



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