

November 13, 2017

Honorable David J. Shulkin
Secretary
U.S. Department of Veterans Affairs
810 Vermont Ave
Washington DC 20420

Dear Secretary Shulkin:

We are writing to you to express our concern about the recently announced collaboration between the Institute for Clinical Effectiveness Review (ICER) and the Department of Veterans Affairs (VA) Pharmacy Benefits Management Services office. As we understand from reports about the collaboration, ICER will work with staff in the VA to integrate ICER reports into the VA formulary management process of evaluating the comparative clinical effectiveness and value of drugs. You may be aware that ICER utilizes a quality-adjusted-life-year (QALY) metric as the basis for its value assessments that is very controversial for its potentially discriminatory impact on people with disabilities and serious chronic conditions. In fact, in 1992, the U.S. Department of Health and Human Services determined the use of QALYs to determine Oregon's prioritized list of services in Medicaid to be discriminatory.

We are also very concerned that ICER does not sufficiently support patient engagement. Its reports have often been criticized by patients for lacking engagement early in the scoping process, not giving patients a vote on the value of treatments under review, and failing to initiate an update of the value framework based on the availability of real-world data. In an era when policy-makers and stakeholders are trying to improve the care that our veterans receive, it has been our hope to see the VA's health system embrace a patient-centered perspective, as opposed to becoming entrenched in a one-size-fits-all perspective of health care value. No two veterans are the same, or have the same health care needs, and each veteran deserves care from a health system that recognizes his or her unique needs and characteristics. Prescription drug coverage determinations based on flawed analyses like those conducted by ICER are not the answer and can only serve to further limit access to care for veterans with disabilities and serious chronic conditions, thereby exacerbating the challenges that they and their caregivers often face.

Alternatively, we strongly support an infrastructure for our engagement to ensure that the health system delivers value to veterans and their caregivers, with the goal of achieving outcomes that matter to them. Veterans with disabilities and serious chronic conditions want to have a strong role in coverage and formulary decisions to ensure that coverage reflects the real world needs of veterans. We want to help the VA be a model for putting patients first.

We recognize that the VA wants to lower health costs, without undermining health care quality. Yet, standardized care decisions create barriers to certain treatments for veterans that don't meet "average" thresholds, leading to increased costs when treatments fail the patient. When patients cannot access treatments that work for them, the VA system bears the cost of reduced treatment adherence, increased hospitalization and other acute care episodes, as well as the societal costs of increased disability over time. In this age of personalized medicine, the VA can reduce costs by

better targeting treatments shown to work on patients with similar characteristics, needs and preferences, thereby avoiding the waste of valuable resources on care that veterans do not value.

We look forward to learning from you about this collaboration with ICER, whether this collaboration may be extended beyond pharmacy benefits and into other clinical services, and the role that veterans themselves will play in ensuring that value determinations reflect our real world needs and concerns.

Sincerely,

Vietnam Veterans of America

The Veterans Health Council

The Retired Enlisted Association

Fleet Reserve Association

VetsFirst, a program of United Spinal Association

ACCSES

Allfocus Technologies

Alliance for Aging Research

Alliance for Patient Access

American Association of Neurological Surgeons and Congress of Neurological Surgeons

American Association of People with Disabilities

American Foundation for the Blind

Arthritis Foundation

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

Bladder Cancer Advocacy Network

Brain Injury Association of America

Cancer Support Community

CancerCare

Center for Autism and Related Disorders

Christopher & Dana Reeve Foundation

COPD Foundation

Department of Population Health Sciences & Duke Clinical Research Institute

Depression and Bipolar Support Alliance

Epilepsy Foundation
Global Liver Institute
Health Hats
Heart Valve Voice-U.S.
Immune Deficiency Foundation
Independence Associates, Inc
Lung Cancer Alliance
LUNGevity Foundation
Lupus and Allied Diseases Association
Miles for Migraine
National Alliance on Mental Illness
National Disability Rights Network
Partnership to Improve Patient Care
RetireSafe
TASH
The Arc
Patricia Heyn, University of Colorado
Deborah Kaplan