GORDON AND BETTY MOORE FOUNDATION
THE PEW CHARITABLE TRUSTS

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, a health policy consulting firm that focuses on quality strategy and measurement, 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,

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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.[1]

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.[2] Roughly a quarter of bereaved family members

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[1] 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.

[2] 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.[3] 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.

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[3] 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 bi-partisan *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.[4] 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.

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[4] 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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