

Dear Dr. Olson:

We are writing to provide comments on the Oregon Health Evidence Review Commission (HERC) proposed guide for use of quality-adjusted life years (QALYs) in HERC's meeting materials, processes and decisions, particularly related to the prioritized list of services for coverage under Medicaid. As patients and people with disabilities have commented in the past, the use of QALYs has no place in health care decisions due to their inherent discriminatory algorithms that drive health inequity. We urge the HERC to delay its vote on the use of QALYs and instead take the time to meet with experts representing patients and people with disabilities as part of its November meeting. This issue is too important to rush to a vote. The alternatives in front of the HERC do not sufficiently address the shortcomings of QALYs.

The HERC states that QALYs are a way for researchers to measure and predict the value of a medical service and its effect on a person's length and quality of life. It is apparent from prior conversations at the HERC that the commissioners do not have a full understanding of the QALY metric and its flaws. The QALY fails to value health care for patients and people with disabilities, particularly people of color disproportionately represented among people with disabilities and chronic conditions, in several ways.

First, the QALY devalues a year of life lived with a disability, including chronic illness and rare diseases by attributing it with a numerical value below a 1 for optimal health, endowing disabled lives with a fraction of the value of "healthy" lives or, in some cases, a negative valuation, meaning a year of life in that health state is worse than death. Second, the QALY and similar metrics such as the equal value of life year gained are overly simplistic. The patient-reported outcomes (PRO) instruments used to collect data to feed the QALY are incredibly broad and fail to capture the nuance of the disease or attribute value to the outcomes that matter to people living with the condition. The "weights" that are then applied to the PRO data are determined from surveys of the general population. Reliance on population-based surveys to calculate health utility weights is especially troubling, as research has shown that disability bias is rampant among the general population.¹ These two things combined lead to metrics that fail to account for the gains in quality of life that are attributed to improvements such as the ability to sit up, the impact on caregiving needs, and ability to work, instead relying on broad surveys to determine whether a treatment's impact is valuable. Third, over-reliance on life extension as part of the calculation disadvantages people whose expected life span may be shorter due to their age, disability, condition, race and ethnicity, or other factors. Lastly, it is well-known that the research driving QALY calculations often does not represent key subpopulations for whom treatments may have a differential impact from the averages or for whom treatment is more valuable due to a history of systemic racism or discrimination that has stymied access to effective treatments.

¹ <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00504>

Patients and people with disabilities shared a letter with the HERC in advance of its consideration of several proposals to consider QALYs in advance of its October, 2022 meeting that we hope you will review again. We believe that advancing the two options for use of QALYs by the HERC will put the state at risk of violating disability and civil rights laws that bar discrimination based on race, color, national origin, sex, age, or disability. Our comments below focus on Option 2.

Option 2: Do not mention QALYs in staff-prepared meeting materials and do not discuss QALYs at Commission meetings. Staff will also search all studies for “QALY” and redact any mention of QALYs from published articles.

We strongly oppose referencing studies that incorporate the use of QALYs into its analysis, recommendations, and determinations. It is not enough to simply redact the term. In a traditional cost effectiveness analysis, you cannot extricate the QALY portion and retain the validity of the remainder of the report. The entirety of the report will inevitably rely on the data and studies used to feed the cost-effectiveness model. These are often very narrow data sets and omit critical research and resources that do not fit within the QALY-based model’s paradigm. This omitted data can include high-quality patient surveys conducted by reputable patient and disability advocacy organizations, patient registries, and real-world evidence.

Many of these reports include “policy recommendations,” which provide suggestions around whether and how to cover treatments and what utilization management strategies to employ. It would be incredibly rare for this section of the report to specifically reference QALYs, yet all of the recommendations are derived from the QALY-based cost-effectiveness model. Should the HERC reference this portion of the study, the HERC would still be referencing a QALY-based model.

In effect, the QALY-based cost effectiveness determination informs the report’s overall conclusions and policy recommendations. Even conceptual considerations that may be included in a report relying on QALYs will be unduly influenced by the narrow scope of evidence that is fit for use in a QALY-based calculation and will fail to comprehensively represent the diversity of the impacted population. There is no part of a study relying on QALYs that is fit for use in making real world decisions about access to health care.

We urge the HERC to convene an expert panel representing the disability community at its next meeting, and delay its vote on this issue until more fully understanding the personal, societal, and legal implications of this decision.

Sincerely,

Alliance for Aging Research
ALS Association
American Association of Kidney Patients
American Behcet’s Disease Association (ABDA)

Asthma and Allergy Foundation of America
Autism Insurance for Oregon
Autistic People of Color Fund
Autistic Women and Nonbinary Network
CancerCare
Caring Ambassadors Program
Center for Autism and Related Disorders
Cystic Fibrosis Research Institute
Diabetes Leadership Council
Diabetes Patient Advocacy Coalition
Disability Policy Consortium
Disability Rights Oregon
Familia Unida Living with MS
Genetic Alliance
GO2 Foundation for Lung Cancer
Health Hats
International Foundation for Autoimmune & Autoinflammatory Arthritis
ICAN, International Cancer Advocacy Network
K.T. Firstenberger (they/them), Disability Resource Community Center
MLD Foundation
NBIA Disorders Association
New York State Sickle Cell Advocacy Network, inc.
Not Dead Yet
Partnership to Improve Patient Care
PXE International
Rosie Bartel
Sara Buscher, Attorney
Syngap1 Foundation
The Bonnell Foundation: living with cystic fibrosis
The Coelho Center for Disability Law, Policy and Innovation