



June 27, 2016

Mr. Andy Slavitt, Acting Administrator
Centers for Medicare & Medicaid Services
Attn: CMS-5517-P
US Department of Health and Human Services
Room 445-G
Hubert H. Humphrey Building
200 Independence Ave. SW
Washington, D.C. 20201

Re: CMS-5517-P, Medicare Program; Merit-Based Incentive Payment System (MIPS) and Alternative Payment Model (APM) Incentive Under the Physician Fee Schedule, and Criteria for Physician Focused Payment Models; Proposed Rule

81 Fed. Reg. 89 (May 9, 2016)

Dear Administrator Slavitt:

The Regulatory Education and Action for Patients (REAP) coalition appreciates the opportunity to comment on the Centers for Medicare and Medicaid Services (CMS) proposed rule, “Medicare Program: Merit-Based Incentive Payment System (MIPS) and Alternative Payment Model (APM) Incentive under the Physician Fee Schedule and Criteria for Physician-Focused Payment Models” (CMS-5517-P). Comprised of multiple patient advocacy organizations representing the concerns of patients and family caregivers confronting a range of chronic, life threatening and disabling conditions, REAP’s mission is to ensure that patient perspectives are included as a prominent part of health-related federal regulatory and rule-making processes.

Our coalition convenes the nation’s leading patient advocacy and public health organizations to advocate for improved health care access, quality, and affordability through policies that optimize outcomes and experiences for all patients and families living in the United States. By bringing together a broad cross-section of patient-driven organizations, REAP is able to collectively identify and communicate the priorities of patients and families that are essential to achieving more person-centered quality care.

REAP supports reforms that will expand equitable access to quality health care for patients and protect them from the often unjust and discriminatory effects of illness. We appreciate CMS’s emphasis on quality of care over quantity of services to meet peoples’ needs without unnecessary costs. Patients and families require reliable and affordable access to high quality therapies and supportive health care services throughout the care continuum in the settings that are best for them. Implementation of the Medicare and CHIP Reauthorization Act of 2015 (MACRA) through the value-based Quality Payment Program (QPP) presents an unprecedented opportunity to prioritize inclusion of information about what matters to patients and families as essential aspects of these reforms, which ultimately can lead to practice innovations that improve the quality of care provided to Medicare beneficiaries and to all patients in the health care system.

As such, the contextual framework of REAP’s comments embeds 4 patient-oriented insights for achieving goal-concordant care:

- Patients and families want understandable, truthful information about the clinical benefits, risks, quality of life impact, and out of pocket costs of different treatment options—information that could influence their treatment choices.
- Understanding what is important to patients and families is paramount to providing high quality, value-based treatments and supportive services aligned with their priorities, needs, and preferences.
- Person-centered, family-oriented care uses skilled communication and coordination to engage patients and families as partners in determining goals of care and what matters to them.
- Patient’s personal priorities and preferences, care experiences, and outcomes constitute clinically essential expertise that patients and families must be invited to bring to the table continuously throughout the care trajectory. This information undergirds shared decision-making, quality care delivery, associated measurement and evaluation efforts.

REAP offers its collective comments on the proposed rule with particular emphasis on the importance of meeting patient and caregiver needs by honoring their preferences.

REAP’s Comments on the Proposed Rule

1. Make patient and family caregiver perspectives about what constitutes “quality” and “value” in health care an integral part of ongoing QPP development, implementation, and evaluation. Changing payment structures and providers’ financial incentives are not sufficient to achieve improved quality and patient outcomes; it is also essential to involve patients and caregivers as partners in health care transformation and give them the power to measure the performance of the system across a range of domains. REAP appreciates that the QPP goal supports health care quality, efficiency, and patient safety, applying a “patient-centered approach to program development that leads to better, smarter, and healthier care.” QPP links payment adjustments and its four categories of performance reporting to value looking primarily through the lens of effectiveness and cost.

While “value” may not be a familiar construct that resonates among patients and families in the context of health care, most do think about it in terms of what is important to them. Patient values typically prioritize considerations beyond clinical outcomes and cost, such as the ability to help them achieve their personal goals. This requires measuring whether the treatments and services provided match what patients identify as important and consistent with their preferences, recognizing that the range of what they want often changes with age, life stage, or care experiences.

CMS’s proposed approach for considering value-based performance should expressly prioritize the patient and family voice and the constellation of what matters to them as key drivers of quality measures development and use. People want to be involved in understanding relevant evidence and making decisions about their health care. Findings of an Institute of Medicine (IOM) national survey of 1,068 US adults who had seen at least one health care clinician in the previous year revealed that the majority strongly agreed they wanted their provider to:

- Listen to them;

- Tell the full truth about diagnosis, even though if it may be uncomfortable or unpleasant;
- Tell about risks associated with each option;
- Explain how options impact quality of life;
- Understand their goals and concerns regarding the options;
- Help them understand how much each option will cost the patient and family; and
- Offer them choices of options.¹

These communication priorities are critical considerations in delivering health care “value” from the patient perspective.

Drawing on these findings in its subsequent consensus report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, IOM recommended that “cancer care team[s] should provide patients and their families with understandable information on cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and estimates of the total and out-of-pocket costs of cancer care.” To accomplish this, IOM expressly called for professional educational programs that provide “comprehensive and formal training in communication.”

The recommendations also called on CMS and other payers to “design, implement and evaluate innovative payment models that incentivize providers to discuss with patients their needs, values and preferences, including consideration of palliative care needs and psychosocial support across the continuum, and document their discussions in each patient’s care plan.”² Consensus recommendations in a subsequent IOM report covering all types of serious illnesses mirrored these communication, training, and payment priorities directed to all primary and specialty care practitioners.³

REAP urges CMS to integrate these perspectives of patients and families as part of the final rule, and to involve patient and family caregiver input consistently as essential stakeholders throughout every step of MACRA’s ongoing implementation and evaluation of its impact.

2. Integrate clinical communication skills development into performance standards, quality measures, and associated payment models throughout MACRA’s QPP implementation. To boost care quality through goals of care clinical conversations and skills development for all Merit Based Incentive Payment System (MIPS) eligible clinicians and those practicing in Alternative Payment Models (APMs), REAP urges CMS to integrate IOM’s communication consensus recommendations into MACRA’s QPP implementation by tying training to performance measurement and payment provisions. MACRA’s MIPS and APM incentive platforms should specifically build in accountability for documenting patient priorities and patient-reported outcomes across system, institutional, and provider performance metrics to improve the patient experience throughout the care continuum. This should include rewards for quality improvement resulting from professional communication skills development so that providers will learn and practice the communication skills they need to meaningfully involve patients and family caregivers as active partners in achieving goal-concordant quality care.

¹Alston C, L Paget, GC Halvorson, B Novelli, J Guest, P McCabe, K Hoffman, C Koepke, M Simon, S Sutton, S Okun, P Wicks, T Udem, V Rohbach, and IV Kohorn. 2012. Communicating with patients on health care evidence: Discussion paper. <https://nam.edu/wp-content/uploads/2015/06/VSRT-Evidence.pdf> (Accessed June 11, 2016)

² Institute of Medicine. *Delivering high-quality cancer care: Charting a new course for a system in crisis*. Washington, DC: The National Academies Press; 2013.

³Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press; 2015.

3. Integrate palliative care as a standard of quality care for all people with serious illness as part of QPP performance measure development and deployment. The underpinnings of high-quality health care are expert attention to patients' physical and psychological symptoms and communication and coordination. All too often, this is not what seriously ill patients get. Today's disease-centric care is fragmented across multiple specialists, subspecialists and settings, creating pressures to navigate pathways-driven treatments that overlook consideration of quality of life, functional outcomes, or other personal priorities that matter a great deal to patients and their families.

Palliative care provides an evidence-based practical solution that can be widely implemented to improve clinical outcomes and health care value throughout the care continuum. Palliative care is an interdisciplinary, team-based model of care that emphasizes care coordination, pain and symptom management, shared decision making, and patient-centered goal-setting. The provision of palliative care has been shown to improve patient experience and satisfaction,^{4 5} reduce caregiver burden,^{6 7} and increase survival⁸; it has also been shown to reduce needless hospital admissions and readmissions through effective care coordination and symptom management^{9 10 11}; and through these gains in quality, it reduces costs.^{12 13 14}

Patients and families receiving palliative care early in the disease trajectory are supported by ongoing discussion of their greatest concerns and hopes, and they receive help with difficult decision-making and with knowing what to expect and how to handle it. By establishing patient and family priorities and achievable goals for care through skilled communication, treatment of distressing symptoms and coordination of care, palliative care delivers the supportive services people need to improve their lived experience.¹⁵ This in turn helps them to avoid unwanted, costly interventions as their condition worsens. We believe this same model of team-based, patient-centered care involving shared decision-making and goal concordant treatment planning can be adopted and applied at various points in a patient's care continuum where critical decisions are being made about diagnosis and treatment.

Without access to these services, families are often left powerless to protect loved ones from falling through the cracks. In recounting her elderly father's long series of "fix-it treatments focused unrealistically on *cure*," Katy

⁴Delgado-Guay MO, et al. Symptom distress, interventions, and outcomes of intensive care unit cancer patients referred to a palliative care consult team, 115(2) *Cancer* 437-45 (2009).

⁵Casarett D, et al., *Do Palliative Consultations Improve Patient Outcomes?* 56 *J Am Geriatric Soc'y* 593, 597-98 (2008).

⁶Gelfman LP, et al., *Does Palliative Care Improve Quality? A Survey of Bereaved Family Members*, 36 *J Pain Symptom Manag* 22, 25 (2008)

⁷Hudson P, et al. *Reducing the psychological distress of family caregivers of home-based palliative care patients: short-term effects from a randomized controlled trial*, *Psycho-Oncology* (2013)(Advance online publication. doi: 10.1002/pon.3242).

⁸Temel JS, et al., *Early Palliative Care for Patients with Metastatic Non- Small-Cell Lung Cancer*, 363 *New Eng J Med* 733, 739 (2010).

⁹Nelson C, et al., *Inpatient palliative care consults and the probability of hospital readmission*, 15(2) *Perm J* 48-51 (2011).

¹⁰Enguidanos S, et al., *30-day readmissions among seriously ill older adults*. 15(12) *J Palliat Med* 1356-61 (2012).

¹¹Lukas L, et al., *Hospital outcomes for a home-based palliative medicine consulting service*, 16(2) *J Palliat Med* 179-84 (2013).

¹²RS Morrison et al., *Cost Savings Associated with US Hospital Palliative Care Consultation Programs*, 168 *Arch Intern Med* 1783, 1785 (2008).

¹³JD Penrod et al., *Hospital-Based Palliative Care Consultation: Effects on Hospital Cost*, 13 *J Palliat Med* 973, 976 (2010)

¹⁴RS Morrison et al., *Palliative Care Consultation Teams Cut Hospital Costs for Medicaid Beneficiaries*, 30 *Health Aff.* 454, 457 (2011).

¹⁵ Kamal AH, LeBlanc TW, Meier DE. Better Palliative Care for All: Improving the Lived Experience with Cancer. *JAMA*. Published online May 31, 2016. doi:10.1001/jama.2016.6491.

Butler's "Imagine a Medicare 'Part Q' for Quality at the End of Life" New York Times article heralded palliative care as a key solution. On receiving a referral for outpatient palliative care services delivered by a nurse, social worker, and occupational therapist at her parents' home, she explained:

"Finally we rested in a coordinated set of hands. The falls stopped. My mother got more sleep. When my father developed pneumonia and qualified for hospice care, the nurse helped facilitate his transfer to an inpatient hospice unit. We could have used their help for years, not months. And we were lucky, because most Medicare patients never get it."¹⁶

In a Harvard Business Review article, "Measuring Quality of Care for the Sickest Patients," Dr. Diane Meier, Director of the Center to Advance Palliative Care, described how palliative care helps ensure that people receive care that is truly valuable to them:

"Most patients value care that helps them stay at home and remain independent for as long as possible; that does not result in financial bankruptcy; and that tries to reduce suffering of all kinds – bodily pain, difficulty breathing, nausea, depression, anxiety, and existential and spiritual distress. Palliative care... provide[s] that support directly to patients and their often exhausted, overwhelmed family caregivers."

Dr. Meier also cautions that knowing a patient's goals is not enough, "We must also align the supports and resources necessary to honor them."¹⁷

Recommendations and standards from the Institute of Medicine, The National Quality Forum, The Joint Commission, and multiple professional organizations and accrediting bodies have consistently called for palliative care integration as a standard of quality care. This is particularly important because the palliative care needs of the aging Medicare population and medically complex adults, children, and adolescents are vast. REAP believes that MACRA's emphasis on quality measurement and value-based payment will help create an environment where providers can focus on patients' quality of life and more assiduously practice goal-directed care and other aspects of palliative care to support these patients and families.

To ensure that every clinician has the primary palliative care knowledge and skills necessary to provide this level of quality care for all patients regardless of diagnosis, treatment setting, or state of disease, training in the fundamental principles and practices of palliative care will be necessary across health care education professional training programs. This will require practitioner accountability, as well as committed investment and incentives.

As with the communication training recommendation detailed above, REAP urges CMS to take specific steps throughout MACRA's QPP implementation that will help standardize delivery of palliative care, including connecting palliative care training to provider performance measurement and payment. In addition, CMS should include in the clinical performance improvement activity inventory a specific opportunity for implementation of palliative care training, such as focusing on what palliative care is and the specific patient needs that could trigger a palliative care referral.

¹⁶ Butler K. Imagine a Medicare 'Part Q' for Quality at the End of Life. *New York Times* 2015; http://opinionator.blogs.nytimes.com/2015/12/09/imagine-a-medicare-part-q-for-quality-at-the-end-of-life/?emc=eta1&_r=1. Accessed June 11, 2016.

¹⁷ Meier DE. Measuring Quality of Care for the Sickest Patients. *Harvard Business Review* 2015; <https://hbr.org/2015/09/measuring-quality-of-care-for-the-sickest-patients>. Accessed June 11, 2016.

4. Selection of Quality Measures: Value-based MIPS performance measures should prioritize patient-reported outcomes and promote goal-concordant care. A value-driven model should reward delivery of care based on what matters to patients. REAP appreciates that CMS encourages in the proposed rule the submission of potential quality measures regardless of whether such measures were previously published in a proposed rule or endorsed by NQF. We also acknowledge the need for measures that are outcome-based (rather than clinical process measures) and include patient and caregiver experience as well as communication and care coordination domains as highlighted in the proposed rule. We agree that quality should be evaluated using a harmonized set of patient-reported outcomes and other appropriate measures that providers can reliably use to understand what matters to patients and families, achieve more goal-concordant care, and improve the patient and family experience and satisfaction.

Patients should be asked to report outcomes across a continuum of care domains including treatment benefit, side effects, symptom management, care coordination, shared decision-making, advanced care planning, and affordability. These patient-reported outcomes are essential data for evaluating what we are doing well, what we need to work on doing better, and whether the care provided really makes a difference in patients' wellbeing. From the patient perspective, high value quality care involves frequent and continuous goal-oriented communication and decision support, quality of life and functional needs assessment, and services coordination throughout the care continuum. It must include flexibility to adjust care plans as patient priorities and preferences evolve, particularly during transitions where disease conditions have either improved or deteriorated.

Few clinical outcomes measures are available for evaluating these key aspects of quality care and care experiences. For example, of the top 5% of patients who drive approximately 60% of healthcare spending, 40% have multiple chronic conditions and functional limitations that they will live with for many years.¹⁸ Treating these patients requires the involvement of an interdisciplinary team that will deliver longitudinal care across populations, diagnoses, and care settings. Yet no measures exist that are useful to providers working in multiple settings with diverse patient populations. Similarly, providers do not currently have a reliable way to capture information about concordance of treatment with the patient's goals of care, nor changes in those goals that may occur over time, that can be shared across settings.

REAP urges CMS to direct funding allocated in MACRA for quality measure endorsement, input, and selection for collaborative development of new measures that address symptoms and goal-directed care and can be used across settings, patient populations, and disease types. As an initial step, CMS should expand the inclusion criteria for existing measures (e.g., patient population, care setting) and add the NQF-endorsed palliative care measures that address pain and symptom management and goal directed care in the MIPS measures list. REAP's membership organizations will be pleased to participate with CMS and stakeholders by contributing the patient and family perspective in determining and developing person-centered measure sets that meaningfully reflect patient and family values around quality of life, communication, care coordination, and other important domains.

5. Expand the definition of MIPS eligible clinician in future rulemaking. Under the proposed rule for the first two years in which MIPS applies to payments, the definition for eligible clinicians include the following disciplines: physician, physician assistant, nurse practitioner, clinical nurse specialist, certified registered nurse anesthetist. REAP supports CMS's stated intention to consider expanding the definition to include additional eligible clinicians (e.g., physical and occupational therapists, clinical social workers, and others) through

¹⁸Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press; 2015.

rulemaking in future years to reflect and encourage interdisciplinary, team-based services necessary to address the full spectrum of patient and family needs and quality of life concerns throughout the care continuum and across health system and community-based care settings.

6. Public Reporting on Physician Compare website should display provider quality performance information that matters to patients. CMS proposes public reporting of eligible clinicians' or groups' quality data on its Physician Compare website. REAP requests that CMS invite stakeholder input early in the process to ensure publication of clear, meaningful information that matters to patients and consumers (such as indicating whether providers regularly integrate patient priorities and goals into treatment plans). This effort should be done in a format that is easy to understand (e.g., using a straightforward approach comparable to the green checkmark CMS uses now to denote participation in CMS quality programs). Patients and families want to know that their health care team is committed to delivering person-centered and family-oriented care consistent with their goals. REAP will be pleased to work with CMS in contributing specific stakeholder input from the patient and family perspective to help ensure that the public reporting strategies and information published on the website meet peoples' needs.

7. Monitor the impact of MACRA implementation continuously to protect patient access to quality care. We applaud MACRA's intention to improve care quality and efficiency while reducing costs and the overall burden on providers from various Medicare reporting requirements. A potential consequence of the proposed rule, however, is that it could advantage large group practices over smaller, community-based practices, contributing to increased health market consolidation as more physicians join hospital staff or decide to discontinue accepting Medicare patients in their practices. This would have a significant impact on the patients we serve.

Patients have expressed high levels of concern about the possibility of their providers no longer accept Medicare, indicating they would have to travel farther to care, pay more out of pocket for care, and/or find a new treatment facility to get care, which could require going to the hospital, another community practice or physician office, or seeking treatment at a facility they believe is not as high quality.¹⁹

Moreover, many chronically and seriously ill patients are already constrained by medical debt, transportation concerns, and/or insurance coverage challenges. These patients simply cannot afford to travel longer distances and/or absorb potentially higher out-of-pocket expenses in the hospital setting. Frequently, they are also too sick to travel long distances to receive treatment.

Although patients across income levels experience problems with travel expenses, a much larger proportion of patients in the lowest income ranges report transportation difficulty than patients in the highest income ranges, even when their average travel miles are considerably less.²⁰

For patients with chronic, debilitating or life threatening diseases who are required to make frequent visits to their physicians, treatment sites, and pharmacies, transportation is essential for maintaining proper treatment protocol in the ongoing care and recovery process.

Lack of available transportation support can result in missed appointments, delayed treatment, and possibly even treatment abandonment. Ultimately, it can lead to poor management of conditions and worsened health outcomes.

¹⁹Patient Advocate Foundation Site of Care Survey May 2016.

²⁰Patient Advocate Foundation Patient Data Analysis Report 2015.

http://www.patientadvocate.org/pdar/2015_PDAR.pdf (Accessed June 12, 2016)

REAP urges CMS to consider these patient-centered concerns in developing detailed plans to monitor outcomes of the new payment models, particularly the impact on patient access to quality care in their preferred treatment location, and to describe what safeguards will be put in place to trigger immediate remedial steps if access is compromised. It is also essential to include safeguards in the payment models that prevent selection against individuals with more complex illnesses or a greater need for social support, as well as to ensure that expansion of population based payments does not lead to disparities in health outcomes.

Closing

REAP appreciates CMS's outreach seeking input from stakeholders on MACRA's implementation and the agency's thoughtful consideration of comments submitted in response. We look forward to working with CMS to achieve our shared goals for improving health care quality and value so that patients and families will ultimately benefit from improvements in how providers deliver more person-centered, goal-directed care. REAP members stand ready to provide further detailed information or answer questions about the patient groups we represent.

Sincerely,

Academy of Integrative Pain Management
Bladder Cancer Advocacy Network
Cancer Support Community
Colon Cancer Alliance
COPD Foundation
Epilepsy Foundation
Fight Colorectal Cancer
Global Healthy Living Foundation
Hypertrophic Cardiomyopathy Association
International Myeloma Foundation
Lung Cancer Alliance
LUNgevity Foundation
Men's Health Network
Mended Hearts
Mended Little Hearts
National Alliance on Mental Illness
National Minority AIDS Council
National Organization for Rare Disorders
National Patient Advocate Foundation
Prevent Cancer Foundation
Susan G. Komen
US Pain Foundation