

[HERC.Info@oha.oregon.gov](mailto:HERC.Info@oha.oregon.gov)

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. The alternatives in front of the HERC do not sufficiently address the shortcomings of QALYs. This letter describes our concerns with Option 1.

**Option 1:** HERC staff will incorporate "adjustments" when referencing QALYs as part of their recommendation development for the HERC to prevent the inappropriate use of QALYs.

We are concerned that the HERC staff believes "making adjustments" when referencing QALYs is sufficient to prevent the inappropriate use of QALYs. The use of QALYs to compare treatments for the same population does not mitigate the inherent flaws of the metric that not only devalue the lives of people with disabilities and older adults, but also devalues the quality-of-life improvements that matter to people living with the condition and fails to consider the impact of treatments for the subpopulations that are the focus of efforts to advance health equity. While QALYs may not be used to rank the prioritized list, their use will impact the utilization management strategies that, in effect, create hurdles for accessing affordable care.

We are similarly concerned that the HERC proposes to search for alternative measures of cost effectiveness to cite in their work without standards for the quality of the cost effectiveness measures being used. There are alternative metrics for assessing cost effectiveness that are potentially less inherently discriminatory if they rely on high quality evidence that captures the real-world experiences and priorities of patients and people with disabilities. We encourage the HERC to shift its focus away from finding a way to endorse the use of QALYs. Instead, the HERC should be abandoning QALYs and leading the field of research and health economics to establish standards for high quality evidence that is credible and reliable for use in decision-making.

In establishing standards, we would encourage the HERC to review the Equity and Inclusion Guiding Principles published by the Patient-Centered Outcomes Research Institute's (PCORI) Patient Engagement Advisory Panel calling for "critical engagement with historically disenfranchised groups whose interests have not been consistently centered due to systemic devaluations based on race, ethnicity, income, geography, age, sexual orientation, disability, and other characteristics." Inclusion and equitable partnerships were cornerstones of their principles for ensuring equity in research. As part of a landscape review, PCORI also identified aspects in measuring value that the HERC should consider in any effort to set standards for high quality research, including patient engagement, patient-centered impacts, patient preferences, patient-reported outcomes, real-world evidence, patient heterogeneity and diversity,

measurement of social needs and social determinants of health, and transparency.<sup>1</sup> We welcome the opportunity to work with the HERC in a standard-setting process.

Multi-Criteria Decision Analysis (MCDA) provides an interesting and potentially positive framework for assessing the value of treatments. While we do not support the use of QALYs as a component of MCDA, we do understand that MCDA provides an opportunity to assess including benefits, harms, costs, values and preferences and delivery system issues relevant to the topic at hand using a variety of nondiscriminatory measures. The use of multiple analytic frameworks for estimating value has strong potential for capturing patient preferences that are not captured in more traditional value frameworks if it is informed by affected stakeholders, i.e. patients and people with disabilities, and high quality evidence representing the diversity of the patient population. We urge the HERC to start with a process for creating standards for the quality of evidence it will use to make decisions.

We strongly support early and increased engagement with consumer advocate members of the HERC. We remain concerned that advocates representing people with lived experience and impacted directly by the HERC's recommendations are not sufficiently engaged in the HERC process. In cases such as this, the HERC should not vote before convening experts from the disability, patient and provider communities to share their expertise directly with the HERC as part of a panel discussion. Also, the word limit on comments is a barrier to full engagement. The HERC members would learn more about the issue on which they are voting, in this case the discriminatory implications of QALYs, if they allowed for more input from outside experts.

We strongly oppose the use of QALYs by the HERC and will continue to advocate against their use in decisions affecting people's lives. Oregon has been on notice for 30 years that its reliance on QALYs is contrary to civil and disability rights laws. As the author of the Americans with Disabilities Act testified to the HERC, "Oregon had 30 years to find new - nondiscriminatory - strategies for prioritizing its Medicaid list of services...The ADA was enacted to counter that bias and stigma for future generations. Combined with Section 504 of the Rehab Act and Section 1557 of the Affordable Care Act, there is no question that metrics like QALYs are not fit for use in our health system."

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

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<sup>1</sup> <https://www.pcori.org/sites/default/files/PCORI-Landscape-Review-Summary-Patient-Stakeholder-Perspectives-Value-Health-Care-August-2022.pdf>

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