



November 20, 2017

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

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

Dear Administrator Verma and Director Bassano,

On behalf of LUNGevity Foundation, the nation's preeminent lung cancer nonprofit that funds research, provides education and support, and builds communities for the 222,500 Americans diagnosed with lung cancer each year and the 527,228 Americans living with the disease, we appreciate the opportunity to submit our comments in response to the request for information (RFI) for the Center for Medicare and Medicaid Innovation (CMMI) within the Centers for Medicare and Medicaid Services (CMS) issued on September 20, 2017.

As a leading patient advocacy group that represents the voice and interest of the national lung cancer survivor community, by accelerating research to patients that is meaningful to them; empowering patients to be active participants in their care and care decisions; and helping remove barriers to access to high quality care, LUNGevity appreciates the opportunity to comment and believes that CMMI has a unique opportunity to improve the quality of care furnished to patients with lung and other cancers while reducing costs to both the patient and the public. Too often the voice of patients is lost in the discussion of "new and improved" models of healthcare, and we are encouraged that this RFI is a step toward ensuring patient-centered innovation.

LUNGevity is especially gratified that the RFI focuses on consumer-driven models of care. We encourage CMMI to involve patients and their caregivers in every aspect of the design, development, implementation, and evaluation of new models. In addition, these models should, to the degree possible, take into account patient-reported experiences and outcomes. To that end, we would like to bring to your attention LUNGevity's patient preference study, *Project Transform*. Our *Project Transform*, in partnership with Johns Hopkins School of Public Health, focuses on developing and applying novel methods to scientifically quantify patient preferences for the benefits and risks of treatments for lung cancer. The results of this initiative are intended to inform stakeholders, including regulators, of the true treatment preferences of people living with lung cancer. In addition to including patient-reported experiences and outcomes, we hope that CMS will focus on the development of patient-centered tools that will assist patients in making informed choices regarding their treatment in order to maximize their ability to achieve the care and outcomes they value.

However, a focus on patient-centeredness for outcomes and evaluations is only as good as the understood definition of the term. We note that in the CMMI's authorizing statute (Section 1115A(b)(4)(A)(i)<sup>1</sup>, CMS is obligated to assess "patient-level outcomes and patient-centeredness criteria" as determined by the Secretary. In addition, the Secretary is instructed to choose assessment measures that reflect national priorities for



“patient-centered” care. However, outside of the regulations for Accountable Care Organizations, we are unaware of any CMS-adopted definition of patient-centered in the development and evaluation of new models. We would encourage CMS to adopt a standardized definition of patient-centeredness, and to solicit significant stakeholder input in the development of such a definition. Adopting such a definition before developing new models, rather than attempting to fit existing models into patient-centered assessment criteria, should result in models where patients and their caregivers are truly at the center of innovation efforts, rather than merely a population to be considered after-the-fact.

We applaud CMMI’s guiding principles that testing should be small scale. To this, we would strongly encourage CMS, to the degree possible, to ensure that participation in models is voluntary for both patients and physicians. Truly patient-centered models must begin with the premise that there is no one-size-fits-all approach to providing and paying for patient care. Beginning with small demonstrations will allow new models to truly demonstrate their value. Congress’ intent in establishing CMMI was to create a testing ground for new patient and delivery models, not to press millions of patients into untested approaches, often without their knowledge. For cancer patients especially, the stakes are too high for the requirement of anything but proven approaches.

CMMI’s guiding principles are strong ones, and adherence to the intent of its authorizing statutes will be critical in ensuring that it continues its groundbreaking work into the future. To that end, we would like to encourage you to utilize the notice and comment rulemaking process as often as possible, so as to ensure that all stakeholders have the opportunity to make their voices heard. In addition, we stress the importance of a strong two-way relationship with authorizing and appropriating committees in Congress, whose members are constantly aware of their constituents’ needs for and issues with the Medicare and Medicaid programs. Innovation is critical to the continued success of these programs, but patient outcomes and access are central to CMMI’s mission of improving care, and should be at the forefront of all its efforts.

LUNGeVity is grateful for the opportunity to comment on this RFI and to engage in the crafting of a new direction for CMMI. The recommendations outlined above can be discussed with my staff, myself, and LUNGeVity’s Scientific Advisory Board, which is made up of some of the world’s leading experts in lung cancer biology, practice management, access to innovative medicines, and overall patient care. I can be reached at 240-454-3100 or [aferris@lungevity.org](mailto:aferris@lungevity.org) if you have any questions or would like to engage in further dialog.

Thank you for your attention to this very important matter.

Sincerely,

A handwritten signature in black ink, appearing to read "Andrea Ferris".

Andrea Ferris  
President and Chief Executive Officer  
LUNGeVity Foundation



**ABOUT LUNGEVITY:**

LUNGeVity's mission is to improve outcomes for people diagnosed with lung cancer. Our goals are three-fold: (1) to accelerate research to patients that is meaningful to them; (2) to empower patients to be active participants in their care and care decisions; and (3) to help remove barriers to access to high quality care. We have the largest lung cancer survivor network in the country and actively engage with them to identify, understand, and address unmet patient needs. We also have a world class Scientific Advisory Board that guides the programs and initiatives of the organization. Additionally, we collaborate with other lung cancer patient advocacy groups and organizations, such as the American Lung Association and CHEST, who serve the lung cancer community.

**REFERENCES:**

- 1) Social Security Act, Section 1115A(b)(4)(A)(i).** [https://www.ssa.gov/OP\\_Home/ssact/title11/1115A.htm](https://www.ssa.gov/OP_Home/ssact/title11/1115A.htm)