

The Honorable Mike Johnson  
Speaker of the House  
United States House of Representatives  
Washington, DC 20515

The Honorable Hakeem Jeffries  
Democratic Leader  
United States House of Representatives  
Washington, DC 20515

The Honorable Steve Scalise  
Majority Leader  
United States House of Representatives  
Washington, DC 20515

The Honorable Katherine Clark  
Democratic Whip  
United States House of Representatives  
Washington, DC 20515

The Honorable Tom Emmer  
Majority Whip  
United States House of Representatives  
Washington, DC 20515

The Honorable Pete Aguilar  
Democratic Caucus Chairman  
United States House of Representatives  
Washington, DC 20515

The Honorable Elise Stefanik  
Republican Conference Chairman  
United States House of Representatives  
Washington, DC 20515

The Honorable James Clyburn  
Assistant Democratic Leader  
United States House of Representatives  
Washington, DC 20515

**February 5, 2024**

**RE: Urge Support for H.R. 485: Banning QALYs in Federal Programs**

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Dear House Leaders,

We write as patient representatives of more than 100 patient advocacy organizations to ask each of you to **support H.R. 485, the Protecting Healthcare for All Patients Act**. This bill will protect vulnerable Americans by banning the use of Quality-Adjusted Life Years (QALY) in all federal programs.

Why do we need to ban QALY? In a time when we are demanding more evidence and scientific rigor from the treatments being developed and approved, why would we turn their coverage determination in federal programs over to an arbitrary metric? The QALY is an antiquated metric that does not meet today's scientific standards for the practice of evidence-based medicine. It is a troubling measure used to place a value on a person's life, discounting the worth of the

disabled, aged, and those living with chronic or life-threatening illnesses<sup>1</sup>. In the simplest of terms, QALYs state that people who are very sick, old, or disabled have a lower value. Ultimately, use of QALYs translates into an ultra-utilitarian view, meaning that fewer resources should be spent on those deemed to be elderly, disabled, or sick because one year of their life is assumed to be “lower quality” and thus worth less than that of a “perfectly healthy” person.

Evidence that the QALY represents a true patient preference or value is nonexistent, perhaps because QALY was originally developed as a policy tool for rationing of healthcare services in the UK’s NHS rather than as an evidence-based, patient-centric measure.<sup>2</sup> QALY values are estimated from population-level surveys around health preferences; these preference-based survey instruments can be notably problematic and have been shown to “perform inconsistently in some populations” including in patients with cardiovascular disease, the leading cause of death in the United States.<sup>3</sup>

The QALY does not represent the value of a medicine or treatment to a patient. It does not measure what it purports to measure.<sup>4</sup> It is a clumsy, blunt instrument, failing to adequately capture or reflect what patients consider to be meaningful improvements in health or what patients say that they value.<sup>5</sup> The full limitations and flaws of the QALY do not need to be rehashed in this letter because they are well documented in published, peer-reviewed literature by world renowned physicians, economists, and policymakers.<sup>6</sup>

As patients, we understand that cost must be weighed against meaningful benefit for medical innovations, but we demand that metrics used to establish a treatment’s value be evidence-based, scientifically rigorous, and unbiased—just as we demand rigorous, unbiased clinical trial evidence to demonstrate safety and efficacy. The QALY is inherently biased, unscientific, and lacking in evidence that would justify its widespread use in policy. This does have a direct impact on patients—we have seen real-world examples of state Medicaid

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<sup>1</sup>Schneider, P. The QALY is ableist: on the unethical implications of health states worse than dead. *Qual Life Res* 31, 1545–1552 (2022). <https://doi.org/10.1007/s11136-021-03052-4>

<sup>2</sup> MacKillop E, Sheard S. Quantifying life: Understanding the history of Quality-Adjusted Life-Years (QALYs). *Soc Sci Med*. 2018 Aug;211:359-366. <https://pubmed.ncbi.nlm.nih.gov/30015244/>

<sup>3</sup> Finch, A.P., Brazier, J.E. & Mukuria, C. What is the evidence for the performance of generic preference-based measures? A systematic overview of reviews. *Eur J Health Econ* 19, 557–570 (2018). <https://doi.org/10.1007/s10198-017-0902-x>

<sup>4</sup> Gafni A. The quality of QALYs (quality-adjusted-life-years): do QALYs measure what they at least intend to measure? *Health Policy*. 1989 Oct;13(1):81-3. doi: 10.1016/0168-8510(89)90112-7. [PMID: 10296157](https://pubmed.ncbi.nlm.nih.gov/10296157/).

<sup>5</sup> Hirpa M, Woreta T, Addis H, Kebede S (2020) What matters to patients? A timely question for value-based care. *PLoS ONE* 15(7): e0227845. <https://doi.org/10.1371/journal.pone.0227845>

<sup>6</sup>Pettitt, David & Raza, Sajid & Smith, James. (2016). The Limitations of QALY: A Literature Review. *Journal of Stem Cell Research & Therapy*. [06. 10.4172/2157-7633.1000334](https://doi.org/10.4172/2157-7633.1000334).

programs citing QALY-based reports to attempt to justify discrimination against patients based on a disability.

Congress must be looking to the future and doing everything in its power to ensure the 21st century treatments and cures available now, and those on the horizon, are valued with unbiased and scientific 21st century instruments, not a 50-year old tool that has never been truly fit for this purpose. We should be looking for ways to measure value based on what it actually means to a patient, and not what we think it should mean to a patient.

Fortunately, innovations in drug pricing mechanisms and outcomes measurement are likely to make the QALY obsolete in coming years. Outcomes Based Agreement programs that align incentives and reward meaningful clinical outcomes for new therapies are just one example of such innovations.<sup>7</sup> The ongoing interest and excitement of policymakers, pharmaceutical manufacturers, hospital groups, and health insurers around such programs highlight that these types of value-based arrangements are the future, representing a patient-centric way to expand access to medicines and control costs. These represent just one new approach, but indicate that there are many possible ways that patients, physicians, pharma, and payers could work together to find solutions that are patient-centric and make sense for specific situations and conditions while creating win-win solutions. The QALY—by placing a restrictive value on the life of a patient, rather than seeking to maximize the value of healthcare dollars to achieve meaningful outcomes—is a relic of the past and creates losing situations for patients.

We should be looking at measures of patient satisfaction and value based outcomes of medicine, rather than placing a value on the life of the *type of patient* before a medicine is even approved.

**We urge you and your colleagues to support and advance the Protecting Healthcare for All Patients Act (H.R. 485) and ban the use of Quality-Adjusted Life Years (QALY) in all federal programs.**

We commend each of you for your ongoing efforts to make sure the access needs of our most vulnerable patients remain a priority and appreciate your leadership and support on this critical patient issue.

Sincerely,

Aimed Alliance

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<sup>7</sup><https://pink.pharmaintelligence.informa.com/PS147749/Cell-And-Gene-Therapy-OutcomesBased-Contracts-In-Medicaid-Need-National-Support-HHS-Says>

Akari Foundation  
Alliance for Aging Research  
Alliance for Patient Access  
Alpha-1 Foundation  
ALS Association  
AMAC Action  
American Association of Kidney Patients  
American Association of People with Disabilities  
American Association on Health and Disability  
American Behcet's Disease Association (ABDA)  
Autistic People of Color Fund  
Autistic Women & Nonbinary Network  
Autoimmune Association  
Autoinflammatory Alliance  
Avery's Hope  
Best Day Ever Foundation  
CancerCare  
Cancer Support Community  
Caregiver Action Network  
Caring Ambassadors Program  
Center for Autism and Related Disorders  
Center for Medicine in the Public Interest  
Children with Diabetes  
Chronic Care Policy Alliance  
Chronic Disease Coalition  
Coalition of Texans with Disabilities  
Color of Gastrointestinal Illnesses  
Cutaneous Lymphoma Foundation  
Cystic Fibrosis Research Institute  
Davis Phinney Foundation for Parkinson's  
Dementia Alliance International  
Derma Care Access Network  
Diabetes Leadership Council  
Diabetes Patient Advocacy Coalition  
Disability Law Center  
Disability Rights California  
Disability Rights Center New Hampshire  
Disability Rights Iowa

Disability Rights Montana  
Disability Rights North Carolina  
Disability Rights Pennsylvania  
Disability Rights South Carolina  
Disability Rights Vermont  
Disability Rights Washington  
EB Legal Aid Society  
Equip for Equality  
Free2Care  
Galatosemia Foundation  
Genetic Alliance  
Global Colon Cancer Association  
Global Healthy Living Foundation  
GO2 for Lung Cancer  
Hawaii Disability Rights Center  
Headache and Migraine Policy Forum  
Hereditary Angioedema Association  
HIV + Hepatitis Policy Institute  
I AM ALS  
ICAN, International Cancer Advocacy Network  
Infusion Access Foundation  
Kentucky Protection and Advocacy  
Lakeshore Foundation  
Lewy Body Dementia Association  
Looms for Lupus  
LuMIND IDSC  
Lupus and Allied Diseases Association  
Lupus Foundation of America  
Mental Health America  
MLD Foundation  
Myasthenia Gravis Foundation of America  
Myositis Support and Understanding  
National Alliance for Caregiving  
National Association for Continence  
National Disability Rights Network  
National Down Syndrome Society  
National Scleroderma Foundation  
Neuropathy Action Foundation

Nevada Disability Advocacy and Law Center  
North Dakota Protection and Advocacy Project  
Ohio Council for Cognitive Health  
Partnership to Advance Cardiovascular Health  
Partnership to Fight Chronic Disease  
Partnership to Improve Patient Care  
Patients Rising  
Patients Rising Now  
Pioneer Institute  
Practicing Physicians of America  
Prevent Blindness  
PXE International  
Rare Access Action Project (RAAP)  
Second Wind Dreams  
Special Operations Association of America (SOAA)  
SSADH Association  
Support for People with Oral and Head and Neck Cancer (SPOHNC)  
Survivors for Solutions  
SYNGAP1 Foundation  
Texas Rare Alliance  
The Akari Foundation  
The Bonnell Foundation  
The Coelho Center for Disability Law, Policy and Innovation  
The Foundation to Eradicate Duchenne  
The PERT Consortium  
The Waiting Room Entertainment  
Triage Cancer  
U.S. Pain Foundation

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cc: The Honorable Cathy McMorris Rodgers, Chair, Energy and Commerce Committee  
The Honorable Frank Pallone, Ranking Member, Energy and Commerce Committee  
The Honorable Jason Smith, Chairman, Ways and Means Committee  
The Honorable Richard Neal, Ranking Member, Ways and Means Committee  
The Honorable Michael Burgess, M.D.  
The Honorable Brad Wenstrup, M.D.