Recently, the Institute for Clinical Economic Review (ICER) announced that their future reports will incorporate more prominently “a calculation of the Equal Value of Life Years Gained (evLYG).” For over a decade, representatives of patients and people with disabilities have communicated to ICER that QALYs are fundamentally flawed and inherently discriminatory. The QALY was developed as a tool to make one-size-fits-all decisions, not facilitate patient-centered health care.

Therefore, I applaud ICER for its long-overdue recognition that use of the cost-per-QALY metric in health care decision-making discriminates. This is not just a “concern” raised by some groups, as suggested in ICER’s materials, but an established reality that is readily acknowledged by many academics.

However, I am deeply disappointed that ICER’s answer is not to treat patients and people with disabilities with respect by putting them at the center of the value equation, but to offer up an alternative standard that is no less paternalistic than the cost-per-QALY itself. The “evLYG” seems to remove the “quality-adjusted” aspect of the QALY, rather than addressing the inherent flaw.

In doing so, ICER presents insurers and others with a false choice between two fundamentally flawed standards, saying we as patients and people with disabilities can either have a standard that avoids the problem of discrimination but ignores many of the health and quality of life benefits that matter to patients and their caregivers, or we can have a standard that includes those benefits but is inherently discriminatory. In the end, any insurer, pharmacy benefit manager, or government program making this choice is saying all its customers or beneficiaries are not equal.

Rather than being forced to choose from ICER’s menu of standards that undermine our access to care, payers should instead demand better approaches that ask us “what do we value” rather than telling us “what we are worth.” We want those decisionmakers to support a new breed of health economists and researchers committed to innovative methods of value assessment that appropriately capture what matters most to patients, seniors, people with disabilities, and people who identify with historically marginalized
populations.

While we acknowledge ICER is attempting to address one of the many shortcomings of the QALY, it does not change the fact that ICER just created another tool to make health care decisions that serves as an arbitrary threshold for coverage and access to care.

I would ask anyone served by health systems what they prefer: (a) an ICER standard that ignores differences in value among patients and treats older cancer patients as “worth less;” (b) an ICER standard that ignores the benefits of treatments with similar survival benefits but fewer side effects; or (c) a new standard that captures what patients value, recognizes the differences in what patients value, and holds health insurance companies accountable for treating each patient accordingly? I hope the answer is option C, and I invite you to join us in building it.