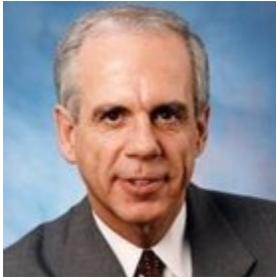


Chairman's Corner: Will ICER's Response to Attacks on the QALY Quiet the Critics?: A Reply from the Partnership to Improve Patient Care

2/8/2019



In response to a recent blog post entitled [“Will ICER's Response to Attacks on the QALY Quiet the Critics?”](#) (December 18, 2018) we must unfortunately reply: Absolutely not. Regrettably, ICER's response suggests that for patients, the only options are a) a metric that is widely acknowledged to discriminate against the elderly and people with disabilities, or b) a metric that ignores elements of value that are critically important to patients. Patients need another option, and PIPC is committed to supporting it.

We appreciate the opportunity to respond to comments made by the researchers at Tufts on our concerns around the QALY. We respect researchers who have invested long years and considerable expertise in QALY-based value assessment. But we also respectfully suggest that it's time to acknowledge that these assessment tools are dangerous and will never be appropriate for decision-making.

We invite all researchers in the field of value assessment to engage directly with patients and foster an open dialogue, so that we can collectively advance the metrics and utility of value assessment.

How the QALY discriminates

Because people with disabilities, seniors, and patients with chronic conditions may experience a potential for health that is less than their “healthier” counterparts, treatment that extends or improves their life may result in fewer QALYs than a treatment developed for a non-disabled or younger population where the treatment is able to return the patient to so-called perfect health. As QALYs are assigned by both quality as well as quantity of life, an incremental QALY assessment would prioritize providing treatment to a non-disabled population with a longer theoretical life expectancy, and otherwise perfect health, over a population with a disability or chronic condition.

When applied to coverage and reimbursement decisions, the result is discrimination against people with disabilities, a legal violation of the Americans with Disabilities Act when applied by

state Medicaid programs and a violation of the statutory ban on use of QALYs when used in Medicare. Both Congress and HHS have recognized this. America's sense of morality and ethic of equality makes it a bridge too far to deny care to those with significant lifetime health needs just because they may never achieve a pre-conceived notion of optimal health.

Why must patients forgo incorporating quality of life to avoid discrimination?

Those who are wed to traditional cost-effectiveness assessments have posited an untenable choice between two flawed metrics: the QALY, which incorporates some measures of value reflecting quantity and quality of life, but discriminates against patients and people with disabilities, or the "equal value of life year gained," the evLYG, which disregards any value of a medicine other than its ability to extend life.

This is a false choice and it further demonstrates that current, conventional cost-effectiveness assessments are not fit for making vital health care decisions.

As the Tufts researchers themselves point out, the "evLYG measure has its own discriminatory implications." Failing to account for symptom and quality of life improvements ignores key aspects of value that are important to patients, and important to different degrees for different patients. However, while the QALY attempts to correct for this, it does not appropriately address this failure because it does not accurately capture quality of life for patients.

Attempts to address the QALY's shortcomings by incorporating more patient-centered measures of value, such as those suggested by the ISPOR Special Task Force, are a valiant effort to seek improvements, but do not address the underlying flaw. We agree that neither the QALY nor the evLYG offers a reliable metric by which to provide a patient-centered measure of a medicine's value to patients, their families, and the health care system.

Rather than resigning to pick between two measures that all agree fall short, and in turn hinder any lasting improvements value assessments can achieve or its utility for patients and our health care system, we must commit to a better path forward.

Moving value assessment forward

We continue to challenge the prevailing notion that patients are unwilling or unable to understand that difficult trade-offs must be made in health care, and therefore incapable of being relied on as partners in the quest for better value in health care. As key stakeholders, we are committed to coming to the table with actionable alternatives and continue to seek out opportunities to collaborate on novel approaches with other experts in the field.

We urge innovative researchers to develop novel ways to measure the value of medicines and other health care interventions. To do so, we encourage researchers to work with us and other patient and disability advocates to learn more about what attributes matter to us and what instruments can capture those attributes. We believe that those researchers will find that patients are eager to improve allocation of health care resources, prioritizing high value care over low value care when that trade off adequately accounts for individual patient value. Unfortunately, today's value assessment tools are incapable of informing these types of

decisions.

There are many forward-thinking researchers beginning to take steps to engage with patients to improve value assessment and even move beyond the QALY.

Some researchers are at the cutting edge of value assessment, including those championing multi-decision criteria assessments (MDCA) and open-source models, like the Innovation & Value Initiative (IVI). The National Health Council has [partnered with](#) the University of Maryland to drive the patient voice into value assessment through direct engagement with patients in developing novel methods.

We are devoted to supporting the development of assessment tools and metrics that properly reflect elements of value that matter to patients and people with disabilities without utilizing discriminatory and flawed measures. Through the development of these tools, informed decisions can be made that will truly improve health care.

While the QALY may seem “reasonable” to some, as patients and people with disabilities, we cannot afford to settle for “good enough” when “good enough” discriminates against those who aren’t “worth enough.”