CANCERcare®
Help and Hope

February 22, 2019

Honorable Andrea Stewart-Cousins
Majority Leader
New York State Senate
188 State Street
LOB 907
Albany, NY 12247

Honorable John Flanagan
Minority Leader
New York State Senate
State Capitol Building Room 315
Albany, NY 12247

Honorable Carl Heastie
Speaker
New York State Assembly
LOB 932
Albany, NY 12248

Honorable Brian Kolb
Assembly Minority Leader
New York State Assembly
LOB 933
Albany, NY 12248

Dear Majority Leader Stewart-Cousins, Speaker Heastie, Minority Leader Flanagan and Minority Leader Kolb:

We represent millions of cancer patients, people with disabilities and serious chronic conditions, and families throughout New York and the U.S. We are writing to oppose an Executive Budget provision under consideration in New York, which explicitly authorizes reliance on a third-party researcher, with no limitations on their research methods such as using quality-adjusted-life-years (QALYS), to decide the value of treatments. These are then used by payers to determine their reimbursement and coverage. As organizations representing patients and people with disabilities, we oppose one-size-fits-all definitions of value being used to create arbitrary thresholds in our state healthcare system, especially when they rely on discriminatory methods such as QALYs, which are typically the basis of third-party value assessments.

QALYs are well-known to discriminate against patients with chronic diseases, seniors, and people with disabilities. QALYs place greater value on years lived in full health, or on interventions that prevent loss of perfect health, while discounting gains of health for individuals with chronic illnesses. As a result of this calculation, it may be determined that people with disabilities and serious chronic conditions are not worth treating.[1] For example, if a QALY methodology was used to determine whether Jimmy Carter's use of immunotherapy

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[1] See https://www.healthaffairs.org/do/10.1377/hblog20181025.42661/full/

would be covered by Medicare, coverage would have been denied and he would not be alive today.

The U.S. has repeatedly rejected the use of cost-effectiveness assessments and QALYs to make coverage decisions for treatments in our public programs, opting for more fair and equitable ways to make coverage decisions. In 1992, the U.S. Department of Health and Human Services rejected the state of Oregon's request to proceed with their prioritized list based on explicit cost-effectiveness ratios derived from QALYs, citing the potential for the method to discriminate against people with disabilities, which would violate the Americans with Disabilities Act.[2] Additionally, federal statute precludes Medicare from making coverage decisions based on QALYs or similar metrics.[3]

Currently, New York's Drug Utilization Review (DUR) Board is not precluded from using the QALY-based standard to determine medicine reimbursement and coverage policies. In fact, the most recently released Executive Budget proposal would make permanent the use of cost-effectiveness assessments conducted by third-parties, such as the QALY-based studies conducted by the Institute for Clinical and Economic Research (ICER). This is being done to limit patient access to medical treatments in New York, without even soliciting their input on the value of treatments.

Thresholds of cost effectiveness fail to consider important differences among patients by relying on averages to define value, but no patient is average. A recent study published by Tufts University found that less than one quarter of cost-effectiveness analyses accounted for even the most basic differences among patients.[4] When coverage polices are based on cost-effectiveness calculations, accountants and actuaries make medical decisions for patients and people with disabilities, overriding individual patient-centered decisions that are based on personal needs, preferences and their physicians' judgments.

While we agree that lowering health care costs and affordability represent important policy challenges, we do not think that the state should facilitate the denial of or restrictions on access to medically necessary treatments that can improve and/or save the lives of patients. State policy should not establish a mechanism that deems some patients and people with disabilities as "too expensive" to receive care.

We urge you not to move forward with this provision of the Executive Budget authorizing the use of a singular third-party to determine the value of treatments. Instead, we encourage the State of New York to prohibit the use of discriminatory methods that rely on a cost-per-QALY or similar metric to determine reimbursement and coverage decisions.

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[2] See https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html

[3] 111th Congress of the United States of America. (2010). H.R. 3590 The Patient Protection and Affordable Care Act. Section 1182. Washington, DC.

[4] T Lavalle, D Kent, et al. "Patient variability seldom assessed in cost-effectiveness studies." Medical Decision Making. 2018.

We look forward to working with you on fair and equitable patient-centered solutions. If you would like to discuss this issue, please contact Ellen Sonet (esonet@cancercare.org) or Trish Goldsmith (pgoldsmith@cancercare.org), or call either of us at 212-712-8400.

Sincerely,

Aimed Alliance
Alliance for Aging Research
Alliance for Patient Access
American Academy of Physical Medicine and Rehabilitation
American Association of People with Disabilities
American Association on Health and Disability
Arthritis Foundation
Association of University Centers on Disabilities (AUCD)
Asthma and Allergy Foundation of America
Autistic Self Advocacy Network
Boomer Esiason Foundation
Brain Injury Association of America
Brain Injury Association of New York State
Cancer Support Community
Cancer*Care*
Caregiver Action Network
Caregiver Voices United
Center for Disability Rights
Cure SMA
Cutaneous Lymphoma Foundation
Cystic Fibrosis Engagement Network
Diabetes Patient Advocacy Coalition
Epilepsy Foundation
Epilepsy Foundation of Long Island
Epilepsy Foundation of Metropolitan New York
Epilepsy Foundation of Northeastern New York, Inc.
Gunnar Esiason, Cystic Fibrosis patient advocate
Lakeshore Foundation
Lung Cancer Alliance
LUNGevity Foundation
Lupus and Allied Diseases Association, Inc.
MLD Foundation
Multiple Sclerosis Foundation
National Alliance on Mental Illness
National Alliance on Mental Illness-New York State (NAMI-NYS)
National MPS Society
New York Association of Psychiatric Rehabilitation Services
NHMH - No Health without Mental Health
Not Dead Yet
NTM Info & Research, Inc.
Partnership to Improve Patient Care
The Headache and Migraine Policy Forum
Tuberous Sclerosis Alliance
United Spinal Association
Whistleblowers of America