

May 9, 2018

Francis J. Crosson, MD
Chairman
Medicare Payment Advisory Commission
425 I Street, N.W. Suite 701
Washington, DC 20001

James E. Mathews, Ph.D.
Executive Director
Medicare Payment Advisory Commission
425 I Street, N.W. Suite 701
Washington, DC 20001

Dear Dr. Crosson and Dr. Mathews:

The undersigned organizations representing patients, people with disabilities, providers and others are writing to express our deep concern with renewed consideration of cost-effectiveness in Medicare policy by the Medicare Payment Advisory Commission (MedPAC). Specifically, we are concerned by the MedPAC sessions dedicated to “Comparative Effectiveness Research in Medicare” in September 2017, to “Cost Effectiveness in Medicare” in March 2018, and to “Medicare Coverage Policy and Use of Low Value Care” in April 2018. We believe cost-effectiveness thresholds are fundamentally flawed as the basis for Medicare coverage or payment policy and are troubled that the negative implications for access to needed care were not adequately discussed during these MedPAC sessions. As we understand, MedPAC staff are drafting a chapter for the June 2018 report that would discuss the role of cost effectiveness in Medicare policy. We urge MedPAC to reject this approach in favor of more patient-centered approaches to pursuing better value and affordability in the Medicare program.

We share an interest in paying for care that is valuable to patients and people with disabilities. With advancing innovation around personalized and precision medicine, as well as tools for shared and informed decision-making, we strongly support alignment of health care access and coverage with the treatment providing the best outcomes for the individual.

By contrast, the most common method for determining incremental cost-effectiveness of healthcare interventions is based on a calculation of quality-adjusted-life-years (QALYs).¹ Unfortunately, it has been recognized by many stakeholders, including health economists, that QALY-based analyses can systematically overlook important differences among people with disabilities and patients with complex conditions.² In 1992 the Secretary of the U.S. Department of Health and Human Services (HHS) publicly recognized the discriminatory impact of QALYs for people with disabilities when used to determine access to care.³ Congress further recognized the risk of QALYs as the basis for health

¹ Partnership to Improve Patient Care; Measuring Value in Medicine: Uses and Misuses of the Quality-Adjusted-Life-Year; Retrieved at http://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc_white_paper_-_measuring_value_in_medicine_-_uses_and_misuses_of_the_qaly.pdf

² Tara A. Lavelle, David M. Kent, Christine M. Lundquist, Teja Thorat, Joshua T. Cohen, John B. Wong, Natalia Olchanski, and Peter J. Neumann; Patient Variability Seldom Assessed in Cost-effectiveness Studies, *Medical Decision Making*, Vol 38, Issue 4, pp. 487 – 494, Jan. 19, 2018.

³ Sullivan, Louis W. M.D. Secy. of Health and Human Services, Washington, (Aug. 13, 1992). Oregon Health Plan is Unfair to the Disabled, *New York Times*. Retrieved at <http://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>.

care decision-making in the Affordable Care Act, including a provision that prohibits use of cost/QALY thresholds in Medicare policy.

For that reason, we have significant concerns about MedPAC's consideration of whether cost-effectiveness has a place in Medicare payment policy. People with disabilities have a long history opposing the use of QALYs as the benchmark to measure the value of health care interventions, because of the potential implications for access to necessary treatments and interventions.⁴

We are concerned that the "incremental approach" suggested by commissioners may be intended to impose cost effectiveness over time, thereby avoiding intense scrutiny despite its methodological flaws and long-term impact on access to care. Additionally, such a policy recommendation would rely on overturning or undermining the law passed in 2010 by Congress banning Medicare from incorporating the QALY metric used in cost effectiveness analyses.

Policymakers look to MedPAC for recommendations that will not only lower health costs, but better align it with high-quality healthcare. Incorporating simplistic average measures of value into Medicare only hinders progress and innovation, as well as increases discrimination against those who do not fit the average. No patient is average. Instead, we want MedPAC proposing policies that allow patients and people with disabilities to get high value care tailored to their unique characteristics, needs and individual response to treatment.

We look forward to engaging with MedPAC so the commissioners and staff are hearing the perspectives of patients and people with disabilities who are ultimately most impacted by your recommendations. We have asked Sara van Geertruyden (sara@pipcpatients.org, 202-688-0226; 100 M St SE, Suite 750, Washington, DC 20003) to be our point of contact for additional questions or concerns.

Sincerely,

Aimed Alliance
Alliance for Aging Research
Alliance for Patient Access
American Association of Neurological Surgeons
American Association of People with Disabilities
American Foundation for the Blind
American Gastroenterological Association
Arthritis Foundation
Association of University Centers on Disabilities
Autism Society of America
Autistic Self Advocacy Network
Bladder Cancer Advocacy Network

⁴ *Id*, Partnership to Improve Patient Care; Measuring Value in Medicine: Uses and Misuses of the Quality-Adjusted-Life-Year.

Brain Injury Association of America
Cancer Support Community
CancerCare
Clinician Task Force
Congress of Neurological Surgeons
Cutaneous Lymphoma Foundation
Epilepsy Foundation
Genetic Alliance
Hydrocephalus Association
International Foundation for Autoimmune & Autoinflammatory Arthritis
Kidney Cancer Association
Lupus and Allied Diseases Association
Mended Hearts
Miles for Migraine
National Alliance for Hispanic Health
National Alliance on Mental Illness
National Infusion Center Association
No Health without Mental Health
Not Dead Yet
Partnership to Improve Patient Care
PXE International
RetireSafe
Robert DeMichelis
Susan Lin
The American Academy of Allergy, Asthma & Immunology
The Arc of the United States
The Davis Phinney Foundation for Parkinson's
The Headache and Migraine Policy Forum
The Society of Thoracic Surgeons
The Veterans Health Council
Tuberous Sclerosis Alliance
Vietnam Veterans of America
Whistleblowers of America