

Oct 31<sup>st</sup>, 2022

Dear Members of the HERC.

Disability Rights Oregon would like to express our strong objections to both options being considered for the use of QALYs by the HERC. 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.

It is apparent from conversations at the last meeting of the HERC that the commissioners do not have any understanding of the QALY metric and were unaware of what it was or how Oregon has used QALYs over the last 30 years when determining what would and would not be covered in the Oregon Health Plan. Staff did not do a thorough or accurate job explaining how a QALY score is created, why so many groups have opposed the use of QALYs or even how CMS has rejected Oregon's past attempts to directly use QALYs in its prioritization process. At no point did staff explain that QALYs were in fact used extensively before 2017, when the HERC was formed, and played a significant role in establishing the initial prioritized list that is largely still intact. So why does DRO and so many other groups care so much about keeping QALY scores out of coverage discussions?

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. The "Quality" portion of the formula is derived by general population surveys and not that of those with lived experience. Lastly, it is well-known that the research driving QALY calculations are not peer reviewed, cannot be replicated by others and often does not represent key subpopulations for whom treatments may have a differential impact from the averages or for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.

DRO in partnership with 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. Disability Rights Oregon believes 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.

DRO strongly opposes referencing studies that incorporate the use of QALYs into its analysis, recommendations, and determinations. If the QALY-based cost effectiveness determination informs the report's overall conclusions and policy recommendations it should not be considered in its entirety. 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,

Meghan W. Moyer  
Public Policy Director  
Disability Rights Oregon

