

December 13, 2019

Honorable Marylou Sudders, MSW, ACSW  
Secretary  
Executive Office of Health and Human Services  
Commonwealth of Massachusetts  
1 Ashburton Place  
Boston, MA 02108

Massachusetts Health Policy Commission  
Mr. David Seltz  
Executive Director  
50 Milk Street  
8th Floor  
Boston, MA 02109

Dear Secretary Sudders and Mr. Seltz:

We are writing in response to proposals from both the Commonwealth of Massachusetts Executive Office and the Massachusetts Health Policy Commission related to their consideration of the “value” of medications as a part of the oversight and administration of prescription drug pricing. The affordability of health care is a significant priority for patients and people with disabilities, and we applaud efforts to reduce the cost of care. Yet, we are concerned about proposals to identify a “value” for a drug by referencing prices paid by other countries, the seriousness and prevalence of the disease or condition that is treated by the drug, and analyses by third parties, which could include the Institute for Clinical and Economic Review (ICER). In these proposals, there is no clear definition for “outcomes,” “seriousness” of a condition, nor “equivalence” of medications, which is problematic as it opens the door to “value” being determined solely by cost versus benefit to people with disabilities and serious chronic conditions.

As you know, the patient and disability communities have long had concerns about the use of the discriminatory Quality-Adjusted Life Year (QALY) to determine cost effectiveness or “value” of treatments. QALYs and similar metrics are referenced in other countries and in studies by independent third parties, such as ICER. The National Council on Disability (NCD), an independent federal agency, recently concluded that QALYs place a lower value on treatments which extend the lives of people with chronic illnesses and disabilities. NCD recommended that policymakers and insurers reject QALYs as a method of measuring cost-effectiveness for medical care and avoid referencing international pricing due to its reliance on QALYs.<sup>1</sup>

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<sup>1</sup> [https://www.ncd.gov/sites/default/files/NCD\\_Quality\\_Adjusted\\_Life\\_Report\\_508.pdf](https://www.ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf)

Historically, the QALY has been opposed by the American public and policy makers. In fact, there is currently a ban on use of the QALY or similar metrics in Medicare.<sup>2</sup> In 1992, a Republican administration established that Oregon's efforts to utilize a cost-effectiveness standard in Medicaid would violate the Americans with Disabilities Act.<sup>3</sup> Therefore, we have concerns that this metric is creeping into our state's health system through the back door of referencing international prices and third party studies such as ICER's flawed QALY-based value assessments.

We know that patients and people with disabilities in the countries that are likely to be referenced frequently experience delayed or lack of access to medications they need. Only 39% of medicines launched globally between 2008 and 2012 were available in Canada in 2013, and 38% of medicines to treat orphan conditions were rejected for coverage in Canada.<sup>4</sup> Between 2007 and 2017, nearly 80% of cancer treatments reviewed by U.K. health officials had some form of access restriction.<sup>5</sup>

Traditional cost effectiveness analyses rely on the QALY and similar one-size-fits-all summary metrics. When conducted by groups such as ICER, patients, caregivers, and clinicians with firsthand experience with the condition under review are excluded from the voting process. Their analyses are intended for use by insurers, evaluating cost effectiveness from the perspective of payers, and omitting data on outcomes that matter to patients.<sup>6</sup> By contrast, it is our goal for the state's public programs to be centered on the needs, outcomes and priorities of patients and people with disabilities.

We oppose opening the door in Massachusetts to the use of cost-effectiveness analyses based on the QALY and similar metrics, which would lead to discrimination and restricted access to care. We urge you to review carefully the recent NCD report raising concerns about the potential implications of use of QALYs under the ADA, particularly Section 504 and Section 1557.

Thank you for your consideration. Please feel free to reach out to Thayer Surette at [thayer@pipcpatients.org](mailto:thayer@pipcpatients.org) or 508-843-1688 with any questions or if you would like to discuss in more depth.

Sincerely,

The ALS Association – Massachusetts Chapter

Epilepsy Foundation New England

The HeartBrothers Foundation

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<sup>2</sup> 111th Congress of the United States of America. (2010). H.R. 3590 The Patient Protection and Affordable Care Act. *Section 1182*. Washington, DC.

<sup>3</sup> <https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>

<sup>4</sup> [http://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc\\_canada.pdf](http://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc_canada.pdf)

<sup>5</sup> [http://www.pipcpatients.org/uploads/1/2/9/0/12902828/united\\_kingdom.pdf](http://www.pipcpatients.org/uploads/1/2/9/0/12902828/united_kingdom.pdf)

<sup>6</sup> [http://www.pipcpatients.org/uploads/1/2/9/0/12902828/2020\\_voh\\_framework\\_comments\\_.pdf](http://www.pipcpatients.org/uploads/1/2/9/0/12902828/2020_voh_framework_comments_.pdf)

Lupus and Allied Diseases Association, Inc.

National Eczema Association

National Infusion Center Association

Partnership to Improve Patient Care