

August 2, 2018

Honorable Seema Verma
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
200 Independence Avenue, SE
Washington, DC 20201

Mr. Adam Boehler
Deputy Administrator and Director
Center for Medicare & Medicaid Innovation
Department of Health and Human Services
200 Independence Avenue, SE
Washington, DC 20201

Dear Administrator Verma and Director Boehler:

We are writing to express our support for the commitment the U.S. Department of Health and Human Services has expressed to patient-centered reforms, and to urge you to apply this commitment to the work of the Centers for Medicare and Medicaid Innovation (CMMI). In particular, as CMMI prepares to launch a new round of demonstrations, we ask that you soon establish critically important safeguards and principles to ensure these demonstrations are genuinely centered on the needs of patients and their families. Advancing patient-centered alternative payment models will require a commitment from the agency as well. Each of our organizations stand ready to collaborate with CMMI in this work. We propose three simple steps to establish the criteria called for by CMMI's statute:

1. Establish, via rulemaking, the “patient-centeredness criteria” mandated under Section 1115A of the Affordable Care Act, which requires evaluation of alternative payment models (APMs) against patient-centeredness criteria.

When this provision was enacted, we were hopeful that it would help pave the way for a shift to truly patient-centered approaches to value in U.S. health care; unfortunately, this provision has never been meaningfully implemented. CMS has set goals for demonstrating that its Innovation Center models lower costs and improve quality, yet there are no clear standards against which demonstrations can be held accountable for truly putting patients first.

2. Convene patient and consumer advisory panels for each of the Innovation Center models under development as well as those currently being implemented, to help ensure each demonstration is meaningfully evaluated against appropriate measures of patient-centeredness.

The panels would consist of representatives of patients and people with disabilities who are beneficiaries of the alternative payment model and have experience sufficient to identify the measurable outcomes that matter to them. Engagement of the panel must begin early in the model design process to ensure support and buy-in from people being served by the new payment model.

3. Define “informed decision-making” as a core criterion of patient-centeredness and a goal of each alternative payment model.

We believe, as you do, that substantial opportunities exist to improve health care value by equipping and empowering patients and their caregivers with the information they need to make the best decisions about their care. Patient advisory panels consisting of organizations representing patients and people with disabilities would be able to discern for each model how contracted entities could best ensure that patients are informed about their participation in an APM, all their treatment choices (as well as the financial incentives driving certain choices), associated out-of-pocket costs and the evidence base that supports their care and treatment. Only then can patients and people with disabilities truly be informed consumers in choosing the care that they value.

Therefore, we recommend that patient-centeredness criteria be explicitly tied to care delivery that seeks to understand and achieve individual patients’ goals for their care. Too often in health care, patients’ goals are silently assumed or dictated to patients, reducing their choices and engagement in their own care decisions. Health systems – both payers and providers – should be accountable for ensuring that a patient communicates information about what is important to them and that time is allotted to conduct the kind of shared decision-making that is called for by the National Quality Partners Playbook: Shared Decision-Making in Health Care. A tangible barrier to achieving patients’ goals for their care is that the time for care planning is not reimbursed or rewarded systematically. A patient advisory panel within each model could assess and provide recommendations to Innovation Center models on best practices for activating patients and people with disabilities, high quality decision aids, coding changes needed to adequately reimburse care planning and quality measures needed to capture outcomes that matter to people participating in the model.

Conclusion

In closing, patient-centered care, if done right, does not result in higher costs, but can indeed lower overall spending. As the agency seeks to change the culture of how we pay for care to put patients first, we urge these small steps toward identifying patient-centeredness criteria that give Innovation Center models a benchmark for meeting its goal. Please contact Sara van Geertruyden (sara@pipcpatients.org) related to our recommendations.

Sincerely,

Allfocus Technologies
Alliance for Aging Research
Allies for Independence
American Association of People with Disabilities
American Association on Health and Disability
American Foundation for the Blind
Arthritis Foundation
Association of University Centers on Disabilities
Autistic Self Advocacy Network

Brain Injury Association of America
Cancer Support Community
CancerCare
COPD Foundation
Davis Phinney Foundation
Depression and Bipolar Support Alliance
Disability Rights Education and Defense Fund
Epilepsy Foundation
Familial Hypercholesterolemia Foundation
Global Campaign for Cancer Survivorship
Global Liver Institute
Health Hats
Hydrocephalus Association
Lakeshore Foundation
Lung Cancer Alliance
Lupus and Allied Diseases Association, Inc.
LymeDisease.org
Men's Health Network
National Alliance on Mental Illness
National Hispanic Medical Association
National Infusion Center Association
National Kidney Foundation
National Multiple Sclerosis Society
National Patient Advocate Foundation
No Health without Mental Health
Not Dead Yet
NTM Info & Research, Inc
Partners for Better Care
Partnership to Improve Patient Care
Patrick Gee
Pediatric Congenital Heart Association
Rare Genomics Institute
Rosie Bartel
The Arc of the United States
The Center for Autism and Related Disorders
The diaTribe Foundation
The Michael J. Fox Foundation for Parkinson's
Research The Veterans Health Council
Tuberous Sclerosis Alliance
United Spinal Association
Vietnam Veterans of America
Whistleblowers of America