



April 30, 2015

The Honorable Sylvia Mathews Burwell
Secretary
Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Burwell:

Thank you for your work to improve quality and patient-centeredness in health care through the *Better, Smarter, Healthier* initiative. We urge you to keep patient needs and patient voices at the center of your effort. We learned through implementation of the Patient-Centered Outcomes Research Institute (PCORI) that the goal of patient-centeredness can only be achieved with a meaningful patient voice. When patients feel heard, they feel valued. When they feel valued, they have more confidence, contributing to a greater sense of well being, which any physician will tell you can only help them in their treatment path.

As you have noted, alternative payment models (such as accountable care organizations, bundled payment, and patient-centered medical homes) hold significant implications for patients and their caregivers. We believe that, if patients are put first, your initiative will foster a patient-centered health system valued by and effectively serving beneficiaries. Otherwise, the risk is that the initiative will define value in a “one size fits all” manner that does not recognize differences among patients, potentially undermining the ability of patients and their providers to tailor care for the outcomes that they prefer and value.

The pivotal shift to value-based payment holds significant implications for the patient-centeredness movement and the related issues of patient access and the physician-patient relationship. Patients’ voices need to be a part of this discussion. Therefore, we urge you to recognize patients as key stakeholders in this discussion, beginning with including patients within the Health Care Payment Learning and Action Network that will accelerate the transition to alternative payment models. Organizations representing patients and people with disabilities could provide a unique and valuable voice, in addition to the voices of state representatives, insurers, providers, business leaders and consumers whose participation has already been solicited.

At the heart of the Network’s activities should be a goal to align value-based payments and alternative payment models with principles of patient-centeredness. This means having a strong infrastructure for beneficiaries, including patients and people with disabilities, to be engaged in defining the measures of their success. The Food and Drug Administration through its Patient-

Focused Drug Development Program and PCORI have created methodologies to actively solicit and support patient engagement that could be modeled in the *Better, Smarter, Healthier* initiative. As you know, reform models most likely to succeed are those that support informed beneficiary decision-making, recognize the critical role of providers and the physician-patient relationship in informed decision-making, and put decisions in the hands of patients.

Therefore, we urge you to actively and specifically invite the participation of patients, patient organizations, and people with disabilities in the Network. We encourage you to build on existing best practices for patient engagement, and make it an explicit goal of the initiative to create a patient-centered health system.

We look forward to a clear and supportive engagement plan for beneficiaries, including patients and people with disabilities, in the *Better, Smarter, Healthier* initiative and in the Health Care Payment Learning and Action Network.

Sincerely,

Organizations

Alliance for Aging Research
Alpha-1 Foundation
Alzheimer's & Dementia Resource Center
American Association for Dermatologic Surgery Association
American Association of People with Disabilities
American Association on Health and Disability
American Gastroenterological Association
Asian & Pacific Islander American Health Forum
Association of Community Cancer Centers (ACCC)
Autistic Self Advocacy Network
Caring Ambassadors
Center for Adoption Support and Education
Central Florida behavioral health network
Citrus Council, National Kidney Foundation of Florida
Colon Cancer Alliance
Community Health Charities of Florida
COPD Foundation
Depression and Bipolar Support Alliance
Easter Seals
Elder Care Advocacy of Florida
Epilepsy Foundation
Epilepsy Foundation Central & South Texas
Epilepsy Foundation New England
Epilepsy Foundation of Greater Los Angeles

Epilepsy Foundation of Indiana
Epilepsy Foundation of Kentuckiana
Epilepsy Foundation of Michigan
Epilepsy Foundation of Nevada
Epilepsy Foundation of Northeastern New York, Inc.
Epilepsy Foundation of Northern California
Epilepsy Foundation of San Diego County
Epilepsy Foundation of Western Ohio
Florida State Hispanic Chamber of Commerce
H.E.A.L.S of the South
HealthHIV
Hepatitis Foundation International
Hispanic Health Initiatives
Immune Deficiency Foundation
Kidney Cancer Association
Lupus Foundation of Florida, Inc
Men's Health Network
Momentum Health Strategies
NAMI Florida
National Alliance for Hispanic Health
National Alliance on Mental Illness
National Association of County Behavioral Health and Developmental Disability Directors
National Health Council
National Kidney Foundation
National Patient Advocate Foundation
National Viral Hepatitis Roundtable
No Health without Mental Health (NHMH)
Not Dead Yet
Patient Services, Inc.
Patient-Centered Primary Care Collaborative (PCPCC)
PatientsLikeMe
Salud USA
Sjogren's Syndrome Foundation
Society for Women's Health Research
The FH Foundation
The Hepatitis C Mentor and Support Group, Inc. (HMSG)
United Cerebral Palsy
United Spinal Association

Individuals

Angel Arroyo

Bettyjo Bouchey

Charlotte Collins

Gwen Mayes

Janet Grace

Julie Moretz

Laura Roix

Lourdes Duarte

Rev. Bruce Hanson

Stephanie Atkinson

Steven Perry