcard.capc.org/wp-content/uploads/2015/08/CAPC-Report-Card-2015.pdf>.

¹⁰ National Center for Health Statistics, "Health, United States, 2010: With Special Feature on Death and Dying," 2011. <http://www.cdc.gov/nchs/data/hus/hus10.pdf>.

¹¹ Joan M. Teno et al., "Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009," *JAMA* 309, no. 5 (2013): 470-7, doi:10.1001/jama.2012.207624.

hardship.¹² Instead, many patients receive aggressive treatments that are inconsistent with their requests and values. This results in significant burdens, such as anxiety, discomfort, emotional trauma, depression, and regret, for patients and their families; it may also result in avoidable financial costs, for the individual and for the healthcare system overall.¹³

Recent consensus reports from NAM highlight the need to address these issues with improved quality measurement and reporting for serious illness care, particularly at the end of life. In 2015, NAM released *Vital Signs: Core Metrics for Health and Health Care Progress*, which identified a set of core measures for health and health care; these were intended to apply at various levels, ranging from individual clinicians to states. The NAM also identified end-of-life measures as a key element of evaluating whether care matches a patient's goals. The report states:

“End-of-life care represents a critical area in need of significant development in terms of both care and its measurement, and one in which patient and family views and perspectives play a critical role.”¹⁴

Dying in America echoed this concern and highlighted the need for improved quality metrics for serious illness care in the following recommendation:

“[T]he federal government should require public reporting on quality measures, outcomes, and costs regarding care near the end of life (e.g., in the last year of life) for programs it funds or administers (e.g., Medicare, Medicaid, the U.S. Department of Veterans Affairs). The federal government should encourage all other payment and health care delivery systems to do the same.”¹⁵

The existing national data demonstrates the healthcare system's failure to provide person-centered care. What is needed now are granular metrics to help systems identify points where specific improvements are needed and eventually to demonstrate improvement.

The Impact of Health System Transformation on Quality

The U.S. healthcare payment system traditionally paid for episodes of care that occurred in specific care settings. Public policy-makers and private-sector stakeholders developed accountability programs to assess and improve the quality of care in these settings; for seriously ill patients, relevant Medicare quality systems include those for home health, hospice, hospital, and nursing home care. Current efforts

¹² The C-TAC, "A Roadmap for Success: Transforming Advanced Illness Care in America," 2015. <http://www.thectac.org/wp-content/uploads/2015/09/Roadmap-Kindle-.pdf>.

¹³ The C-TAC, "Advanced Illness Policy Review: The Landscape for Improving Advanced Illness Care in America," 2013. <http://www.thectac.org/wp-content/uploads/2015/04/Advanced-Illness-Policy-Review-Landscape-for-Improving-Advanced-Illness-Care-in-America.pdf>.

¹⁴ Institute of Medicine, *Vital Signs: Core Metrics for Health and Health Care Progress* (Washington, D.C.: National Academies Press, 2015).

¹⁵ Committee on Approaching Death, "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life."

to transform the healthcare system are now focused on linking payments more closely to these quality programs. As such, it is important that Medicare uses measures in these quality improvement programs that address care for the serious illness population. Unfortunately, these programs are not currently using measures that are designed to comprehensively assess the quality of serious illness care in these settings.

However, the U.S. healthcare delivery and financing system is also in a period of rapid transformation. Prior to passage of the Patient Protection and Affordable Care Act (ACA) in 2010, quality improvement and cost containment strategies focused on increased use of managed care and a limited number of demonstration projects permitted under Medicare. The ACA accelerated transformation by creating the Center for Medicare and Medicaid Innovation (CMMI) and providing it with significant authority and funding to implement and scale innovative models. These efforts have been guided by the National Quality Strategy's three-part aim of better care, healthier communities, and affordable care.¹⁶ Additionally, the Department of Health and Human Services (HHS) set an ambitious goal of having 90 percent of fee-for-service payments tied to value and 50 percent of all Medicare payment in alternative payment models (APMs) by 2018.¹⁷ In 2015, Congress passed a law that will move all physicians not participating in APMs to the Merit-Based Incentive Payment System (MIPS), which will adjust physician reimbursement based on their measured quality and cost of providing care.

Any system that pays for care based on the value of that care requires robust measures to assess the quality of services that patients receive. This is especially true for patients with serious illness, who are particularly vulnerable and costly to care for. Accordingly, the increased use of alternative payment models, such as accountable care organizations (ACOs), requires the implementation of quality measures in these models to ensure that seriously ill patients receive high-quality care consistent with their preferences. Without targeted metrics, the extent to which alternative payment programs benefit people with serious illness will be unclear.

Current State of Performance Measurement for Serious Illness Care

Existing Measures

Measuring the quality of care delivery through the use of high-value structure, process, and outcome measures for serious illness is fundamental to evaluating and improving care for this population. Previous work has determined that important topics of measurement for serious illness care include access and availability of services, person- and family-centered care, goals and care planning, care coordination, provider competency, and appropriateness/affordable care.¹⁸

¹⁶ "About the National Quality Strategy (NQS)," Agency for Healthcare Research and Quality, accessed Jan. 25, 2017.

<http://www.ahrq.gov/workingforquality/about.htm#aims>.

¹⁷ Sylvia M. Burwell, "Setting Value-Based Payment Goals—HHS Efforts to Improve U.S. Health Care," *New England Journal of Medicine* 372 (2015): 897-899, doi: 10.1056/NEJMp1500445.

¹⁸ National Quality Forum, "Performance Measurement Coordination Strategy for Hospice and Palliative Care: Final Report," 2012.

http://www.qualityforum.org/Publications/2012/06/Performance_Measurement_Coordination_Strategy_for_Hospice_and_Palliative_Care.aspx.

The National Quality Forum (NQF), which endorses measures based on input from stakeholders, endorsed 23 performance measures in 2016 that address palliative and end-of-life care.¹⁹ The NQF-convened Measure Applications Partnership (MAP) annually reviews a list of metrics assembled by CMS called the Measures Under Consideration (the MUC list). These measures are candidates for inclusion in one of Medicare's quality programs. A number of serious illness-related measures have been validated by NQF (i.e., deemed as fully specified or tested in a healthcare setting) and are now used by federal quality programs.²⁰

While some serious illness-related measures exist, are NQF-endorsed, and are in use in Medicare quality programs, significant gaps remain. These gaps include areas where no measures are available to evaluate priority serious illness-related issues, and areas where measures are still at the concept or indicator level (i.e., not fully specified in how data should be collected) and have not been validated. In some cases, palliative care programs are using locally developed, nonvalidated indicators, since fully specified and tested relevant measures are not available.²¹

There have been efforts to develop measures for the seriously ill population to fill these gaps, including the University of North Carolina's PEACE (Prepare. Embrace. Attend. Communicate. Empower) Hospice and Palliative Care Quality Measures, RAND's two measure sets — the Assessing Care of Vulnerable Elders (ACOVE) measures and the Assessing Symptoms Side Effects and Indicators of Supportive Treatment (ASSIST) measures — as well as the Measuring What Matters initiative led by the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association.^{22,23,24} However, relatively few of these measure development initiatives have successfully brought new quality measures through NQF endorsement and ultimate inclusion in federal quality programs. In part, this is due to the challenge of clearly identifying the serious illness population for measurement purposes, and the resources needed for full measure specification, testing, and endorsement processes.

Application of Measures

In addition to the need to develop serious illness-related measures, substantial research is needed to improve the implementation of quality measures to advance the field of palliative care and improve care. The Measuring What Matters initiative identified three areas as methodological research priorities for furthering progress in this area, including:²⁵

¹⁹ "Palliative and End-of-Life Care Project 2015-2016," National Quality Forum, accessed Jan. 25, 2017. <http://www.qualityforum.org/ProjectMeasures.aspx?projectID=80663>.

²⁰ Centers for Medicare & Medicaid Services, "List of Measures under Consideration for December 1, 2016," 2016. <http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=83923>.

²¹ Sydney M. Dy et al., "Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association," *Journal of Pain and Symptom Management* 49, no.4 (2015): 773-81, doi:10.1016/j.jpainsymman.2015.01.012.

²² Ibid.

²³ American Academy of Hospice and Palliative Medicine and Hospice & Palliative Nurses Association, "Top Ten Measures that Matter," Clinical ed. 2014. http://aahpm.org/uploads/education/AAHPM15_MWM_Handout_Clinical_FINAL.pdf.

²⁴ American Academy of Hospice and Palliative Medicine and Hospice & Palliative Nurses Association, "Top Ten Measures that Matter," Non-Clinical ed. 2014. http://aahpm.org/uploads/education/AAHPM15_MWM_Handout_Nonclinical_FINAL.pdf.

²⁵ Sydney M. Dy et al., "Methodological Research Priorities in Palliative Care and Hospice Quality Measurement," *Journal of Pain and Symptom Management* 51, no.2 (2016): 155-162, doi: 10.1016/j.jpainsymman.2015.10.019.

- *Defining the denominator or population of interest for quality measurement:* Establishing a denominator or population of interest is essential for quality measurement of serious illness care, as it allows for systematic evaluation of efforts to improve the delivery across populations and settings where care is needed. The field of palliative care has worked to further define the cohort;²⁶ however, gathering the proper data to accurately define the patient population remains challenging.
- *Developing methods to measure quality from different data sources:* While traditional medical record review and retrospective claims data analysis may provide good information, it is often burdensome and not effective for timely, agile, accurate, and actionable quality improvement efforts in the serious illness population. Newer approaches such as electronic health record (EHR) data, prospective data collection as part of registries, and patient- or family-reported data may help to provide a more comprehensive assessment of quality.²⁷
- *Conducting research to advance the development of patient- and-family-reported outcome measures:* In recent years, CMS placed emphasis on the importance of collecting information directly from patients and caregivers to supplement structure and process data and to provide a more comprehensive view of quality. While a promising area, incorporating patient and family experiences into measurement requires further exploration. Measurement burden on physicians, patients, and caregivers, as well as inadequate measurement tools and processes are among the issues that need to be addressed.²⁸

Building Additional Serious Illness Measures into Medicare Programs

Project Background

The Gordon and Betty Moore Foundation and The Pew Charitable Trusts, with research support from Discern Health and Pew staff (see Appendix A for project team members), identified quality measures that could be implemented in the short term to fill gaps in existing CMS quality programs and key areas where new measures needed to be developed. This work intentionally sought to build on previous measurement initiatives, such as the PEACE, ACOVE, and ASSIST measures, as well as Measuring What Matters.^{29,30,31}

²⁶ Amy S. Kelley et al., "Identifying Older Adults with Serious Illness: A Critical Step Toward Improving the Value of Health Care," *Health Services Research* (2016), doi: 10.1111/1475-6773.12479.

²⁷ Sydney M. Dy et al., "Methodological Research Priorities in Palliative Care and Hospice Quality Measurement," *Journal of Pain and Symptom Management* 51, no.2 (2016): 155-162, doi: 10.1016/j.jpainsymman.2015.10.019.

²⁸ Ibid.

²⁹ American Academy of Hospice and Palliative Medicine and Hospice & Palliative Nurses Association, "Top Ten Measures that Matter," Clinical ed. 2014. http://aahpm.org/uploads/education/AAHPM15_MWM_Handout_Clinical_FINAL.pdf.

³⁰ American Academy of Hospice and Palliative Medicine and Hospice & Palliative Nurses Association, "Top Ten Measures that Matter," Non-Clinical ed. 2014. http://aahpm.org/uploads/education/AAHPM15_MWM_Handout_Nonclinical_FINAL.pdf.

³¹ Sydney M. Dy et al., "Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association," *Journal of Pain and Symptom Management* 49, no.4 (2015): 773-781, doi:10.1016/j.jpainsymman.2015.01.012.

The project team relied heavily upon an expert panel of 16 healthcare leaders (Appendix B) throughout the work. Staff received input from the panel on the priority gap areas, the measures used to fill the gaps, and areas where future measure development was needed; the panel provided its feedback during two webinars, a full-day meeting in Washington, DC, and online surveys conducted at key junctures. Ultimately, the final recommendations from this scope of work were sent to the new presidential administration for consideration.

This project is part of larger bodies of work that the Gordon and Betty Moore Foundation and Pew have each undertaken to improve serious illness care in America. The Moore Foundation is encouraging the development of community-based programs that provide comprehensive care to individuals with serious illness by investing in public education about late life and end-of-life issues; workforce development; supports for family caregivers; tools and educational programs to facilitate the spread of community-based model programs; and the development of an accountability program. As part of a landscape analysis, the Moore Foundation also engaged Discern Health to assess the current state of performance measures and payment models for serious illness care.

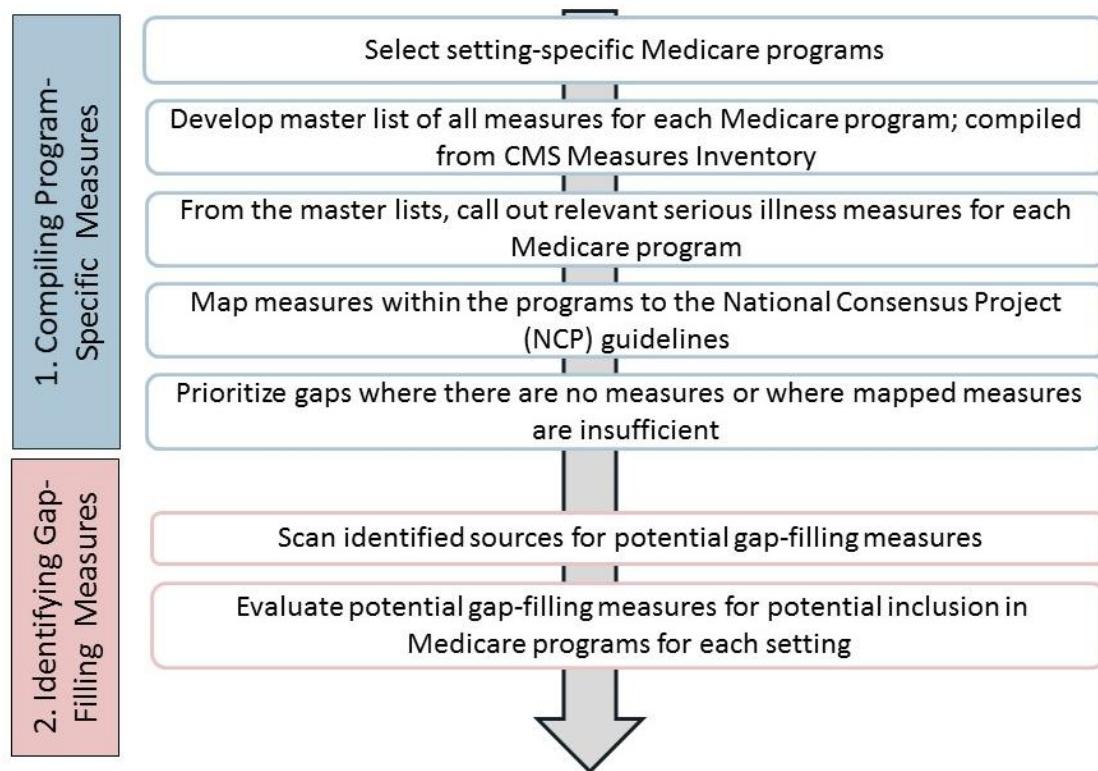
Pew seeks to improve end-of-life care by advancing policies that help people make informed decisions about their treatment preferences, improve the documentation of these preferences, and hold healthcare providers accountable for honoring patient wishes and delivering high-quality care.

Project Overview

The project team went through a rigorous stepwise process and solicited expert panel guidance at key junctures. The first step was for the staff to select a conceptual framework for the provision of serious illness care that could be used to support the project's work. Next, the team identified existing quality programs within Medicare and measures within these programs that could assess serious illness care. The team then mapped measures used by Medicare programs—along with existing quality measures for serious illness care not used by Medicare—to the domains for care laid out by the Clinical Practice Guidelines for Quality Palliative Care.³² The staff identified domains where the measures in use were not adequate and unused measures could be implemented, and brought these gap priority areas to the panel for feedback. After incorporating feedback from the panel, the project staff identified specific measures that Medicare could use to fill these gap areas. Figure 2 describes the stepwise process used by the project team to identify measures to fill gaps in Medicare programs.

³² The C-TAC and AHIP Foundation, "The Advanced Care Project," 2015. <http://www.thectac.org/wp-content/uploads/2015/06/ACP-Report-6-18-15-FINAL.pdf>.

Figure 2. Measure Scan Stepwise Process

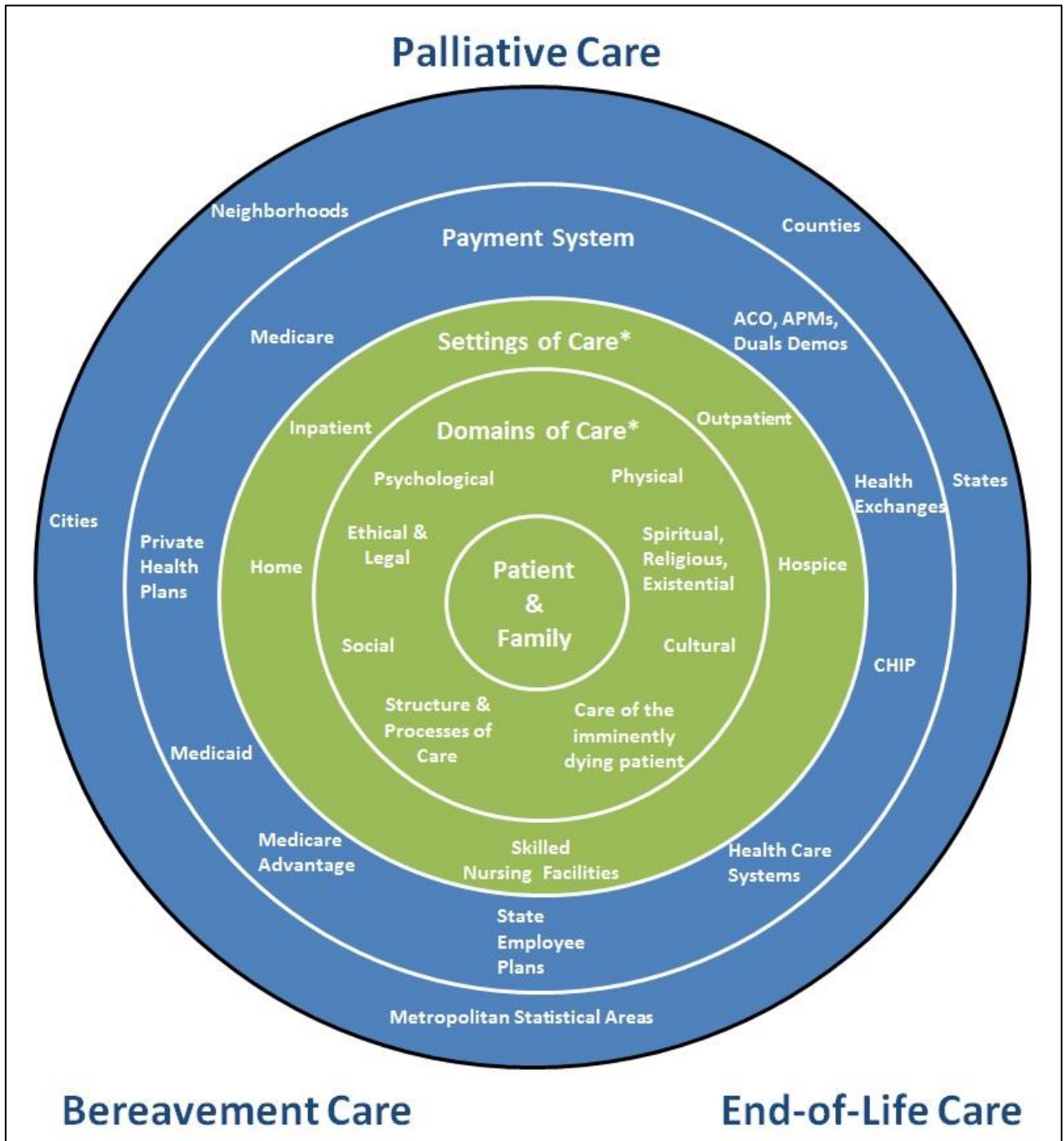


After extensive discussion, the panel recommended that Medicare adopt two measures that could address some of the gaps. Finally, the panel recommended that Medicare prioritize developing measures that could address some of the remaining gap areas. These recommendations were incorporated into a letter sent to the administration on March 14, 2017. The rest of this paper describes the work of the project in detail.

Frameworks for Serious Illness Care Measurement

To ground this work, the project team researched frameworks for serious illness and measurement. Figure 3 depicts a framework adapted from the NQF's Palliative and End-of-Life Care Standing Committee's 2016 report that demonstrates how measurement might be applied to the different characteristics of populations with serious illness and different domains of care. It also illustrates how measurement can be applied to care settings, payment systems, and community-based programs. Whether one is looking at characteristics of patient populations or levels of care, however, the patient and family are at the core of the framework—signifying the importance of person- and family-centeredness in measurement.

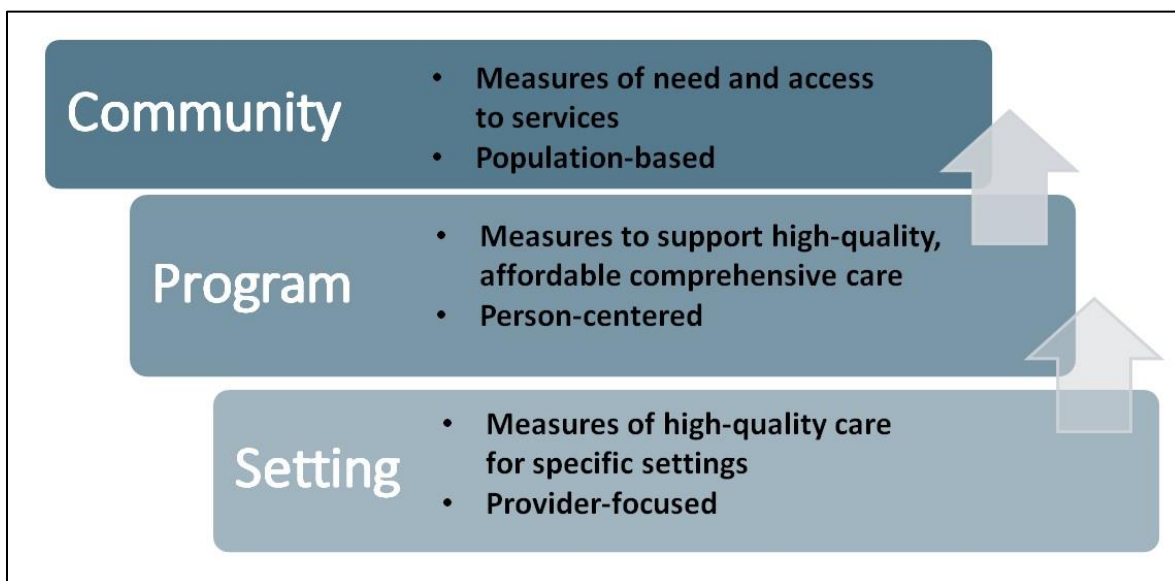
Figure 3. Palliative and End-of-Life Care Framework



Data Source: Green circles: NQF Palliative and End-of-Life Standing Committee Report, 2016.
Blue circles: Added by the project team.

The project team also defined the types of serious illness–related measures needed at the setting, program, and community levels of care. Although this project focused on setting-specific measures for Medicare, the need to shift away from setting-based, fee-for-service approaches toward value-based payment will facilitate movement toward more comprehensive, community-based care. Figure 4 indicates the types of measures needed at each level and what they should assess. For example, measures at the setting level are typically provider-focused, whereas distinctly different measures are needed at the program level to support high-quality, affordable, comprehensive, person-centered care. Further, population-based measures are needed at the community level to assess access to services.

Figure 4. Levels of Measurement and Types of Measures for Serious-Illness Care



Measure Environmental Scan

Setting Selection

As a first step, the project team identified the settings of care that were used most by people with serious illness and the related Medicare quality programs (Table 1). Each of these four settings has well-established public regulatory processes for measure selection and implementation that occur through the annual Medicare rulemaking process. Quality reporting programs, often referred to as “pay-for-reporting” programs, incentivize the collection of important clinical data for publicly available benchmarking by reducing payments for providers that do not report data. Meanwhile, value-based purchasing programs, also known as “pay-for-performance” programs, encourage providers to make practice improvements that will reach and exceed measurement performance thresholds; the latter typically have a greater impact on provider payments. Finally, so-called “compare programs” are setting-specific websites designed to help consumers make informed choices about the health care they receive through Medicare and combine measures from both value-based purchasing programs and quality reporting programs.

Table 1. Settings, Selection Rationale, and Setting-Specific Programs Reviewed

Setting	Rationale for Selection	Medicare Quality Programs
Home Health	<ul style="list-style-type: none"> ❖ Significant growth in home- and community-based services ❖ Would benefit from greater focus on quality, given issues with fragmented care and fraud ❖ Proliferation of new models that focus on responding to serious illness through community-based care ❖ Opportunity with IMPACT Act for measure alignment and data collection 	<ul style="list-style-type: none"> ❖ Home Health Quality Reporting Program ❖ Home Health Value-Based Purchasing Program ❖ Home Health Compare
Hospice	<ul style="list-style-type: none"> ❖ Eligibility rules require everyone in hospice to have a serious, life-limiting illness ❖ Shows a commitment to improving care for the most seriously ill ❖ Despite recent adoption of setting-specific quality measures, this is an opportunity to ask if there is room for improvement 	<ul style="list-style-type: none"> ❖ Hospice Quality Reporting Program
Hospital	<ul style="list-style-type: none"> ❖ Highly regulated, high-volume healthcare access point for chronically ill patients ❖ Opportunity for inclusion of specific measures applicable to the Meaningful Use program ❖ Medicare bundled payments for cardiovascular events and procedures will push providers to coordinate care with others in the community ❖ Challenge: the denominator for various measures is less well-defined than for other settings 	<ul style="list-style-type: none"> ❖ Value-Based Purchasing ❖ Inpatient Quality Reporting Program ❖ Outpatient Quality Reporting Program ❖ Meaningful Use for Eligible Hospitals ❖ Hospital Compare ❖ Long-Term Care Hospital Quality Reporting Program
Nursing Home	<ul style="list-style-type: none"> ❖ Advance care planning happening but not captured in quality assessments ❖ Opportunity with IMPACT Act for measure alignment and data collection ❖ Opportunity to rationalize use of facility and home- and community-based services 	<ul style="list-style-type: none"> ❖ Skilled Nursing Facility Quality Reporting Program ❖ Skilled Nursing Facility Value-Based Purchasing Program ❖ Nursing Home Compare

Measure Scan and Gap Analysis

Once project staff identified the settings of care and their respective Medicare quality programs, the staff conducted a measure scan and gap analysis to answer the following questions: What measures are currently in use by the various Medicare quality programs? Where are the gaps in measurement and what are the priorities among those gaps? What measures might be recommended to fill those priority gaps?

The team captured this information in a series of spreadsheets. For each setting, the team created a spreadsheet with the master list of all the measures for the relevant Medicare reporting program from the CMS Measures Inventory (a compilation of measures used by CMS in various quality, reporting and

payment programs).³³ The spreadsheets also contain the list of the relevant serious illness–related measures utilized by Medicare for that setting identified by the team.

Measures were not included as relevant if they excluded patients who died (except in cases such as where parameters for the measure included patients who died in the previous reporting period), were mortality or cost measures, were not applicable to serious illness, or were narrowly defined, condition-specific measures. Since the scan was specifically focused on populations of people who are seriously ill and are likely to die as their disease progresses, it was important to capture the measures that were intended to evaluate this population’s interaction with the healthcare system. Additionally, as this scan was specifically focused on improving the care provided to patients with serious illness, the team decided to omit measures that looked only at the cost of care, specific diseases, and measures that did not relate to the care of the seriously ill. However, condition-specific cancer measures were included as an exception to the rule due to the high prevalence of serious illness care principles within that population.

Each serious illness measure was mapped to at least one guideline within the eight domains from the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care:³⁴

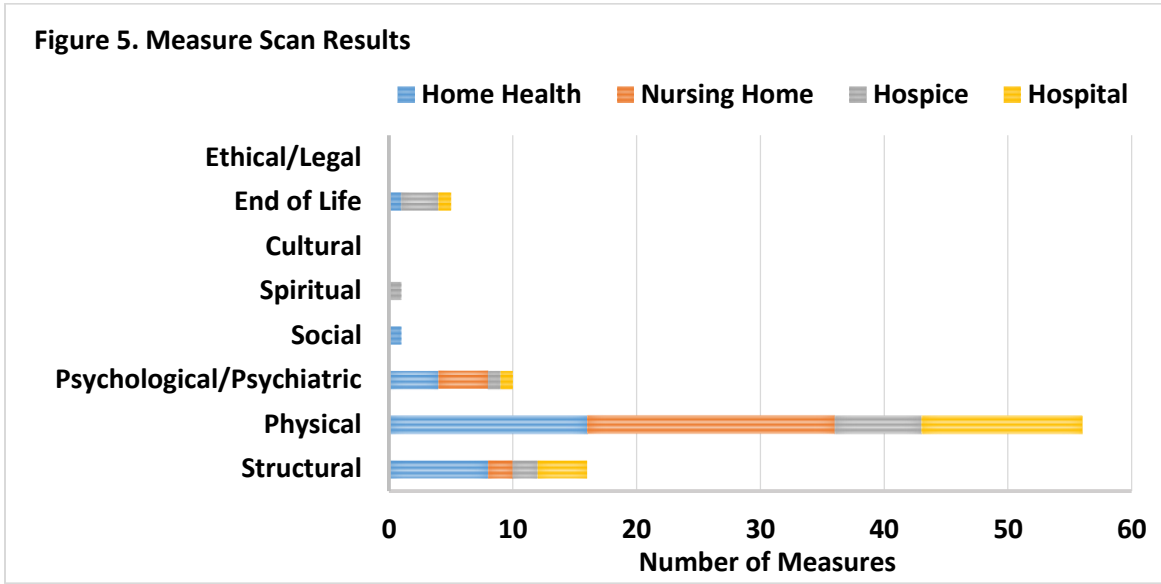
- Domain 1: Structure and Processes of Care
- Domain 2: Physical Aspects of Care
- Domain 3: Psychological and Psychiatric Aspects of Care
- Domain 4: Social Aspects of Care
- Domain 5: Spiritual, Religious, and Existential Aspects of Care
- Domain 6: Cultural Aspects of Care
- Domain 7: Care of the Patient at the End of Life
- Domain 8: Ethical and Legal Aspects of Care

While other guidelines were reviewed, the NCP guidelines were chosen because they were determined to be the most comprehensive in the description of best practices. Unlike some guidelines, they can also be used across care settings, which was important in a project that worked across multiple settings. Each of the eight NCP domains contains multiple guidelines; a full list of the domains and guidelines can be found in Appendix C. In our analysis for each setting, NCP guidelines that did not have any measures or had insufficient measures within the Medicare programs were deemed gap areas.

The results of the measure scan by NCP domain are shown in Figure 5. The majority of the existing serious illness–related measures within the Medicare quality programs for the four settings fell under Domain 2: Physical Aspects of Care. No existing serious illness–related measures were found in the Medicare programs for the ethical/legal or cultural domains of the NCP guidelines. This is not surprising, given that the current healthcare system is focused on medical care, rather than the needs of patients more holistically.

³³ “CMS Measures Inventory,” Centers for Medicare & Medicaid Services, last modified Jan. 17, 2017. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityMeasures/CMS-Measures-Inventory.html>.

³⁴ The C-TAC and AHIP Foundation, “The Advanced Care Project,” 2015. <http://www.thectac.org/wp-content/uploads/2015/06/ACP-Report-6-18-15-FINAL.pdf>.



Based on the results of the measure scan, the project team identified priority measure gaps. A priority measure gap for this project was defined as where the NCP guideline had no or insufficient existing measures within the Medicare programs mapped to it, but where measures were available to potentially fill those gaps. Prioritization of gaps was important, as the goal of the project was to identify a small number of immediately available measures per setting that were applicable.

In preparation for the in-person convening, the Pew and Discern staff presented its work to this point with the expert panel on a webinar. Following the webinar, the project team developed a brief survey for the expert panel to review the results of the measure scan and provide feedback and recommendations on prioritization of gap areas.

The expert panel generally agreed with the preliminary mapping and gap prioritization conducted by the project team. NCP guideline 1.2 was deemed by the panelists as the highest-priority guideline for all four settings. This guideline states, *“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.”*

NCP guideline 4.1 was deemed by panelists as the second-highest-priority guideline for three of the four settings: home health, hospital, and nursing home. This guideline states, *“The IDT [interdisciplinary team] assesses and addresses the social aspects of care to meet patient-family needs, promote patient-family goals, and maximize patient-family strengths and well-being.”*

Identifying Gap-Filling Measures

The project team scanned the following sources for potential gap-filling measures:

- CMS inventory of measures currently implemented in setting-specific Medicare quality programs. Measures that were removed or rescinded from Medicare programs were also considered as potential gap-filling measures.

- National Quality Forum’s Quality Positioning System³⁵ measures.
- Measures being considered for endorsement as part of the NQF Palliative and End-of-Life Care Project in 2016.
- PEACE,³⁶ ACOVE,³⁷ ASSIST,³⁸ and Measuring What Matters^{39,40} measure sets.
- 2014-2015⁴¹ and 2015-2016⁴² MAP MUC lists.

Other known sources deemed to contain relevant quality measures, such as the Agency for Healthcare Research and Quality’s National Quality Measures Clearinghouse, were also used to identify measures for filling gaps. However, only fully specified serious illness–related measures that would be suitable for immediate implementation into Medicare quality programs were considered.

As with identification of priority measure gaps, the Pew and Discern staff consulted the expert panel on the identification of gap-filling measures. The expert panel provided feedback and recommendations on available gap-filling measures that may have not been included in the scan or were excluded in the relevant measures. Two measures were overwhelmingly identified by the panel for implementation in Medicare quality programs.

The first measure, Advance Care Plan ([NQF #0326](#)) — a metric tracking the percentage of patients 65 and older who have an advance care plan, named a surrogate decision maker, or did not wish to or could not do either — was mapped to NCP guideline 1.2, the highest-priority guideline identified by the panel. This measure received considerable support across settings as an important potential gap-filling measure to be implemented in Medicare quality programs. NCP guideline 4.1, the second-highest-priority guideline, did not have any potential gap-filling measures mapped to it, so the project team ultimately did not select it as a priority gap area.

The second measure, Consumer Assessments and Reports of End of Life (CARE) Survey ([NQF #1632](#)), which assesses the perceived quality of care for deceased patients who were seriously ill, through the responses of family members, was recommended as a potential gap-filling measure by the expert panel. However, this measure is currently undergoing redesign and is not NQF-endorsed. NQF-endorsed measures were given preference, as they have successfully completed a rigorous, multi stakeholder endorsement review process. Consequently, this measure was not selected as a recommended

³⁵ “Quality Positioning System™,” National Quality Forum, accessed Jan. 25, 2017. www.qualityforum.org/qps/.

³⁶ “PEACE Hospice and Palliative Care Quality Measures,” UNC School of Medicine, accessed Jan. 25, 2017. <https://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>.

³⁷ RAND Corporation, “ACOVE Quality Indicators Applicable to Medical Records and Administrative Data.” http://www.rand.org/content/dam/rand/www/external/health/projects/acove/docs/acove_qimedadmin.pdf.

³⁸ Karl A. Lorenz, “Quality Measures for Supportive Cancer Care: The Cancer Quality-ASSIST Project,” *Journal of Pain and Symptom Management* 37, no.6 (2009):943-64, doi: 10.1016/j.jpainsymman.2008.05.018.

³⁹ American Academy of Hospice and Palliative Medicine and Hospice & Palliative Nurses Association, “Top Ten Measures that Matter,” Clinical ed. 2014. http://aahpm.org/uploads/education/AAHPM15_MWM_Handout_Clinical_FINAL.pdf.

⁴⁰ American Academy of Hospice and Palliative Medicine and Hospice & Palliative Nurses Association, “Top Ten Measures that Matter,” Non-clinical ed. 2014. http://aahpm.org/uploads/education/AAHPM15_MWM_Handout_Clinical_FINAL.pdf.

⁴¹ Centers for Medicare & Medicaid Services, “List of Measures under Consideration for December 1, 2014,” 2014. https://www.qualityforum.org/Setting_Priorities/Partnership/Measures_Under_Consideration_List_2014.aspx

⁴² Centers for Medicare & Medicaid Services, “List of Measures under Consideration for December 1, 2015,” 2015. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityMeasures/Downloads/2015-Measures-Under-Consideration-List.pdf>

measure. The decision to not recommend the CARE Survey in this project affected the guideline prioritization for the nursing home and home health settings. Thus, the guidelines to which this measure was mapped and originally considered a priority were removed from the priority list, as there were no other available measures to fill the gap.

Table 2 lists the final priority guidelines based on the staff analysis and results of the pre-convening survey.

Table 2. Priority NCP Guidelines as Associated with Measure Gaps			
Home Health	Hospice	Hospital	Nursing Home
7.2: The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan.	1.2: 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.	1.2: 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.	1.2: 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.
	6.2: The palliative program strives to enhance its cultural and linguistic competence.	2.1: The interdisciplinary team assesses and manages pain and/or other physical symptoms and their subsequent effects based upon the best available evidence.	1.9: The physical environment in which care is provided meets the preferences, needs, and circumstances of the patient and family, to the extent possible.
	7.2: The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan.	6.1: The palliative care program serves each patient, family, and community in a culturally and linguistically appropriate manner.	7.2: The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan.
		6.2: The palliative program strives to enhance its cultural and linguistic competence.	
		7.2: The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan.	

Project Team Initial Measure Recommendations

Within the final priority gap areas, the project team reviewed the available measures and made recommendations for measures to be added to the Medicare programs in the four target settings. Measures were evaluated for suitability against the measure selection criteria listed in Appendix D.

Project staff categorized the measures into two groups for each setting: top-tier recommendations and second-tier recommendations. The top-tier recommendations were defined as measures that addressed the goals of the project, were specifically focused on the serious-illness population, and met measure selection criteria as related to aspects such as measure impact and feasibility. The second-tier recommendations included measures that looked promising but may be outside the scope of serious illness care, could create additional provider burden when implemented, or had open questions about current use. These recommendations were shared with the expert panel prior to the convening in preparation for settings-specific breakout sessions. Appendix E lists the top- and second-tier measures for each setting and provides a full discussion of the rationale for measure selection.

Convening

On September 7, 2016, the expert panel met in Washington, DC, to review the work so far and come to agreement on the small set of measures suitable for immediate implementation within each of Medicare's four settings and high-priority areas where new measures needed to be developed.

To accomplish this, panel members broke out into four assigned sessions that aligned with the project's four settings of care. The goal of the breakout sessions was to allow some of the panelists to evaluate a small number of the metrics recommended by the project team. Each breakout group was asked to characterize the project team's recommended gap-filling measures (see Appendix E) in the context of the following questions:

- Does the measure fill a gap in the respective setting?
- What impact would the implementation of the measure have on care delivered in the relevant setting?
- How feasible is the measure for the relevant setting?

Additionally, the breakout groups were asked to make recommendations on which reporting program the measures should be added to within each specific setting. After reviewing the initial recommended measures, the breakout groups were asked to select those they felt would be most appropriate for the goal of the project and report their discussion and recommendations back to the full group for further discussion.

Breakout Session Results and Panel Discussion

A summary of each of the breakout group deliberations can be found in Appendix F. The recommendations from each breakout group were then discussed by the panel as a whole.

The panel decided to put forward two quality measures for that they felt would fill an important gap in measurement of person-centered care within the hospital setting. Table 3 lists these final measures.

Table 3. Final Measure Recommendations

Setting	Measure	Quality Reporting Program
Home Health	No measure recommended	
Hospice	No measure recommended	
Hospital	NQF #0326: Advanced Care Plan	Recommended for Inpatient Quality Reporting Program, Outpatient Quality Reporting Program, and Long-Term Care Hospital Quality Reporting Program
	NQF #1626: Patients Admitted to ICU who Have Care Preferences Documented	Recommended for Inpatient Quality Reporting Program
Nursing Home	No measure recommended	

The first measure recommended by the panel was the Advance Care Plan measure ([NQF #0326](#)), which was initially identified by panelists as an important measure. The group also selected [NQF #1626](#) (Patients Admitted to the ICU who have Care Preferences Documented, an assessment of the percentage of seriously ill elderly patients admitted to the intensive-care unit (ICU) who have their care preferences documented within 48 hours or have documentation as to why this was not done), which was not one of the original gap-filling measures recommended by the project team. In addition to filling crucial gaps in measurement, these two measures combine to help ensure there are ongoing conversations between providers and patients and family members so that as a patient’s condition changes, his or her treatment preferences are revisited and updated appropriately.

For the home health and nursing home settings, many panelists were concerned with supporting the staff-recommended measures of hospice admissions ([NQF #0215](#) and [NQF #0216](#)) due to potential unintended consequences. Many felt the population being evaluated by the measures was not clearly enough defined, which could lead to over- or under provision of hospice services. For the hospice setting, many panelists felt that the measure recommended by staff—[NQF #0326](#) Advance Care Planning—duplicated an existing measure in the Hospice Quality Reporting Program with little benefit other than the potential naming of a surrogate decision-maker.

This feedback meant that the panel did not recommend the adoption of any existing measures for the hospice, home health, and nursing home settings. Despite the project’s goal of identifying a small number of measures for each setting, the panel felt only the hospital setting had valuable measures relevant to the care of individuals with serious illness that were ready for implementation.

Future Measure Development Issues

The outcome of the deliberations left the expert panel dissatisfied with the measures that were immediately available for potential inclusion in setting-specific Medicare programs, with consensus around the need for measures that will help push for rapid action at the provider level but can also be used to assess how well Medicare as a whole is meeting the needs of individuals with serious illness. This would require collecting data to help researchers more systematically define the seriously ill population, harmonizing measures across settings as well as payment systems and models, and collecting information directly from individuals and their families on their care needs and outcomes.

The expert panel identified four priority areas where action needed to be taken to meet the needs of patients with serious illnesses. First, health systems and payers need measures to assess the quality of shared decision-making, particularly at the end of life. One option may be to develop a short survey of patients and their families that would assess the specific needs of patients with serious illness. Alternatively, existing surveys designed to capture family perspectives of care—such as the Hospice Consumer Assessment of Healthcare Providers and Systems (CAHPS) or the Veterans Health Administration’s Bereaved Family Survey—could be used in more widespread settings.

Second, efforts to assess the quality of care for seriously ill people, especially at the end of their lives, have been hampered by the lack of consensus around how serious illness is defined or the size of the population (also known as the denominator problem). Defining the denominator would allow for systematic evaluation and improvement of delivery across populations and settings. A recent analysis using data from the Health and Retirement Study offers one example of a prospective approach to identifying people with serious illness, several panel members noted. That analysis, which explored ways to define populations of adults with serious illness, provides a starting point for how this problem could be addressed.⁴³

Another solution to the denominator problem may lie with the Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014, according to several panel members. The IMPACT Act promotes patient-centered care for beneficiaries using Medicare post-acute care services by developing and implementing equivalent quality measures in these settings using standardized assessment data.⁴⁴ A key domain of this effort is functional status and changes in function, which are central components to existing research defining the seriously ill population. The IMPACT Act applies to providers of home health services, nursing homes, inpatient rehabilitation facilities, and long-term-care hospitals.

Third, the health system needs to develop quality metrics focused on outcomes that are meaningful to patients and providers rather than focusing on processes of care. Members of the panel strongly recommended that measures assessing the patient-provider relationship be developed to adequately assess experiences of care, person-centeredness, and concordance with patient goals and preferences.

Finally, future measure development must not become siloed within care settings. Many panelists recognized that the future of delivery and payment reform is connected directly to alternative payment models that currently have no measures of quality for seriously ill populations. At the same time, however, future measures must be able to assess care at all levels, including settings, payment programs, and communities.

⁴³ Amy S. Kelley et al., “Identifying Older Adults with Serious Illness: A Critical Step Toward Improving the Value of Health Care,” *Health Services Research* (2016), doi: 10.1111/1475-6773.12479.

⁴⁴ Tara McMullen and Michelle Brazil. “Quality Measures and the IMPACT Act” (presentation, Centers for Medicare & Medicaid Services and Medicare Learning Network, Jul. 7, 2016). <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Post-Acute-Care-Quality-Initiatives/Downloads/2016-07-07-IMPACT-Act-Presentation.pdf>.

Building Consensus

As a way to facilitate change, panel members agreed that the recommendations generated from the convening should be developed into a letter for the incoming administration to provide practical direction for improving serious illness–related measurement in Medicare programs.

After the convening, the project team synthesized the results of the meeting, developed draft recommendations for the new administration, and sent out a post-convening survey to the expert panel for feedback. Appendix G summarizes the recommendations of the project team and the pros and cons of the recommendations. Overall, the results of the survey showed that the expert panel members agreed with the project team’s recommendations. Based on those results, the project team drafted a letter to the administration containing the recommendations. A second web meeting was held to discuss the results of the survey and the draft letter with recommendations to the administration. The expert panel supported the draft letter and final recommendations. The letter was shared with the administration on March 14, 2017.

Expert Panel Consensus Recommendations

The final expert panel recommendations are as follows (the final letter to Tom Price, Secretary of Health and Human Services and Seema Verma, Administrator of the Centers for Medicare & Medicaid Services can be found in Appendix H):

1. Implement Existing Quality Measures Applicable to the Seriously Ill in Medicare Quality Programs

Based on the expert panel’s review of the quality measure currently used in Medicare’s quality programs, and an analysis of gaps in how care is being assessed for the serious illness population, the panel’s final recommendations include:

- Adding the measure Advance Care Plan ([NQF #0326](#)) to the Hospital Inpatient Quality Reporting Program, the Hospital Outpatient Quality Reporting Program, and the Long-Term Care Hospital Quality Reporting Program. This measure assesses the percentage of patients over the age of 65 who have executed an advance care plan, have named a surrogate decision-maker, or did not wish to or could not do either. It is currently being used in the Home Health Value-Based Purchasing Program and the physician MIPS. People who participate in advance care planning discussions and have their wishes documented are less likely to receive unwanted aggressive medical treatment in their last weeks of life, less likely to die in a hospital or ICU, and more likely to enroll in hospice.⁴⁵ Further, adding this measure to the additional programs would align measures across settings and promote communication between clinicians and patients
- Adding the measure Patients Admitted to the ICU Who Have Care Preferences Documented ([NQF #1626](#)) to the Hospital Inpatient Quality Reporting Program. This measure determines the percentage of seriously ill elderly patients admitted to the intensive care unit who have their care preferences documented within 48 hours or have documentation as to why this was not done. Half of all Americans who die in hospitals are in the ICU during the last three days of life.⁴⁶ Roughly a quarter of

⁴⁵ Alexi A. Wright et al., “Associations between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment,” *JAMA* 300, no. 14 (2008): 1665–1673, doi: 10.1001/jama.300.14.1665.

⁴⁶ Anne Wilkinson et al., “Literature review on advance directives,” US Department of Health

bereaved family members report that their loved ones received care they did not want while in the ICU.⁴⁷ This measure works in concert with the Advance Care Plan measure by ensuring that as a patient's condition changes and critical care is needed, his or her treatment preferences are revisited and updated as appropriate.

To minimize the burden on hospital systems, CMS should develop electronic specifications for each of the measures. This has already been done in systems such as the Veterans Health Administration and the University of Washington.

Unfortunately, while there were many other gaps in serious illness–related measures within the Medicare programs of the four settings, the expert panel did not find other existing measures that they could recommend for adoption in the programs. This finding highlights the urgent need to develop new measures for these settings to assess the quality of serious illness care.

2. Improve Collection of Patient and Caregiver Feedback

In addition to the measure-specific recommendations, the expert panel also provided recommendations regarding the need to improve collection of patient and caregiver feedback on their experience with care. In particular, the panel suggested that improvement efforts should ensure that collection of feedback:

- Ask questions that are meaningful and appropriate for people with serious illness;
- Assess experiences across all care settings, and specifically for those who move from one setting to another; and
- Enable proxy reporting when individuals cannot answer for themselves or have died.

The expert panel urged CMS to consider the following options: First, CMS could implement a supplemental set of questions (also known as items) in the CAHPS surveys across all Medicare settings, particularly hospitals. Alternatively, CMS could implement a new tool, such as the Veterans Health Administration's Bereaved Family Survey, which captures veterans' end-of-life care experiences from family members of the deceased. This additional data would provide needed information on patients' perceptions and preferences to improve the quality of serious illness–related care.

3. Standardize Data Collection to Help Identify Vulnerable Individuals

Given the measure denominator issue, which is a barrier to assessing care for the serious-illness population, the expert panel urged the standardized collection of data evaluating patients' functional status across all providers. This recommendation is consistent with the intent of the bipartisan IMPACT Act of 2014, which requires post-acute-care providers including nursing homes and home health agencies to collect standardized information. To address this gap, Medicare should require that all facilities, particularly hospitals, collect standardized functional data at both admission and discharge in their electronic medical records systems. In the long term, physicians' offices and primary care settings should also incorporate functional

and Human Services (2007). <https://aspe.hhs.gov/sites/default/files/pdf/75141/advdir/r.pdf>.

⁴⁷ Joan M. Teno et al., "Is Care for the Dying Improving in the United States," *Journal of Palliative Medicine* 18, no. 8 (2015): 662-666, doi: [10.1089/jpm.2015.0039](https://doi.org/10.1089/jpm.2015.0039).

information into their data collection. In addition, assessment of the cognitive status of beneficiaries who exhibit signs of dementia will complement the collection of functional data, and the administration should strongly consider developing better tools to evaluate and document cognitive status.

4. Create New Tools to Ensure Patients Are in Control of Their Care

Although determining whether a patient received care based on the patient’s goals and preferences is difficult to measure, this assessment is essential to delivering patient-centered care and should be a priority for any future measure development. The Medicare Access and Chip Reauthorization Act (MACRA) of 2015 set aside \$75 million to develop new quality metrics for physicians. The expert panel recommends that CMS allocate a portion of this funding to developing measures to ensure that the care delivered by clinicians, providers, health systems, and payers reflects a patient’s goals, preferences, and values over time.

5. Develop and Implement Measures that Align with New Payment Models

Medicare has traditionally paid for and assessed care delivery according to care setting. Hospitals, nursing homes, hospices, and home health agencies all have their own programs to measure quality. However, patients with serious illness receive care across many settings, and efforts to assess whether a patient’s care is consistent with his or her wishes must examine the totality of care provided across all settings. As the healthcare system focuses on delivering quality and value, better assessments of the patient experience will also ensure that vulnerable populations are not neglected during the transition away from traditional fee-for-service care. Yet none of the measures evaluating ACOs, Medicare Advantage plans, or other alternative payment models addresses the needs of seriously ill populations. The expert panel recommended that Medicare implement meaningful quality measures that can be used to assess the care that seriously ill patients are receiving under these new payment models.

Path Forward

While quality measures have proliferated across the U.S. healthcare system, measures that assess whether seriously ill patients are receiving high-quality care remain a significant omission. As a result, policy-makers, health systems, providers, and payers are not able to evaluate whether the healthcare system is meeting the needs of and attending to the preferences of seriously ill patients and their families. Without this ability to determine quality, it is difficult to determine areas of the system most in need of improvement and assess whether quality improvement activities are effective.

Working with the expert panel, the Gordon and Betty Moore Foundation, The Pew Charitable Trusts, and Discern Health identified steps to improve the quality measures used to assess the care that Medicare beneficiaries with serious illness receive in the home health, hospice, hospital, and nursing home settings. Participants in the expert panel also outlined a number of priority areas for improving serious illness care measurement, along with ideas for how to address the issues. Taken together, these recommendations outline a path to transforming the care that seriously ill people receive near the end of life.

Although setting-specific measures for Medicare programs were the focus of this project, they are only a starting place. Serious illness care measures are needed at the community and program levels, as well as at the care setting level. Better measures can also facilitate the ongoing shift away from setting-based fee-for-service to value-based payment, and drive the healthcare system toward more comprehensive, community-based care.

Appendices

Appendix A: Project Team

The Gordon and Betty Moore Foundation	The Pew Charitable Trusts	Discern Health
Janet Corrigan, PhD, MBA Chief Program Officer for Patient Care	Allan Coukell Senior Director, Health Programs	Tom Valuck, MD, JD Partner
Beth Berselli, MBA Program Officer	Josh Rising, MD Director, Healthcare Programs	Donna Dugan, PhD, MS Vice President
	Lee Goldberg, JD Director, Improving End-of-Life Care	Laura Ibragimova, MPH, PMP Project Manager
	Katy Barnett, MPS Senior Associate, Improving End-of-Life Care	
	Sarah Holmes Associate, Improving End-of-Life Care	

Appendix B: Expert Panel

Participant	Affiliation
Robert Arnold	University of Pittsburgh
Katherine Ast	American Academy of Hospice and Palliative Medicine
Helen Burstin	National Quality Forum
Julie Bynum	Dartmouth College
David Casarett	Duke University Health System
Barbara Gage	George Washington University
Maureen Henry	National Committee for Quality Assurance
Arif Kamal	Duke University
David Longnecker	Coalition to Transform Advanced Care
Karl Lorenz	Stanford University
Diane Meier	Center to Advance Palliative Care
Sean Morrison	National Palliative Care Research Center
Debra Ness	National Partnership for Women and Families
Justin Sanders	Harvard Medical School
Joan Teno	University of Washington
Deborah Waldrop	University of Buffalo

Appendix C: NCP Domains and Guidelines

NCP Domain	NCP Guidelines
Domain 1: Structure and Processes of Care	<p>1.1: A comprehensive and timely interdisciplinary assessment of the patient and family forms the basis of care.</p> <p>1.2: 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.</p> <p>1.3: An interdisciplinary team (IDT) provides services to the patient and family consistent with the care plan.</p> <p>1.4: The palliative care program is encouraged to use appropriately trained and supervised volunteers.</p> <p>1.5: Support for education, training, and professional development is available to the interdisciplinary team.</p> <p>1.6: In its commitment to quality assessment and performance improvement, the palliative care program develops, implements, and maintains an ongoing data-driven process that reflects the complexity of the organization and focuses on palliative care outcomes.</p> <p>1.7: The palliative care program recognizes the emotional impact of the provision of palliative care on the team providing care to patients with serious illnesses and their families.</p> <p>1.8: Community resources ensure continuity of the highest-quality palliative care across the care continuum.</p> <p>1.9: The physical environment in which care is provided meets the preferences, needs, and circumstances of the patient and family, to the extent possible.</p>
Domain 2: Physical Aspects of Care	<p>2.1: The interdisciplinary team assesses and manages pain and/or other physical symptoms and their subsequent effects based upon the best available evidence.</p> <p>2.2: The assessment and management of symptoms and side effects are contextualized to the disease status.</p>
Domain 3: Psychological and Psychiatric Aspects	<p>3.1: The IDT 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.</p> <p>3.2: A core component of the palliative care program is a grief and bereavement program available to patients and families, based on assessment of need.</p>
Domain 4: Social Aspects of Care	<p>4.1: The IDT assesses and addresses the social aspects of care to meet patient-family needs, promote patient-family goals, and maximize patient-family strengths and well-being.</p> <p>4.2: A comprehensive, person-centered interdisciplinary assessment (as described in 1.1) identifies the social strengths, needs, and goals of each patient and family.</p>
Domain 5: Spiritual, Religious, and Existential Aspects of Care	<p>5.1: The IDT assesses and addresses spiritual, religious, and existential dimensions of care.</p> <p>5.2: A spiritual assessment process, including a spiritual screening, history questions, and a full spiritual assessment as indicated, is performed.</p>

	5.3: The palliative care service facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.
Domain 6: Cultural Aspects of Care	6.1: The palliative care program serves each patient, family, and community in a culturally and linguistically appropriate manner.
	6.2: The palliative program strives to enhance its cultural and linguistic competence.
Domain 7: Care of the Patient at the End of Life	7.1: The IDT identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of patients and families.
	7.2: The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan.
	7.3: Respectful postdeath care is delivered in a respectful manner that honors the patient and family culture and religious practices.
	7.4: An immediate bereavement plan is activated postdeath.
Domain 8: Ethical and Legal Aspects of Care	8.1: The patient or surrogate's goals, preferences, and choices are respected within the limits of applicable state and federal law, 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.
	8.2: The palliative care program identifies, acknowledges, and addresses the complex ethical issues arising in the care of people with serious or life-threatening illness.
	8.3: The provision of palliative care occurs in accordance with professional, state, and federal laws, regulations, and current accepted standards of care.

Appendix D: Methodology for Evaluating Potential Gap-Filling Measures

Each potential gap-filling measure mapped to priority NCP guidelines was evaluated against the following set of questions:

- ◆ Does the measure address a program goal/objective?
- ◆ Does the measure improve quality for serious illness, palliative, or end-of-life care?
- ◆ Does the measure fill a gap in the program measure set?
 - Compare the measure to the entire program measure set to ensure that it is not a duplicate measure or if a better measure already exists in the program.
- ◆ Is the measure fully tested for the program's setting or level of analysis?
- ◆ Determine the feasibility of the measure based on its data source (e.g., electronic data preferred over manual chart abstraction).
 - Does the measure decrease reporting burden for providers?
- ◆ Is the measure currently in use?
- ◆ Is the measure NQF-endorsed for the program setting and level of analysis?
- ◆ Does the measure contribute to alignment across programs and settings, including clinical and community-based settings (e.g., care coordination measure), and is an efficient use of measurement resources?
- ◆ Is it a high-value measure (e.g., outcome, broad population, alignment across settings)?

Appendix E: Project Team Recommendations Discussed by the Expert Panel during the In-Person Convening Breakout Sessions

Project Team Initial Measure Recommendations Summary Table	
Setting	Measure
Home Health Top Tier	NQF #0215: Proportion of Patients Who Died from Cancer Not Admitted to Hospice
	NQF #0216: Proportion of Patients Who Died from Cancer Admitted to Hospice for Less than 3 Days
Home Health Second Tier	*There are no second-tier recommendations for the Home Health setting.
Hospice Top Tier	NQF #0326: Advanced Care Plan
	NQF #1919: Cultural Competency Implementation
Hospice Second Tier	NQF #1919: Cultural Competency Implementation
Hospital Top Tier	NQF #0326: Advance Care Plan
	NQF #1638 and #1639: Dyspnea Treatment and Dyspnea Screening
Hospital Second Tier	NQF #1824: L1A: Screening for Preferred Spoken Language for Health Care
	NQF #1919: Cultural Competency Implementation Measure
Nursing Home Top Tier	NQF #0215: Proportion of Patients Who Died from Cancer Not Admitted to Hospice
	NQF #0326: Advance Care Plan
	NQF #0216: Proportion of Patients Who Died from Cancer Admitted to Hospice for Less than 3 Days
Nursing Home Second Tier	NQF #0691, #0692, and #0693: NH CAHPS—Instruments for Discharged Residents, Long Stay Residents, and Family Members

Project Team Initial Measure Recommendations and Rationale

Home Health

Within the home health setting, the project team recommended two measures. These two measures fell under NCP guideline 7.2. The first recommendation was Proportion of Patients who Died from Cancer Not Admitted to Hospice ([NQF #0215](#)) and the second recommendation was Proportion of Patients who Died from Cancer Admitted to Hospice for Less than 3 Days ([NQF #0216](#)). Both measures emphasize the importance of provider accountability for admitting patients to hospice in a timely manner. People enrolled in hospice experience increased survival time and decreased utilization of resources no longer appropriate for their care. Both measures are high-value process measures that promote effective communication and care coordination. Data is feasibly collected through claims and registry, and the measures are NQF-endorsed.

Both measures are being used in the public domain. Both were proposed for use in MIPS, were implemented in the CMMI Oncology Care Model (OCM), and are part of the CMS/America’s Health Insurance Plans (AHIP) Oncology Core Measure Set. [NQF #0216](#) is also part of the American Society of Clinical Oncology’s (ASCO’s) Quality Oncology Practice Initiative (QOPI) 2016 Qualified Clinical Data Registry (QCDR) measures. Furthermore, both measures were validated in cancer and noncancer

hospitals using Medicare claims and Surveillance, Epidemiology, and End Results (SEER)-Medicare linked data obtained from the National Cancer Institute and are being used at the physician level in CMS programs. Neither measure has been specifically tested in the home health setting; however, data for this setting may be feasibly collected. Both measures had been reviewed for re-endorsement and received recommendation by the NQF Palliative and End-of-Life Standing Committee. Public commenters of the NQF process indicated that these measures should also apply to a broader serious illness population and not just to cancer patients.

Hospice

Within the hospice setting, the project team recommended top-tier and second-tier measures for implementation into Medicare programs. For the top-tier recommendations, the same measure, Advance Care Plan ([NQF #0326](#)), was recommended for two NCP guidelines, 2.1 and 7.2. This is a high-value measure that has been validated across all four settings. It is currently in use in Physician Quality Reporting System and Home Health Value-Based Purchasing, is feasible, and aligns across three NCP guidelines: 1.2, 2.1, and 7.2.

[NQF #0326](#) is related to Hospice and Palliative Care—Treatment Preferences ([NQF #1641](#)), which is already in use in the Hospice Quality Reporting Program. Although NQF #0326 has been recommended by the MAP in 2014-2015 for use in the hospital setting, there were concerns about the applicability of this measure across Medicare programs. It was noted that this measure might be more appropriate in primary care settings and other settings where the patient has an established and ongoing relationship with the provider.

While [NQF #0326](#) does address NCP guideline 7.2, alternative measures may have a more significant impact on the quality of hospital care for seriously ill populations. For example, a number of ASCO-developed measures mapped to guidelines 7.1 and 7.2 address this need for individuals with serious illness. However, there are concerns about the unintended consequences of these measures in terms of aggressive marketing. ASCO is currently looking at ways to validate these measures in other settings.

For the second-tier recommendation, Cultural Competency Implementation Measure ([NQF #1919](#)) was recommended for NCP guideline 6.2. This measure has been validated across multiple settings, including the four settings reviewed under this project. In addition, this is the only available measure that best suits this NCP guideline. Although this measure promotes alignment across settings and populations, there are some concerns about provider reporting burden that need to be addressed.

Hospital

Within the hospital setting, the project team recommended top-tier and second-tier measures for implementation into Medicare programs. As in the hospice setting, [NQF #0326](#) was a top-tier recommendation under NCP guideline 1.2 and was already mapped to NCP guideline 7.2 for the hospital setting. For the hospital setting, this measure can drastically improve quality by increasing the number of documented advance directives upon admission. In addition to the related measure [NQF #1641](#), which was also mapped to NCP guideline 1.2, Patients Admitted to ICU who Have Care Preferences Documented ([NQF #1626](#)) is also included in the measure scan under this guideline.

Under NCP guideline 2.1, Hospice and Palliative Care—Dyspnea Treatment ([NQF #1638](#)) and Hospice and Palliative Care—Dyspnea Screening ([NQF #1639](#)) were top-tier recommendations to be implemented in a Medicare program for the hospital setting. The two are paired measures and, therefore, were recommended together. Currently, there are no existing measures in hospital quality programs that assess or treat this symptom. These measures are currently in use in the hospice setting.

The two measures have been reviewed for re-endorsement by the NQF Palliative and End-of-Life Standing Committee. [NQF #1639](#) was initially rejected by the committee due to lack of demonstrable improvement. The committee reconsidered the measure and formally recommended it in August 2016.

The second-tier recommendations for the hospital setting include Screening for Preferred Spoken Language for Health Care ([NQF #1824](#)) under NCP guideline 6.1 and [NQF #1919](#) under NCP guideline 6.2. [NQF #1824](#) fills a priority gap area in the measure scan that did not originally have measures mapped to it; it promotes alignment across a broad population including in the emergency department, hospital, and outpatient settings; and data for the measure is feasibly collected through electronic sources. This measure is preferable to its paired measure Patients Receiving Language Services Supported by Qualified Language Services Providers ([NQF #1821](#)), which looks only at the availability of actual translators. For [NQF #1919](#), the benefits and limitations for implementing this measure in Medicare programs for the hospital setting are consistent with the hospice setting (see above).

Nursing Home

Within the nursing home setting, the project team recommended top-tier and second-tier measures for implementation into Medicare programs. Similar to the hospice and hospital settings, [NQF #0326](#) was a top-tier recommendation under NCP guideline 1.2 and was already mapped to NCP guideline 7.2. In addition, [NQF #0215](#) and [NQF #0216](#) were also top-tier recommendations for NCP guideline 7.2. The measure analysis is consistent with the recommendation for this measure described in the home health setting (see above).

The second-tier recommendations for the nursing home setting include Nursing Home CAHPS: Communication & Respect—Discharged Resident Instrument ([NQF #0691](#)), Nursing Home CAHPS: Communication & Respect—Long Stay Resident Instrument ([NQF #0692](#)), and Nursing Home CAHPS: Nursing Home Provides Information/Encourages Respondent Involvement—Family Member Instrument ([NQF #0693](#)). These measures were mapped to NCP guidelines 1.2 and 1.9. The individual items within these instruments assess the patient and family/caregiver experiences of adequate and respectful communication from the provider during their stay at the nursing home. This is particularly important for patient-provider and patient-family relationships so the patient and family feel supported during the patient's care. These measures also apply to the above guidelines by reporting the patient and family/caregiver experience of care according to the care plan and expressed overall preferences during their short or long stay.

NQF endorsement was not maintained for these surveys, as they are not currently being used. CMS has also chosen not to include these surveys in any of the nursing home programs. Several related issues prohibit the surveys' endorsement and use in the field. The biggest issue may be with the required sample size and new prerequisites to submit these measures to NQF for re-endorsement. Nonetheless,

the project team considered the Nursing Home CAHPS surveys to be of high value, and they should be reconsidered for re-endorsement and use in the field.

Furthermore, individual items within each of the surveys were identified for their value toward improving quality in the nursing home setting. These include items on environment, autonomy, and activities ([NQF #0691](#) and [NQF #0692](#)) as well as nurses'/aides' kindness/respect towards residents, nursing home staffing, care of belongings, cleanliness, and overall rating of nursing home ([NQF #0693](#)).

Appendix F: Summary of Breakout Group Deliberations

Home Health

The home health group recommended one measure, Proportion of Patients Who Died from Cancer Admitted to Hospice for Less than 3 Days ([NQF #0216](#)), for implementation in the Home Health Quality Reporting Program. This measure is designed to capture the percentage of patients who were admitted to hospice, and spent less than three days there before dying from cancer. The benefits of this measure include promoting timely access to hospice to allow patients to experience the maximum possible benefits of hospice care. The limitations of this measure include small sample sizes due to the relatively few home health patients dying at home who are not already on home-hospice. Additionally, the current denominator includes only cancer patients who often have different end-of-life experiences from the general home health population. The denominator also includes both those patients with cancer who were in hospice for less than three days and those who were in hospice for longer than three days, but eliminates those patients who died from cancer without any hospice care.

Hospice

The hospice group recommended one measure, Advanced Care Plan ([NQF #0326](#)), for implementation in the Hospice Quality Reporting Program. This measure is designed to capture the percentage of patients aged 65 years and older who have an advance care plan (ACP), a documented surrogate decision-maker, or documentation that an ACP was discussed but the patient either refused or was unable to name a surrogate decision-maker. The benefits of this measure include increasing the use of ACPs and the naming of a surrogate decision-maker, which is particularly important for patients not able to express their care preferences. Although this is a low-bar measure, because it evaluates only whether someone had an advance care plan and not the quality or comprehensive nature of the plan, it could motivate CMS to develop a better ACP measure in the near term. There is also an opportunity for alignment across settings, since Home Health Value-Based Purchasing and PQRS currently use this measure. This measure is limited in that it overlaps with Hospice and Palliative Care—Treatment Preferences ([NQF #1641](#)), which is currently required for the hospice setting and captures the percentage of patients with documentation of preferences for life-sustaining treatment. In addition, hospice patients are likely to have completed some version of an ACP prior to being admitted, so this measure may be duplicative. Further limitations include the vague definition of ACP, the likelihood that it may become a check-box measure for many clinicians and easily top out with no care improvements, and the need to make it electronically specified to reduce the administrative burden on hospices.

Hospital

The hospital group recommended two measures for implementation. The first, Advanced Care Plan ([NQF #0326](#)), was recommended for the Inpatient Quality Reporting Program, the Outpatient Quality Reporting Program, and the Long-Term Care Hospital Quality Reporting Program. The benefits and limitations of this measure are consistent with what has been described in the hospice group above. The second measure, Patients Admitted to ICU who Have Care Preferences Documented ([NQF #1626](#)), was recommended for implementation in the Inpatient Quality Reporting Program. This measure is designed to capture the percentage of vulnerable adults admitted to the ICU who survive for at least 48 hours and have their care preferences documented within 48 hours, or documentation as to why this was not done. The measure benefits patients without documented care preferences by requiring

hospitals to report the reasons that documentation of care preferences is lacking, likely encouraging compliance or at least a dialogue about patient care preferences. This measure raises awareness among providers and policy-makers of the need for documenting care preferences. It also facilitates re-evaluation of patient goals as prognosis changes. This measure is limited in that it needs to be electronically specified for use at a national level.

Nursing Home

The nursing home group recommended one measure, Proportion of Patients who Died from Cancer Not Admitted to Hospice ([NQF #0215](#)), for implementation in the Nursing Home Quality Reporting Program. The benefits of this measure include encouraging nursing homes to transfer patients to hospice in a timely manner. The limitations of this measure include that the denominator population is specific to cancer patients who may have a different end-of-life experience from a typical nursing home patient. In addition, this measure, as it is currently specified, does not encourage timely admission to hospice because the measure lacks a hospice length of stay. The nursing home group also encouraged exploration of current efforts by nursing homes to collect patient- and family/caregiver-reported data as part of survey and certifications processes, and exploration of whether that data could be repurposed for public reporting.

Appendix G: Post-Convening Project Team Recommendations

Setting Specific Breakout Recommendations	Pros	Cons	Final Project Team Recommendations
<p>The Home Health breakout group presented one measure (NQF#0216—Proportion Admitted to Hospice for Less Than 3 Days) for implementation in the Home Health Quality Reporting Program (QRP). This measure is designed to capture the percentage of patients who were admitted to hospice, and spent less than three days there, before dying from cancer. To review the measure specifications, visit www.qualityforum.org/qps/0216.</p>	<ul style="list-style-type: none"> ◆ This measure could promote timely access to hospice as compared with patients who are admitted to hospice too late to fully benefit from hospice services. 	<ul style="list-style-type: none"> ◆ This measure may have a small sample size because there are relatively few home health patients dying at home who are not already on home hospice; ◆ The current denominator includes only cancer patients, who may have a different end-of-life experience from typical home health patients; and ◆ The denominator of the measure includes both those patients with cancer who were in hospice for less than three days and those who were in hospice for longer than three days; unfortunately, it leaves out completely those patients who died from cancer without any hospice care. 	<p>Based on the conversation with the full group and weighing the advantages and disadvantages as listed above, the project staff does not recommend moving forward with this measure for implementation in the Home Health Quality Reporting Program (QRP).</p>
<p>The Hospice breakout group presented one measure (NQF#0326—Advance Care Plan) for implementation in the Hospice QRP. This measure is designed to capture the percentage of patients aged 65 years and older who have an advance care plan (ACP) or surrogate decision-maker documented in the medical record or documentation in the medical record that the patient discussed an advance care plan but did not wish or was unable to name a surrogate decision-maker or provide an advance care plan. To review the measure specifications, visit www.qualityforum.org/qps/0326.</p>	<ul style="list-style-type: none"> ◆ For people not ready to complete or who already have an ACP, the measure could increase the naming of a surrogate decision-maker, which would be very helpful, particularly with patients who are later not able to express their wishes; ◆ The low bar set by this measure could motivate CMS to develop a better ACP measure; and ◆ There is an opportunity for alignment across settings since Home Health Value-Based Purchasing (VBP) and the 	<ul style="list-style-type: none"> ◆ This measure overlaps with NQF#1641 (Treatment Preferences), which is currently required for hospice settings and captures the percentage of patients with chart documentation of preferences for life sustaining treatment (to see the full measure specifications, visit www.qualityforum.org/qps/1641); ◆ If the patient is in hospice, it is likely he or she has already done some advance care planning to arrive at that setting; 	<p>Based on the conversation with the full group and weighing the advantages and disadvantages as listed above, the project staff does not recommend moving forward with this measure for implementation in the Hospice QRP.</p>

	<p>Physician Quality Reporting System (PQRS) currently use this measure.</p>	<ul style="list-style-type: none"> ❖ This measure contains a vague definition of ACP; ❖ This measure may become a check box for many clinicians and easily top out with no care improvement; and ❖ This measure would need to be e-specified to reduce the administrative burden on hospices. 	
<p>The Hospital breakout group presented two measures for implementation. The first measure (NQF#0326—Advance Care Plan) was suggested for the Inpatient Quality Reporting (IQR), Outpatient Quality Reporting (OQR), and Long-Term Care Hospital (LTCH) QRP.</p>	<ul style="list-style-type: none"> ❖ This measure could raise awareness among providers and policy-makers of the need for ACPs; ❖ The low bar set by this measure could motivate CMS to develop a better ACP measure; and ❖ There is an opportunity for alignment across settings, since Home Health Value-Based Purchasing (VBP) and the Physician Quality Reporting System (PQRS) currently use this measure. 	<ul style="list-style-type: none"> ❖ This measure contains a vague definition of ACP; ❖ As the measure is specified currently, discussions of ACPs would happen at every encounter; ❖ There is concern that for many clinicians this measure will be a check-box and easily top out with no care improvement; ❖ Additional testing is needed before this measure is used in inpatient and LTCH settings; and ❖ This measure would need to be e-specified to reduce the administrative burden on hospitals. 	<p>Based on the conversation with the full group and weighing the advantages and disadvantages as listed above, project staff recommends moving forward with this measure for implementation in the Inpatient Quality Reporting (IQR), Outpatient Quality Reporting (OQR), and Long-Term Care Hospital (LTCH) QRP, contingent on (1) additional testing for inpatient and LTCH settings and (2) it being e-specified.</p>
<p>The Hospital breakout group also presented NQF#1626—Patients Admitted to ICU who Have Care Preferences Documented for the IQR only. This measure is designed to capture the percentage of vulnerable adults admitted to the ICU who survive for at least 48 hours who have their care preferences documented within 48 hours, or documentation as to why this was not done. To review the measure specifications, visit</p>	<ul style="list-style-type: none"> ❖ For patients without documented care preferences, this measure requires hospitals to record the reason(s) for this lack, likely encouraging compliance or at least a conversation of preferences; ❖ This measure could raise awareness among providers and policymakers of the need for documenting care preferences; and 	<p>This measure needs to be e-specified; it is currently only e-specified for the VA system.</p>	<p>Based on the conversation with the full group and weighing the advantages and disadvantages as listed above, project staff recommends moving forward with this measure for implementation in the IQR only, contingent on it being e-specified for use outside of the VA system.</p>

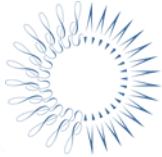
www.qualityforum.org/qps/1626 .	<ul style="list-style-type: none"> ■ This measure offers opportunities to re-evaluate patient goals as a patient’s prognosis changes. 		
<p>The Nursing Home breakout group presented one measure (NQF#0215—Proportion Not Admitted to Hospice) for inclusion in the Nursing Home QRP. This measure is designed to capture the percentage of patients who died from cancer and were not admitted to hospice. To review the measure specifications, visit www.qualityforum.org/qps/0215.</p>	<ul style="list-style-type: none"> ■ This measure could encourage nursing homes to transfer patients to hospice. 	<ul style="list-style-type: none"> ■ The current denominator includes only cancer patients, who may have a different end-of-life experience from a typical nursing home patient; and ■ This measure does not encourage timely admission to hospice because the measure lacks a hospice length of stay. 	<p>Based on the conversation with the full group and weighing the advantages and disadvantages as listed above, project staff does not recommend moving forward with this measure for implementation in the Nursing Home QRP.</p>

Cross-Cutting Recommendations

Specific Breakout Recommendations	Final Project Team Recommendations
<p>There appeared to be consensus from the full group that current data collection requirements do not adequately capture information essential to define the population in need of palliative care for a serious illness (the so-called denominator problem). In particular, data on patients’ functional (i.e., Activities of Daily Living) and cognitive status would fill this gap.</p>	<p>In order to address this problem, we propose recommending that healthcare providers regularly collect this data. As a first step, we would recommend that CMS require this data be collected at the time of hospital admission and discharge. Ultimately, this data could be combined with other clinical information obtained from claims data and electronic health records to construct new quality measures that assess whether patients are receiving appropriate care.</p>
<p>There was consensus among the full group that the current system does not adequately capture the experience of seriously ill patients and their families, or the experience of the families of patients who have deceased</p>	<p>This could be addressed by expanding the Consumer Assessment of Healthcare Providers and Systems (CAHPS) or by implementing the Bereaved Family Survey (BFS) in non-VA settings. Because of the administrative burden associated with survey implementation and the overlap in the resulting data, the staff recommends that only one of these changes be implemented. With that in mind, please consider the following options: *</p> <p>A. Creating a supplemental CAHPS module for seriously ill populations across settings, including hospitals, allowing for proxy responses from patients who cannot speak for themselves or are deceased and removing all reporting exclusions for patients who were admitted to a post-acute provider; OR B. Implementing the BFS in non-VA settings.</p>
<p>There appeared to be consensus from the full group that new measures are needed to assess the extent to which care was delivered in concordance with patients’ goals and preferences.</p>	<p>To address this lack of concordance measures, we propose recommending that CMS fund measure development in this key area, and then adopt such measures.</p>

There appeared to be consensus from the full group that measures are needed that cut across settings.

To address this shortcoming, we propose recommending that CMS explore the development and validation of serious illness measures for use in Medicare Advantage plans, Accountable Care Organizations (ACOs), and other Alternative Payment Models (APMs).



March 14, 2017

The Honorable Tom Price
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Seema Verma
Administrator
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Price and Administrator Verma,

For more than 20 years, quality measures have proliferated in nearly all areas of medicine, with a glaring exception: the U.S. health care system lacks the ability to effectively measure whether patients and families are receiving high-quality care in their last years of life. As a result, the health care system often fails to provide vulnerable individuals and families with what experts call patient-centered care.

Given that approximately 80 percent of people who die in the United States each year are Medicare beneficiaries, this new Administration has an opportunity to significantly improve the quality of care that individuals with serious illnesses receive. The development and implementation of quality measures for this group of people will help prioritize the needs of the seriously ill as the health care system focuses on delivering quality and value. Better assessments of the patient experience will also ensure that vulnerable populations are not neglected during this transition period as the health system moves away from traditional fee-for-service care.

In September 2016, The Pew Charitable Trusts and the Gordon and Betty Moore Foundation, with support from Discern Health, convened an expert panel to recommend ways to address these challenges. The panel, composed of thought leaders from 16 leading organizations, identified practical steps that can be taken immediately by the new Administration. Many of the recommendations build on the success of Congress in developing bipartisan legislation to

improve health care quality such as the *Medicare Access and CHIP Reauthorization Act*. Described in more detail in the attached document, these recommendations include:

1. Implementing Existing Quality Measures
 - a. Medicare should add Advance Care Plan (NQF #0326) to the Hospital Inpatient Quality Reporting Program, the Hospital Outpatient Quality Reporting Program, and the Long-Term Care Hospital Quality Reporting Program; and
 - b. Medicare should add Patients Admitted to the ICU Who Have Care Preferences Documented (NQF #1626) to the Hospital Inpatient Quality Reporting Program.
2. Collecting Patient and Caregiver Feedback.
 - a. Medicare should implement in all settings a supplemental set of questions in the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys, with the goal of capturing the experiences of patients who have died and/or who cannot speak for themselves; or
 - b. Medicare should implement the Veterans Health Administration's (VA's) Bereaved Family Survey across all settings of care.
3. Standardize Data Collection to Help Identify Vulnerable Individuals
 - a. CMS should require that all facilities, particularly hospitals, collect standardized functional and cognitive data at both admission and discharge.
4. Developing Tools to Ensure Patient Control of Their Care
 - a. The Administration should allocate a portion of funding from the bi-partisan *Medicare Access and CHIP Reauthorization Act of 2015* ("MACRA") to develop measures that ensure that patients' goals, preferences, and values are honored.
5. Assessing Quality in the Era of Value-Based Care
 - a. Medicare should implement meaningful quality measures that can be used to assess care of seriously ill patients in new payment models.

We have also released a report detailing the process involved in developing these recommendations. A full copy of the report can be found on the [Discern Health website](#). We are pleased to share with you the summary report from the expert panel proceedings, and look forward to working with you to implement this vision.

Sincerely,



Janet Corrigan, PhD, MBA
Chief Program Officer for Patient Care
The Gordon and Betty Moore Foundation



Josh Rising, MD
Director, Healthcare Programs
The Pew Charitable Trusts

**Building Additional Serious Illness Quality Measures into Medicare Programs:
A Path Forward for the New Administration**

The Pew Charitable Trusts and the Gordon and Betty Moore Foundation convened an expert panel to discuss how best to improve the quality measures used to assess the care that Medicare beneficiaries with serious illnesses receive. Expert panel participants, identified in the appendix to this document, outlined a number of key priority areas for improving palliative and end-of-life care measurement efforts, along with suggestions on how Medicare could make progress in each area. Taken together, these recommendations outline a path for Medicare to transform the care that seriously ill people receive near the end of life.

1. Implement Existing Quality Measures Applicable to the Seriously Ill in Medicare Quality Reporting Programs

The expert panel reviewed the quality measures currently used by Medicare’s quality reporting programs and analyzed gaps in how care is being assessed for the serious illness population. They then determined whether there are existing quality measures that could fill those gaps, giving preference to measures endorsed by the National Quality Forum (NQF). The panel identified two measures that could be used to fill a key gap area: determining whether hospitals had documented the care preferences of Medicare beneficiaries. People who participate in advance care planning discussions and have their wishes documented are less likely to receive unwanted medical treatment in their last weeks of life, less likely to die in a hospital or ICU, and more likely to enroll in hospice; all of which are associated with better quality of life for both patients and family caregivers.⁴⁸

The first measure recommended by the expert panel was Advance Care Plan (NQF #0326). This measure assesses the percentage of patients over the age of 65 who have executed an advance care plan, named a surrogate decision maker, or did not wish to or could not do either. This measure is currently used in the Home Health Value-Based Purchasing Program and the physician Merit-Based Incentive Payment System (MIPS), as well as in Medicare Special Needs Plan reporting. Adding it to the Hospital Inpatient Quality Reporting Program, the Hospital Outpatient Quality Reporting Program, and the Long-Term Care Hospital Quality Reporting Program, would align metrics across settings and promote communication between clinicians and patients.

The second measure recommended by the expert panel was Patients Admitted to the ICU Who Have Care Preferences Documented (NQF #1626) for use in the Hospital Inpatient Quality Reporting Program. This measure determines the percentage of seriously ill elderly patients admitted to the intensive care unit who have their care preferences documented within 48 hours or have documentation as to why this was not done. Half of all Americans who die in hospitals are in the ICU during the last three days of life.⁴⁹ Roughly a quarter of bereaved family members

⁴⁸ Alexi A. Wright et al., “Associations between End-of-Life Discussions, Patient Mental Health, Medical Care near Death, and Caregiver Bereavement Adjustment,” *JAMA* 300, no. 14 (2008): 1665–1673.

⁴⁹ Wilkinson A, Wenger N, Shugarman LR. Literature review on advance directives. US Department of Health and Human Services, 2007. Available at: <https://aspe.hhs.gov/basic-report/literature-review-advance-directives>

say their loved ones received care they did not want while in the ICU.⁵⁰ This measure will work in concert with the Advance Care Plan measure by ensuring that as a patient's condition changes and critical care is needed, his or her treatment preferences are revisited and updated as appropriate.

In order to minimize any burden on hospital systems, CMS should develop electronic measure specifications (eSpecifications) so that the measures, and their applicable data elements, can be collected through electronic health records. Demonstrating the feasibility of this process, the University of Washington and the Veterans Health Administration have already adapted NQF #0326 and #1626 for collection through their electronic medical record systems.

Despite the significant number of gaps in the measures currently used to assess the quality of serious illness care, the expert panel did not find other measures that they could recommend for adoption in the programs Medicare uses to monitor home health agencies, hospices, nursing homes, or hospitals. The absence of relevant serious illness quality measures highlights the urgent need to develop new measures that can be adopted within these settings and used to assess a patient's care regardless of where that care is received.

2. Improve Collection of Patient and Caregiver Feedback

A critical part of improving the quality of care that people with serious illnesses receive is soliciting patient and family satisfaction with this care; unfortunately the system currently fails to capture these critical details. Any effort that seeks to improve this information collection must: 1) ask questions that are meaningful and appropriate for people with serious illnesses, 2) assess experiences across all settings of care, 3) ensure that the experiences of patients who move from one care setting to another (such as from a hospital to a nursing home) are captured, and 4) allow for families to respond when individuals cannot speak for themselves or have died.

To collect patient feedback, Medicare routinely conducts Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys, which ask consumers to report on and evaluate their experiences with the care they have received. However, CAHPS surveys currently fall short for patients with serious illness. To begin with, the surveys ask primarily about facility staffing, the facility's environment, and other topics that do not capture key parts of the patient experience. What is more, CAHPS surveys are not routinely conducted in all settings, including nursing homes where many seriously ill patients reside.

Furthermore, the experiences of patients transferred to other facilities, particularly from hospitals to post-acute care providers such as nursing homes, are not currently captured in the hospital CAHPS surveys; this is also an issue in the home health and hospice CAHPS surveys. Understanding the experiences of people who move between care settings is essential to improving and coordinating care. Finally, all currently implemented CAHPS surveys for Medicare settings, except hospice, exclude individuals who have died and deny families the opportunity to provide feedback on care; this information could be captured through family member reporting.

⁵⁰ Joan Teno, Vicki Freedman, Judith Kasper, Pedro Gozalo and Vincent Mor, "Is Care for the Dying Improving in the United States", 2015, *Journal of Palliative Medicine* 18, no. 8. DOI: 10.1089/jpm.2015.0039.

Medicare should take steps to address these gaps in understanding patient and family experiences. To do this, the agency could implement a supplemental set of questions (also known as items) in the CAHPS surveys across all Medicare settings, particularly hospitals, and address the other weaknesses in CAHPS outlined above. Alternatively, CMS could implement a new tool, such as the Veterans Health Administration's Bereaved Family Survey, which captures veterans' end-of-life care experiences through proxy reports and includes key populations excluded in current CAHPS reporting. This survey, which has been used since 2008, has proven to be an extremely effective tool for monitoring quality. It would need to be adapted to providers outside the Veterans Health Administration network and expanded to include home-based care including home health and home-based hospice.

Adding this additional data to what Medicare currently captures on patient and family experiences will provide needed information on patients' perceptions, attitudes, and preferences and improve the quality of health care for people with serious conditions.

3. Standardize Data Collection to Help Identify Vulnerable Individuals

Efforts to assess the quality of care for seriously ill people, especially at the end of their lives, have been hampered by the lack of a uniform definition for serious illness. It is impossible to implement measures that assess the quality of care for these individuals as there is currently no way to determine the people who should be included in these metrics (also known as the denominator problem). However, patients' functional limitations may be indicators of serious illness and the need for additional support. Functional limitations as identified through data could be used to drive both measurement and quality improvement. For example, although there are measures that evaluate all cancer patients' pain treatment plans, a more targeted measure could help speed interventions for the sickest patients with cancer by looking at those who can no longer bathe or feed themselves. Unfortunately, data points such as these are not uniformly captured.

Accordingly, the expert panel urged the standardized collection of data evaluating patients' functional status across all providers. This recommendation is consistent with the intent of the bipartisan *Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014*, which requires post-acute care providers including nursing homes and home health agencies to collect standardized information.

To meet this goal, the panel recommended that Medicare require all facilities, particularly hospitals, collect standardized functional data at both admission and discharge in their electronic medical records systems. The addition of hospitals to the standardized data collection effort required by IMPACT is critical, since hospitals are often the first point of care for patients and can provide care for a lengthy period of time before patients are admitted to nursing homes or seen by home health agencies. Hospital data is needed to build quality metrics to assess care delivered to patients who will see multiple providers over the course of their illness and to identify individuals who might benefit from additional supportive care. In the long-term, physicians' offices and primary care settings should also incorporate functional information into their data collection. In addition, assessment of the cognitive status of beneficiaries who exhibit

signs of dementia will complement the collection of functional data, and the Administration should strongly consider developing better tools to evaluate and document cognitive status.

4. Create New Tools to Ensure Patients Are in Control of Their Care

Patients are more likely to have their goals, values, and preferences known and respected if they have advance care plan documents such as an advance directive. Additionally, patients and their families are more satisfied with the care provided after they have these goal-based care planning discussions with clinicians.⁵¹ Unfortunately, there is currently no measure that can determine whether the care a patient ultimately receives was consistent with his or her individual goals, wishes, and preferences. Without such a measure, it is impossible to hold the health care system accountable for this outcome.

Although determining whether a patient received goal-based care is difficult to measure, this assessment is essential to delivering patient-centered care and should be a priority for any future measure development. The bi-partisan *Medicare Access and CHIP Reauthorization Act of 2015* (“MACRA”) set aside \$75 million to develop new quality metrics to evaluate physicians. We strongly urge the Administration to allocate a portion of this funding for developing measures that ensure the care delivered by clinicians, providers, health systems, and payers reflects a patient’s goals, preferences, and values over time.

5. Develop and Implement Measures that Align with New Payment Models

Medicare has traditionally paid for and assessed care delivery according to care setting. Hospitals, nursing homes, hospices, and home health agencies all have their own programs to measure quality. However, patients with serious illness receive care across many settings and efforts to assess whether a patient’s care was consistent with his or her wishes must examine the totality of care provided across all settings.

As the health care system focuses on delivering quality and value, better assessments of the patient experience will also ensure that vulnerable populations are not neglected during the transition away from traditional fee-for-service care. For example, models like Next Generation Accountable Care Organizations (ACOs), which are being used to incentivize physicians to adopt new payment structure under MACRA, require quality measures that span all settings of care. Yet none of the measures used to evaluate ACOs, or even Medicare Advantage plans and other alternative payment models, address the needs of seriously ill populations. Medicare should implement meaningful quality measures that can be used to assess the care seriously ill patients are receiving in new payment models.

⁵¹ Karen M. Detering et al., “The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial,” *BMJ (Clinical Research Ed.)* 340 (2010): c1345.

Appendix

Building Additional Serious Illness Quality Measures into Medicare Programs: A Path Forward for the New Administration

Expert Panel

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A Path Forward for the New Administration**

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