

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,

#ENDEPILEPSY

Alliance for Aging Research

Alpha-1 Foundation

Alpha-1 Foundation

Alzheimer's & Dementia Resource Center

American Association for Dermatologic Surgery Association

Association of Community Cancer Centers (ACCC)

American Association of People with Disabilities

American Association on Health and Disability

American Gastroenterological Association

Angel Arroyo

Asian & Pacific Islander American Health Forum

Autistic Self Advocacy Network

Bettyjo Bouchey

Caring Ambassadors

Central Florida behavioral health network

Charlotte Collins

Citrus Council, National Kidney Foundation of Florida

Colon Cancer Alliance

Community Health Charities of Florida

COPD Foundation

COPD Foundation

COPD Foundation

Depression and Bipolar Support Alliance

Easter Seals

Elder Care Advocacy of Florida

Epilepsy Foundation

Epilepsy Foundation Central & South Texas
Epilepsy Foundation of Greater Los Angeles
Epilepsy Foundation of Indiana
Epilepsy Foundation of Kentuckiana
Epilepsy Foundation of MI
Epilepsy Foundation of Nevada
Epilepsy Foundation New England
Epilepsy Foundation of Northern California
Epilepsy Foundation of Northeastern New York, Inc.
Epilepsy Foundation of Northeastern NY
Epilepsy Foundation of San Diego County
Epilepsy Foundation of Western Ohio
Florida State Hispanic Chamber of Commerce
Gwen Mayes
H.E.A.L.S of the South
HEALS of the South
HealthHIV
Hepatitis Foundation International
Hispanic Health Initiatives
Immune Deficiency Foundation
Janet Grace
Julie Moretz
Kidney Cancer Association
Laura Roix
Lourdes Duarte
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 Patient Advocate Foundation
National Viral Hepatitis Roundtable
No Health without Mental Health (NHMH)
Not Dead Yet

PatientsLikeMe

Patient Services, Inc.

Patient-Centered Primary Care Collaborative (PCPCC)

Rev. Bruce Hanson

Salud USA

Sjogren's Syndrome Foundation

Society for Women's Health Research

Stephanie Atkinson

Steven Perry

The FH Foundation

The Hepatitis C Mentor and Support Group, Inc. (HCMSG)

United Cerebral Palsy

United Spinal Association