



November 20, 2017

Seema Verma, Administrator  
Centers for Medicare & Medicaid Services  
Hubert H. Humphrey Building  
200 Independence Avenue, S.W., Room 445-G  
Washington, DC 20201

Amy Bassano, Acting Director  
Center for Medicare & Medicaid Innovation  
7500 Security Boulevard  
Baltimore, MD 21244

Dear Administrator Verma and Director Bassano,

The undersigned organizations, members of the Cancer Innovation Coalition (CIC) and the Regulatory Education and Action for Patients (REAP) Coalition appreciate the opportunity to provide feedback to the Center for Medicare and Medicaid Services (CMS) New Direction Request for Information. Collectively, our organizations represent the voices of millions of adults, children and families coping with chronic and serious illnesses nationwide.

REAP is a diverse group of patient advocacy organizations whose mission is to communicate collaborative perspectives on regulatory and legislative priorities to federal and state policymakers. REAP assures a wide range of patient concerns are considered in policy development to maximize care access and improved outcomes as well as minimize unintended consequences upon regulatory implementation. The Cancer Innovation Coalition is comprised of oncology-focused organizations that share an interest in addressing opportunities to foster innovative care delivery and payment models with the patient's voice at the center.

Our organizations share CMS' objective to foster an affordable, accessible healthcare system that puts patients first and empowers them to make informed decisions and we applaud CMS for formally soliciting stakeholder input on value-based innovation models and strategies that could effectively achieve these objectives.

People confronting serious, complex or chronic illness want reliable and affordable access to the medications and services they need to preserve quality of life and functioning, so they can live well with their conditions, and they want support that reduces burden on their caregivers. Meeting these quality markers will require value-based measures and payment innovations that reward better communication and care coordination while also strengthening the link between patient experience and financial performance.

Providing quality care for these high risk, high need populations involves expert attention to physical and psychological symptoms and person-centered communication and coordination throughout the care continuum. It also entails listening to what patients and their caregivers say is important to them so that treatments and services are matched with their goals, and wasteful overuse of drugs and technologies they may not want, or need is avoided. These are core palliative care skills that help maximize quality of life for the patient and family that should be

applied alongside disease treatment at any age or stage and in every care setting. All innovation models should integrate these clinical communication and coordination competencies as essential aspects of providing high quality care.

Overall, the six proposed guiding principles represent an important opportunity for the Innovation Center to drive delivery of person-centered care models that account for people's priorities and socioeconomic realities in providing treatments and services concordant with what's important to them. We agree that CMS must collaborate with health plans and providers to make necessary patient-centered changes. **We want to reinforce the critical importance of treating patient and caregiver perspectives as essential stakeholders for contributing person-focused expertise about quality and value throughout every aspect of model and measures design, development, implementation and evaluation.** As such, our comments address three person-centered and family-focused recommendations for building new and enhancing existing innovation models. Specifically, our organizations urge CMS to:

1. **Develop and use transparent processes** for consistently including patient and family stakeholder perspectives about quality and value important to them in every aspect of model design, development, implementation and evaluation;
2. **Use or create publicly reported quality measures** evaluating availability of skilled communication, care coordination and essential support services to equip patients and families with person-centered tools and information they need in making informed choices based on what matters to them; and
3. **Include patient- and family-reported experiences and outcomes measures** capturing attributes of care quality and professional performance that are important to them.

#### ***Develop processes for including patient and family stakeholder perspectives earlier***

Understanding how patients define and measure value on their terms is essential for meaningful quality improvement and value assessment. Clinicians also need this information to guide patients and families through the decision-making process and to make personalized recommendations about treating disease and optimizing quality of life. Yet care delivery and performance measurement has often involved interventions having only a small clinical benefit while at the same time neglecting many aspects of care that are important to patients and their families.

To achieve more person-focused quality care models, we urge CMS to develop and deploy transparent and consistent processes for soliciting and including patient and caregiver stakeholder input about what they value to inform the full arc of model design, development, implementation and evaluation. This would include enhancing opportunities to embed patient perspectives in the work of the Physician Focused Payment Model Technical Advisory Committee (PTAC). In making this recommendation, we encourage CMS to think expansively beyond Technical Expert Panel (TEP) participation to capture essential person-centered and family-focused stakeholder expertise and feedback earlier and continually throughout the process of model conceptualization, specification, testing, implementation and maintenance.

We are particularly appreciative and encouraged about the increase in patient stakeholder outreach efforts by the Innovation Center’s Division of Stakeholder Engagement, as staff have recently initiated a more consistent and proactive pattern of patient advocacy organization engagement and would like to see dedicated CMS attention and support for enhancing these outreach activities that can include perspectives of patient and caregiver stakeholders earlier and more consistently in every stage of the innovation model process.

***Publicly report person-centered quality measures and information that matters to consumers***

High-quality care includes person-focused goals that are responsive to a patient's most pressing problems or concerns as they experience them throughout their illness. While we support the formation of consumer-directed care models, we urge CMS to equip people with transparent information through publicly reported measures and tools describing plan offerings that emphasize quality and services availability addressing priority needs they care about and with less intense reliance on price.

People coping with serious, complex or chronic illness consider many factors that extend beyond cost and clinical outcomes in weighing healthcare benefits, risks and tradeoffs. They also think about how treatments will improve or diminish their lived experience and quality of life, including their ability to remain independent, maintain function, continue working and not be a burden on family or finances. Reporting appropriate quality measures addressing these domains will empower consumers to assess a plan or provider’s capacity to address what they need most when serious illness strikes.

It is our experience that skilled communication about what’s important to patients and their families, including treating the person beyond the disease, plays a central part in fostering shared decision-making that helps people consider tradeoffs and make informed choices aligned with their values. Findings from recent person-centered care research indicate that many patients define “value” of their care delivery experience in terms of having a relationship with their provider rooted in respect, trust and compassion.<sup>1</sup> Patients attach great importance to the quality of their relationships and conversations with clinicians that help them feel heard, and they also value care coordination, symptom management and access to supportive services that assist their families.

Fortunately, as value-driven quality improvement activities continue to evolve, practical solutions grounded in the person-centered principles of palliative care offer important guidance and a practical approach for involving patients and caregivers in defining how the concept of value applies to them when making treatment choices. Specifically, this approach uses skilled communication to explicitly ask patients and their families about what matters most to them, and uses the information elicited as the foundation for providing decision-making support that helps match disease treatments and supportive services with stated values.

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<sup>1</sup> Patient Advocate Foundation. The Roadmap to Consumer Clarity in Healthcare Decisionmaking. 2017. Available at: [https://www.npaf.org/wp-content/uploads/2017/07/RoadmapWhitePaper\\_ecopy.pdf](https://www.npaf.org/wp-content/uploads/2017/07/RoadmapWhitePaper_ecopy.pdf)

Models that best serve patients in terms of cost, quality and access should report on how prepared health plans, systems and professionals are to communicate about and coordinate person-centered care and provide support for family caregivers – key quality care competencies that are particularly important for medically complex populations coping with multiple chronic conditions. These person-centered considerations are valued by patients and caregivers as health care consumers, and they also constitute a foundational element of quality care delivery that helps balance health reform’s heavy reliance on clinical outcomes and cost in making value determinations about health care services and spending. Striking this balance to preserve personal choice, control and quality of life while minimizing costs is important for patients and their caregivers because it helps them engage meaningfully in shared decision-making and avoid subsequent decisional regret and associated distress.

Shared decision-making often involves a high degree of variability among both patients and providers. Concurrently, patients and caregivers typically receive little or no preparation on how to be part of the decision-making process.<sup>2</sup> Testing a standardized approach in emerging models could shed light on the best ways to operationalize meaningful patient engagement through skilled person-centered communication strategies. Any models testing shared decision-making approaches should seek to better prepare and train both patients and health professionals to effectively communicate about person-centered priorities and preferences in the context of care planning that matches treatments with goals.

We encourage CMS to work with stakeholders in developing and testing publicly reportable quality measures and other tools that empower consumers to assess various innovation models’ capacity to specifically address their medical, social and functional needs, including ability to reliably provide palliative care services in all settings as well as counseling, education and other support for family caregivers. Publicly reported measures evaluating communication, care coordination and support services preparedness will also help incentivize plans and their networks to pursue available evidence-based training for providers. Such training is necessary for all clinicians and case managers to enhance person-centered communication skills, symptom management and care delivery.<sup>3</sup>

***Include PROs on professional performance and care quality attributes that matter to patients***

Implementation of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) and its Quality Payment Program (QPP) holds potential to drive value-based care delivery innovation that improves the lives of patients living with serious, complex and chronic illness. To harness its true potential, patient reported outcomes (PRO) data informed by the expertise and experiences of patients themselves and their caregivers will be instrumental to meaningfully

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<sup>2</sup> Stiggelbout AM et al. Shared decision-making: concepts, evidence and practice. *Patient Education and Counseling*, 2015; 98:1172-79.

<sup>3</sup> See, e.g., VITALtalk communication skills development resources at [www.vitaltalk.org](http://www.vitaltalk.org) and Center to Advance Palliative Care communication, coordination, pain and symptom management curricula for generalists and specialists at [www.capc.org](http://www.capc.org).

measure the success of new models. Building on MACRA's momentum, CMS can use PROs to prioritize skilled communication, symptom management and quality of life as part of high quality disease treatment planning and shared decision-making throughout the care continuum to improve patient and family experiences and outcomes by linking PROs to financial performance.

Currently, the financial incentives in existing CMMI programs that might ensure a positive patient and family experience are weak. Using PROs can elevate the importance of person-centered clinical communication skills that help match treatments and services to patient values as a core competency integral to delivery of high quality care. They can also promote early integration of primary palliative care approaches in specialty practices to maximize patient and caregiver quality of life and their lived experience during treatments and care transitions.

PRO data can improve the quality of clinical conversations about person-centered priorities and needs, enhance patient-provider relationships and increase workflow efficiency and physician satisfaction.<sup>4</sup> More specifically, models could incorporate PROs that allow patients and caregivers the opportunity to assess and report on the quality of communication with their clinical team in terms of identifying and addressing the priority care needs and concerns most pressing for them. For example, Medicare's Oncology Care Model could test using PRO metrics that supplement the currently required physician-reported care plan measures to capture patient and caregiver feedback about their conversations experiences during clinic visits where treatment planning, goal setting, or care transition discussions take place, such as by asking them their level of agreement with the following statements:

- My care team asked me (and my caregiver) about what problems, symptoms and/or quality of life concerns are most important to me
- The care plan discussed and provided to me included information about how to help address the problems, symptoms and/or quality of life concerns most important to me
- The care plan discussed and provided to me included information explaining who will be responsible for addressing various aspects of my care, including help to manage the problems, symptoms and/or quality of life concerns most important to me

This person-centered PRO approach extends beyond the disease management focus of clinical guidelines adherence measures by facilitating better communication about patient-defined priorities, problems and quality of life concerns that build healthier connections for meeting

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4 Rotenstein LS, Huckman RS and Wagle NW. Making Patients and Doctors Happier – The Potential of Patient-Reported Outcomes. Perspective. *New England Journal of Medicine*. 2017;377(14).

patient and family needs<sup>5</sup> and improving their lived experience during and after treatment.<sup>6</sup> Embedding these person-centered communication strategies as part of treatment planning and quality reporting also aligns with the most current evidence and consensus standards calling for earlier integration of palliative care in multiple disease specialties.<sup>7 8</sup> Experts in the field have developed evidence-based communication skills development courses available through VITALtalk and the Center to Advance Palliative Care,<sup>9</sup> for example, that the Innovation Center could consult in considering proposed person-centered and family-focused models and measures. In addition, the National Academies of Sciences, Engineering and Medicine Roundtable on Quality Care for People with Serious Illness has published directly relevant workshop proceedings featuring resources and strategies for integrating patient and caregiver voices into serious illness care and models for integrating palliative care principles into care for people with serious illness.<sup>10</sup>

Our organizations are ready to continue providing feedback from the patient, caregiver and family perspectives throughout design and measurement of new innovative payment and delivery models. Please contact Nicole Braccio, policy director at National Patient Advocate Foundation ([Nicole.Braccio@npaf.org](mailto:Nicole.Braccio@npaf.org)), for further details or assistance.

Respectfully Submitted,

Arthritis Foundation  
Bladder Cancer Advocacy Network  
Cancer Support Community  
COPD Foundation  
Epilepsy Foundation  
FORCE: Facing Our Risk of Cancer Empowered  
Fight Colorectal Cancer  
Huntington's Disease Society of America  
International Myeloma Foundation  
Lung Cancer Alliance

LUNGeivity Foundation  
Mended Hearts and Mended Little Hearts  
National Alliance on Mental Illness  
National Multiple Sclerosis Society  
National Patient Advocate Foundation  
Susan G. Komen  
ZERO - The End of Prostate Cancer

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<sup>5</sup> Back AL, Arnold RM, Baile WF, et al. Faculty Development to Change the Paradigm of Communication Skills Teaching in Oncology. *Journal of Clinical Oncology*. 2009;27(7):1137-1141.

<sup>6</sup> Kamal AH, LeBlanc TW, Meier DE. Better palliative care for all: Improving the lived experience with cancer. *JAMA*. 2016;316(1):29-30.

<sup>7</sup> Ferrell BR, Temel JS, Temin S, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology*. 2017;35(1):96-112

<sup>8</sup> Braun LT, Grady KL, Kutner JS, et al. Palliative Care and Cardiovascular Disease and Stroke: A Policy Statement from the American Heart Association/American Stroke Association. *Circulation*. 2016;134(11): 198-225.

<sup>9</sup> VITALtalk <http://vitaltalk.org/clinicians> and Center to Advance Palliative Care <https://www.capc.org/topics/communication-and-palliative-care/> communication skills training curricula and resources for clinicians.

<sup>10</sup> National Academies of Sciences, Engineering and Medicine Roundtable on Quality Care for People with Serious Illness workshop proceedings and presentations accessible at <http://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable.aspx>.