



Measuring Value in Medicine: Uses and Misuses of the QALY

*Ethical Issues with QALYs and
Alternative Measures of Value*

Partnership to Improve Patient Care

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Executive Summary

Value assessment in general, and the use of cost-effectiveness in particular, is receiving renewed interest as a tool for controlling health care spending (Feeley, 2016; Doshi & Willke, 2017). Currently, the most common method for determining incremental cost-effectiveness of healthcare interventions is based on a calculation of quality-adjusted-life-years (QALY). While the model has a basic appeal for making population-level decisions (by reducing patient populations to single, aggregate numeric values), it also poses several significant concerns from the vantage point of patient-centeredness and efforts to preserve access to needed care for individual patients and people with disabilities.

In particular, QALYs are:

- Heavily dependent on the measurement instrument being used;
- Intended as a theoretical tool for academic researchers, not for decision-making that will impact actual patient lives;
- Developed from population averages, and are not patient-centered; and
- Widely acknowledged by experts to discriminate against people with disabilities.

While not without their place in academic research, QALYs are not the appropriate tool for assessing the value of healthcare interventions for real-world applications and decision-making. This brief provides an overview of the QALY, assesses its suitability as a mechanism to determine health care “value,” and provides information on alternative measures of value.

Table of Contents

PART ONE Advancing a Value Framework that Aligns with Principles of Patient-Centeredness	4
PART TWO Background on QALYs	6
PART THREE Ethical Issues with the QALY: Individuals with Disabilities and Chronic Conditions	11
PART FOUR Uses (and Misuses) of QALYs	15
PART FIVE Alternatives to the QALY for Assessing Treatment Value	17
PART SIX Conclusion	19
PART SEVEN References	21

Part One

Advancing a Value Framework that Aligns with Principles of Patient-Centeredness

Since its founding, the Partnership to Improve Patient Care (PIPC) has been at the forefront of applying principles of patient-centeredness in comparative effectiveness research (CER). Central to our mission is ensuring that the patient voice is heard in judgments about care value – whether in the context of comparative effectiveness research or emerging “value-based” payment incentives. For example, in explaining his support for creation of the Patient Centered Outcomes Research Institute (PCORI) in 2010, PIPC Chairman Tony Coelho noted that the institute is authorized to study the comparative clinical effectiveness of treatments, not to assess cost-effectiveness as done in England and other countries in a manner that often leads to denied coverage for new treatments (Coelho, 2014). He emphasized the “millions of patients and providers who are relying on the institute to produce strong evidence to help inform their health care decisions in ways that meet their individual, personal needs.” To do so, PCORI-funded projects bring patients to the table to determine the research questions and the outcomes to be measured so that studies are not purely academic, but instead patient-centered and useful in care decision-making.

Having driven the concept of patient-centeredness in the conduct of research, PIPC brings the voices of patients, people with disabilities, and their families to the discussion of how to advance patient-centered principles throughout an evolving health care system. In this brief, we identify the potential contradiction of, on the one hand, advancing a definition of value in health care that is centered on the characteristics, needs and preferences of the individual patient versus defining value based on what is cost effective for an “average” patient. While there are significant efforts to advance value definitions that are patient-centered, there is significant interest among academics to advance value determinations that are based on more traditional cost effectiveness metrics that rely on what works at the lowest cost for the average patient. It would seem that we are at a crossroads, with one path moving toward personalized medicine and patient-centered care, and the other relying on standardized metrics of care value largely based on what works for the “average” patient. Yet, no patient is average.

PIPC is particularly concerned about the implications of healthcare coverage policy built on population-based value assessments on people with disabilities and patients with chronic conditions who may or may not be cured, but regardless are seeking access to treatments and health interventions that improve their quality of life. More specifically, people with disabilities and patients with chronic conditions have a long history opposing the use of quality-adjusted-life-years (QALYs) as the benchmark to measure the value of health care interventions. As applied to real-world policy and decisions about access and coverage, they argue QALY-based metrics often conclude that people with disabilities are not worth it - that their lives are not valuable - and results in denied access to

care. Such simplistic average measures of value are perceived to reinforce the old paternalistic system of health care and work against the nation's efforts to achieve personalized medicine and to develop targeted individualized therapies through the Precision Medicine Initiative.

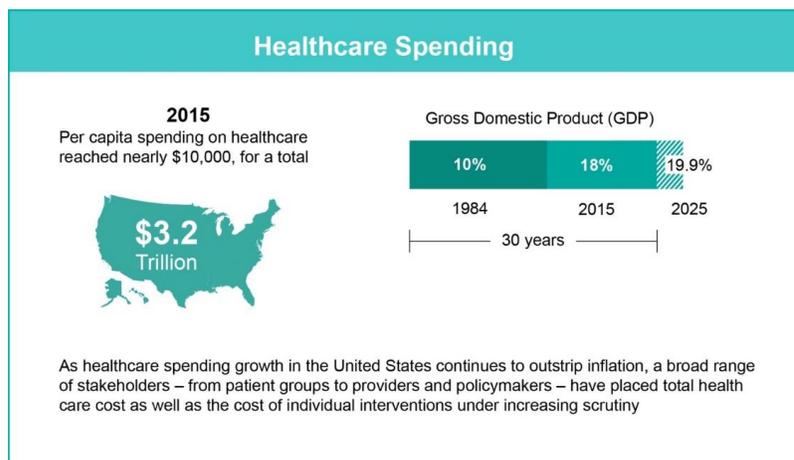
Policy-makers recognize the dangers of misusing cost-effectiveness standards in ways that undermine high-quality, individualized care. For example, the Patient Protection and Affordable Care Act (ACA) explicitly prohibits PCORI from “[developing] or [employing] a dollars per quality adjusted life year (or similar measure that discounts the value of life because of an individual’s disability) as a threshold to establish what type of health care is cost effective or recommended” and further restricts the use of QALYs by mandating that “the Secretary [for Health and Human Services] shall not utilize such an adjusted life year (or similar measure) as a threshold to determine coverage, reimbursement, or incentive programs” in the Medicare Program (111th Congress of the United States of America, 2010). Yet, policymakers and thought-leaders have recently shown renewed interest in policies that rely on use of cost-effectiveness standards (Roberts, 2016).

Alternatively, PIPC aims for policymakers to focus on health care payment and delivery reforms that activate and engage patients and people with disabilities and that support shared decision-making between patients and people with disabilities, and their providers. We believe that solutions that center on delivering care that patients and people with disabilities value are the best approaches to improving overall health care efficiency and quality.

Part Two

Background on QALYs

In 2015, per capita spending on healthcare in the United States reached nearly \$10,000, for a total of \$3.2 trillion (Centers for Medicare and Medicaid Services, 2016). Total spending on healthcare as a share of gross domestic product (GDP) has nearly doubled over the course of 30 years, from 10 percent in 1984 to nearly 18 percent in 2015 (Centers for Medicare and Medicaid Services, 2016). The Congressional Budget Office has called current trends “unsustainable” (Congressional Budget Office, 2016), and the Centers for Medicare and Medicaid Services (CMS) Chief Actuary projects that spending as a share of GDP will reach 19.9 percent by 2025 (Keehan, et al., 2017). As healthcare spending growth in the United States continues to outstrip inflation, a broad range of stakeholders – from patient groups to providers and policymakers – have placed total health care cost as well as the cost of individual interventions under increasing scrutiny.



Paying for “value” in health care is emerging as a potential solution to escalating costs and spending, whereby the healthcare system focuses on providing “higher value” interventions and reducing the use of “lower value” products and services. Payers and policymakers have proposed various carrots and sticks to drive healthcare consumption towards a more value-based system, with proposals ranging from enhanced payments for “high value” interventions, to higher cost-sharing, strict utilization management, or even non-coverage for interventions that are considered “low value.”

While there is broad support for incentivizing value in healthcare, defining and quantifying “value” is a difficult proposition. Indeed, there is no single, commonly accepted method for defining value, and several of the proposed methods present more problems than solutions. In recent years, numerous organizations – from provider groups and professional societies, to health technology assessment (HTA) organizations and payers – have attempted to create various frameworks for defining and interpreting value. These frameworks include the Institute for Clinical and Economic Review’s (ICER) Value Assessment Framework, Memorial Sloan Kettering Cancer Center’s DrugAbacus, the American Society for Clinical Oncology’s (ASCO) Conceptual Framework to Assess the Value of Cancer Treatment Options, and the American College of Cardiology and the American Heart Association’s (ACC-AHA) Statement on Cost/Value Methodology in Clinical Practice Guidelines and Performance Measures. Several of these efforts rely on the QALY as one of the underpinning

metrics for measuring value because of its simplicity, while other organizations have explicitly avoided relying on the QALY because of its known limitations.

We recognize that efforts to advance value-based health care are rooted in efforts to lower health costs, without undermining health care quality. Yet, there is growing concern from health care stakeholders that standardized care decisions create barriers to certain treatments for individuals that don't meet "average" thresholds, leading to increased costs when treatments fail the patient. When patients cannot access treatments that work for them, our health care system bears the cost of reduced treatment adherence, increased hospitalization and other acute care episodes, as well as the societal costs of increased disability over time. In this age of personalized medicine, we can reduce costs by better targeting treatments shown to work on patients with similar characteristics, needs and preferences, thereby avoiding the waste of valuable resources on care that patients do not value.

WHAT IS THE QUALITY-ADJUSTED-LIFE YEAR?

The QALY is a measure developed by health economists to measure and compare the benefits of healthcare interventions for cost effectiveness analyses relied on to allocate health care resources (Weinstein, Torrance, & McGuire, 2009). Because the wide-ranging diversity of healthcare interventions and the heterogeneity of outcomes experienced by patients makes comparing therapies difficult, the QALY was proposed as a single metric that distilled the outcomes and benefits experienced by patients – regardless of individual preferences or perspectives – into a single summary number.

Calculating the QALY: 45 Year Old Patient with Tuberculosis (TB)

Value of perfect health	1.0
Value of health while suffering from TB	0.726
Duration of health condition	6 months
QALY	0.36

QALYs are calculated as a combination of the value of a particular health status as measured by surveys, duration of condition, and discount rate (Sassi, 2006).

Practically speaking, QALYs assume that certain health states (i.e., perfect health, represented by "1") are more desirable than others (i.e., death, represented by "0"). (Craig, Pickard, Stolk, & Brazier, 2013) Researchers use preference surveys or questionnaires to measure how much patients may prefer one health state over another and then assign a value to these different health states. The conventional QALY examines the desirability of a particular health state. (Weinstein, Torrance, & McGuire, 2009) Alternative calculations of QALYs attempt to assign a value to how long an individual remains in "poor" or "good" health and the QALY then is used to calculate the incremental QALY, or benefit, provided by a particular treatment, assuming that health or health improvement can be measured or valued based on amounts of time spent in various health states. (Nord, Daniels, & Kamlet, QALYs: Some Challenges, 2009)

While the QALY seeks to simplify a complex issue (relative value) for those making decisions at the population level, its very simplicity limits its practical applicability. In describing the use of QALYs, one author noted, "...decision-makers may also have other objectives such as equity, fairness, and

political goals, all of which currently must be handled outside the conventional QALY cost-effectiveness model.” (Weinstein, Torrance, & McGuire, 2009) A deeper look at how QALYs are calculated can help us understand their limitations.

MEASURING AND CALCULATING THE QALY

Traditional or conventional QALYs are measured using several different survey instruments that are designed to assess how much patients value different health conditions or “states.” For example, “generic-preference based measures of health,” are often generated from surveys asking individuals to rate their health along domains such as: ability to engage in self-care, pain or discomfort, anxiety or depression, emotional well-being, and social engagement. Researchers may also ask individuals to rank hypothetical scenarios such as: trading 10 years of “excellent” health with a 20 percent risk of sudden death vs having only “good” health for 10 years coupled with a lower (5 percent) risk of sudden death (Craig, Pickard, Stolk, & Brazier, 2013). Even a survey instrument with only five domains can assess 243 different health states along the continuum from “full” or “perfect” health to the “worst health” imaginable leading to thousands of different preferences (Janssen, et al., 2012). By surveying multiple individuals across the population, health economists identify an “average set of preferences” for numerous different health states and assign a “value” to each of the hypothetical conditions.

Commonly used tools for measuring QALYs:

- Euro-QOL 5-item Scale (EQ-5D)
- 7-item Health Utilities Index 2 scale
- 8-item Health Utilities Index 3 scale
- 6-item SF-6D scale
- 4-item Quality of Well-Being scale
- The 15-item 15D scale
- 5-item Assessment of Quality of Life scale

While the QALY is theoretically based on patient preferences, it is widely accepted that the generic-preference based measures that form the foundation of traditional QALYs are inadequate at capturing preferences among patients with chronic health conditions and disabilities, or even how patients’ preferences may change over time as they become more familiar with managing their health (Whitehead & Ali, 2010). Below we examine several methodological issues with calculating and using the QALY in greater detail. In summary, the limitations of the QALY are centered around two distinct issues: 1)

the wide range of values depending on which survey instrument is used, and 2) the inability of the QALY to account for patient heterogeneity because of the level of aggregation.

METHODOLOGICAL SHORTCOMINGS OF TRADITIONAL QALYs: MANY TOOLS, MANY RESULTS

The theoretical underpinning of the QALY is that something as ephemeral as quality of life can be measured and distilled down to a single number. Of course, quality of life is a concept that philosophers, scientists, and policy-makers have struggled with through the ages, making it difficult to imagine that the QALY could capture the evanescent nature and value of a person’s life in a single measure. Thus, while the simplicity of the QALY makes it a deceptively attractive metric for researchers, this very simplicity means it is, by definition, an inherently limited measure of the

complexities surrounding patient preferences and values. Indeed, because the QALY was developed as a theoretical tool for academia, it allows for “states worse than death,” which is at odds with the more pragmatic way that most individuals view their own health. This is a disconcerting incongruity in a tool that is rapidly becoming the underlying metric for many healthcare valuation efforts impacting access to care and treatment, despite concerns about their implications for people with disabilities, patients with serious chronic conditions, and for the delivery of personalized medicine and individualized care (Harrison, et al., 2009; Whitehead & Ali, 2010). As noted by PIPC and the patient advocacy group Not Dead Yet, using a “one sized fits all [definition of value] ...does not recognize differences among patients, potentially undermining the ability of patients and their providers to tailor care to the outcomes they prefer... a system that determines value based on ‘majority rule’ ... will fail to meet the needs of individuals and will violate the core principles of self-determination” (Not Dead Yet, 2015).

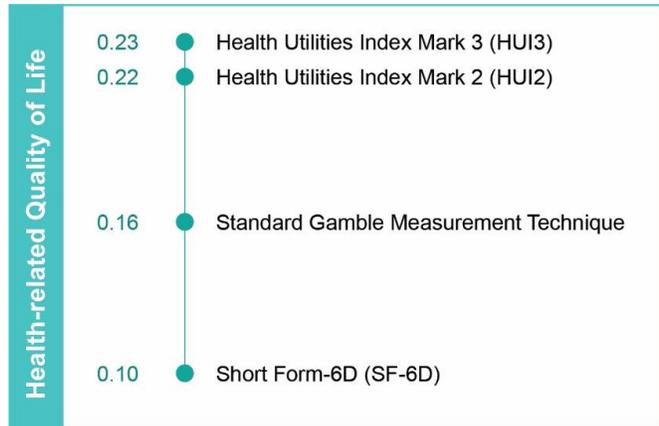
The disconnect in using an academic tool to influence real-life policy based on a presumed ability to quantify the quality of individual patients’ lives can be seen in how QALYs are measured and calculated. Many individuals included in population-based surveys can only imagine their response to theoretical scenarios and may be unable to realistically answer how much they value their lives in a particular state of health or what they are willing to trade to treat a hypothetical health condition or symptom. A recent survey found that among more than 2,000 American adults who were asked to imagine losing their vision, nearly half considered blindness to be worse than death, HIV infection, or the loss of a limb (Scott, Bressler, Ffolkes, Wittenborn, & Jorkasky, 2016). Although this particular study was not designed to determine a QALY for vision loss or impairment, it demonstrates how difficult it is for individuals to assign value to hypothetical health scenarios. While blindness can undoubtedly have a significant impact on quality of life, it is also generally accepted that with support and training, individuals who are blind can “be as happy and lead as full a life as anybody else” (Washington State, n.d.). In fact, several studies examining the impact of 29 different chronic conditions on health-related quality of life (HRQoL) found that conditions such as Parkinson’s disease, rheumatism, cardiac disease, and obesity had a greater impact on quality of life than “severe vision reduction” as reported by individuals actually living with these conditions (Brettschneider, et al., 2013; Saarni, et al., 2006).

There is a long history of research related to hedonic adaptation that provides an explanation for the return to a perceived higher quality-of-life for people with long-term disabilities. In the immediate aftermath of loss of function, there is a significant reduction in perceived quality-of-life that is recovered from after rehabilitation (assuming access to rehabilitation). This hedonic adaptation, also known as return to happiness, underscores a fundamental flaw in the process for determining QALYs. One particularly insightful study found that overall life satisfaction and quality of life increased with time for patients with permanent, but not temporary, colostomies. Knowing that the need for an colostomy was permanent allowed the patient to adapt and to achieve a higher perceived quality-of-life that may have been unimaginable prior to needing the ostomy (Smith, et al, 2009).

The seminal Second National Panel on Cost Effectiveness notes that the “quality and usefulness of QALYs depends on the quality and validity of the utility scores used to calculate them” (Neumann,

Sanders, Russell, Siegel, & Ganiats, 2017). The methodological difficulty in measuring patient preferences becomes clear when examining the sheer number of survey instruments and methods to measure QALYs. There is no one, single accepted way to determine how to best quantify the value of a particular health state or intervention (Gafni, 1994; Ryan & Farrar, 2000).

Indeed, research has shown that using different scales can yield wildly different results. For example, a recent study examining the value that patients place on hip replacement found an increase in health-related quality of life from total hip arthroplasty to be 0.10 using the Short Form-6D (SF-6D); 0.16 using the standard gamble measurement technique; 0.22 using the Health Utilities Index Mark 2 (HUI2); and 0.23 using the Health Utilities Index Mark 3 (HUI3) (Feeny, Wu, & Eng, 2004).



Because the hallmark of a robust and valid measure is replicability, the fact that there is such wide variability in the results depending on which tool is used to measure patient preferences should give us pause when we consider using the QALY to drive policy and coverage decisions. Indeed, if used in a cost-effectiveness or value-threshold, these wildly divergent valuations of hip replacement would result in the highest cost-effectiveness ratio being double the lowest, depending on which survey instrument was being used.

Part Three

Ethical Issues with the QALY:

Individuals with Disabilities and Chronic Conditions

In addition to the methodological issues with measuring QALYs, there are serious ethical concerns with how QALYs are developed and ultimately used. For example, it is well known that QALYs fall short in measuring health preferences for patients with chronic diseases and disabilities (Neumann, Sanders, Russell, Siegel, & Ganiats, 2017). QALYs place greater value on years lived in full health, or on interventions that prevent loss of perfect health while discounting gains in health for individuals with chronic illnesses (Nord, Daniels, & Kamlet, QALYs: Some Challenges, 2009). Considering that half of all adult Americans suffer from one or more chronic health conditions, using a measure that is understood to undervalue the life lived with a chronic condition is a serious limitation. Indeed, when health economists discuss the limitations of QALYs, they note that QALYs do not appropriately “incorporate certain fairness and distributional concerns that are important in group decision-making,” i.e. the impact of QALYs on the allocation of health care resources (Lipscomb, Drummond, Fryback, & Gold, 2009). In fact, some ethicists believe that “social well-being is defined by the worst-off member of society and reject the QALY framework” in its entirety (Neumann, Sanders, Russell, Siegel, & Ganiats, 2017; Rawls, 1971).

“Social well-being is defined by the worst-off member of society” leading some ethicists to “reject the QALY framework” in its entirety. (Rawls, 1971)

Because people with disabilities and patients with chronic conditions may experience a potential for health that is less than their “healthier” counterparts, treatment that extends their lives or improves their quality of life may result

in fewer QALYs than the identical treatment provided to a non-disabled individual. However, people with disabilities and patients with chronic conditions may value the treatment just as highly as a person without a disability or chronic condition, regardless of the fact that they may achieve a maximum health status that is considered by academia to be less healthy. The way in which conventional QALYs assign value to health gains from an intervention prioritizes care to individuals with a higher baseline health status, which may result in individuals with disabilities or chronic conditions being disadvantaged.

Alternatively, many people with disabilities or patients with chronic conditions may enjoy a comparable quality of life to non-disabled individuals, but may face a shorter life expectancy compared to someone without their condition. Because QALYs are assigned by both quality as well as quantity of life, an incremental QALY assessment would prioritize providing treatment to a non-disabled person with a longer theoretical life expectancy over a person with a disability or a patient with a chronic condition. This is at odds with the idea that individuals who may face a shorter life span should be able to enjoy the highest quality of life possible during that period. The inclusion of

“quantity of life” in the QALY assessment may also serve to devalue the health gains of older individuals over younger patients.

Finally, a concurrent condition may also complicate a particular treatment regimen for a totally unrelated health care issue, resulting in worse outcomes compared to the “average” beneficiary of an intervention. Because of the way that QALYs are calculated, treating a person with a disability would also, in this instance, be valued less than providing that same therapy to a non-disabled individual due to the possibility that a complicating co-morbidity may reduce treatment effectiveness. The real-world effectiveness of healthcare interventions is so heterogeneous across all patient populations that it seems unfair that QALYs inherently disadvantage the disabled or individuals with chronic conditions in the cost-value calculation. Even a small increase in quality of life may be extremely valuable to a person that lives with a disability or chronic condition.

From an ethical perspective, valuing “perfect health” over pre-defined “less than perfect” states of health is fraught with issues. As the use of QALYs extends beyond the original academic purpose of comparing treatments to using QALYs to determine coverage and access to healthcare interventions, we must carefully assess whether the QALY

“The problem of whether CEA [cost effectiveness analysis] unjustly discriminates against the disabled remains a deep and unresolved difficulty for the use of CEA and QALYs to prioritize healthcare”

- Second National Panel on Cost-Effectiveness

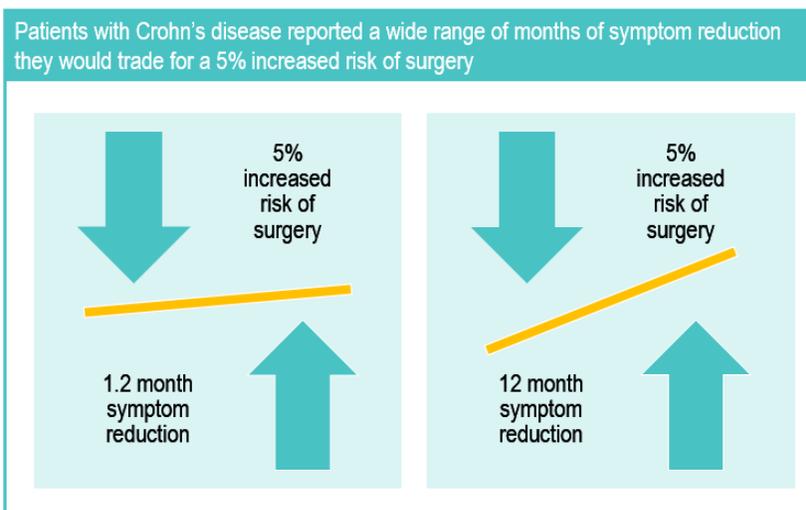
measure can assess the benefit that a patient may receive from an intervention at the individual level. Indeed, our nation’s constitutional foundation of equality and our public policies such as Emergency Medical Treatment and Labor Act (EMTALA), a federal law that requires anyone coming to an emergency department to be stabilized and treated regardless of their insurance status or ability to pay, indicates our ethic to support patients and people with disabilities to maximize their individual potential for health, not a pre-defined definition of health status (Centers for Medicare & Medicaid Services, 2012; Rosenbaum, 2007; Ervin, Hennen, Merrick, & Morad, 2014). To define a life as less valuable because a person’s unique circumstances deviate from “average” puts that American ethic at risk. An individual living with a chronic condition may be just as satisfied with their life as another individual with perfect health, and should not be afforded less access to treatment (Pettitt, et al., 2016).

Indeed, despite the persistent belief that people with disabilities cannot achieve the highest quality of life through any healthcare intervention, researchers and ethicists believe that disability is not necessarily “linked to (lower) quality of life” (Bickenbach, 2016). As noted by thought-leaders on the Second National Panel on Cost Effectiveness, “the problem of whether CEA [cost effectiveness analysis] unjustly discriminates against the disabled remains a deep and unresolved difficulty for the use of CEA and QALYs to prioritize healthcare” (Neumann, Sanders, Russell, Siegel, & Ganiats, 2017).

LACK OF PATIENT-CENTRIC FOCUS

In addition to the methodological and ethical challenges, the reliance of QALYs on generic measures aggregated across populations is at odds with the movement toward personalized medicine and achieving outcomes that matter to patients, also known as patient-centered outcomes. The use of surveys to cast a wide net to construct a single, average measure of patient preference does not reflect the wide heterogeneity of patient preferences. Researchers frequently only have results of a health utility survey conducted in the general population rather than in individuals suffering from the specific condition being assessed, undermining the applicability of the resultant QALY to distinct situations and conditions (Sackett & Torrence, 1978; Hurst, et al., 1994).

The inability of the QALY to assess individual patient preferences is intrinsic to its design. Researchers observe that a major criticism of the QALY is “that the value attached to quality of life may be determined by wholly disinterested and ill-informed third parties. This represents a significant challenge to those who advocate for the wider use of the QALY as a measure of outcome” and is the antithesis of patient-centricity (Kind, Lafata, & Raisch, 2009). Additionally, experts acknowledge that there is no robust way to “[aggregate] ... individual preferences into a social welfare function” and experts acknowledge that measures such as QALYs fall short in “recognizing that social values may differ from individual values so that social measures of welfare cannot be derived solely from individual measures” (Neumann, Sanders, Russell, Siegel, & Ganiats, 2017). For example, two patients with the same condition may value life (mortality) and health (morbidity) differently, but because they are assigned an average preference based on a population wide survey, they may be given the same QALY score. An intervention that restores a patient to full health for one full year would be assigned a QALY score of “1.” At the same time, a different intervention that provides 2 years of moderate health could also result in a value of “1.” Yet, these are two very different outcomes that may realistically be valued differently by individual patients. Yet, the reductive nature of the QALY cannot distinguish between these two outcomes, or allow for patients to prefer one over the other.



A recent study of individuals with Crohn's disease found that the “common practice of reporting average estimates of risk tolerance could lead to incorrect inferences for many patients” (Johnson, Reed, & Bewtra, 2016). When asked how many months of symptom reduction they would need to accept a 5% increased risk for surgery from a particular treatment option, patient responses ranged from a

reduction in moderate symptoms anywhere from 1.2 months to more than 12 months. Thus, taking the average of these responses would result in a significant misrepresentation of nearly all patients and their actual preferences.

Several organizations have proposed using the QALY as a major component in determining the value of healthcare interventions. In a recent call for comments for ICER's value framework, numerous patient groups, including PIPC, the Asthma and Allergy Foundation of America, the Arthritis Foundation, and the National Multiple Sclerosis Society, among others, reiterated the limitations of the QALY to truly measure individual patient preferences and noted its lack of patient-centric focus (Institute for Clinical and Economic Review, 2016). These organizations, whose mission it is to serve patients and prioritize their needs, recognize the significant limitations of the QALY to capture the heterogeneity of patient experiences and preferences, and articulated these concerns in their public caution against wholesale application of this measure. Based on these concerns, PIPC strongly urges use of patient-centered measures that enable patients and their clinicians to “conduct personalized assessments...in ways that reflect the differences in individual patient needs” rather than using measures derived from population-based averages (Partnership to Improve Patient Care, 2014).

Finally, because of the inherent shortcomings of QALYs, the Patient Centered Outcomes Research Institute (PCORI) is statutorily prohibited from developing or employing “a dollars-per-quality adjusted life year...as a threshold to establish what type of health care is cost effective or recommended.” PCORI instead conducts comparative clinical effectiveness research, which focuses on patient-centered outcomes as the measure of treatment effectiveness (111th Congress of the United States of America, 2010).

It is widely acknowledged that a summary measure such as the QALY will never be able to adequately capture the vast differences in individual preferences and values. Although the superiority of tools such as patient preference methods over the traditional QALY has been demonstrated in the health economics literature, the simplicity of the QALY continues to attract attention (Bridges, 2003; Ryan & Farrar, 2000).

Part Four

Uses (and Misuses) of QALYs

Despite well-documented shortcomings of the QALY for healthcare decision-making, policymakers continue to propose cost-per-QALY metrics to guide coverage determinations, reimbursement policies and clinical decision-making in public programs. QALYs were originally developed by health economists as a theoretical way to assess and compare the value of healthcare interventions at the population level. As discussed, QALYs are the most common input – along with cost – to assess the cost-effectiveness of healthcare interventions. Yet, their use has expanded over time to influence coverage and payment policies in private and public programs that impact individual access to care.

Cost-effectiveness calculations are often used to determine the “value” of a healthcare intervention. Researchers may calculate a price-per-QALY, but there is no hard and fast rule regarding what cost-per-QALY actually constitutes “good value.” Healthcare decisions, particularly for serious, potentially fatal conditions, should not be based on the availability of a “convenient, round number” (Neumann, Cohen, & Weinstein, 2014).

Despite widely acknowledged limitations of the QALY, several health technology assessment (HTA) organizations use QALYs as the theoretical underpinning for assessing

the “value” of healthcare interventions. For example, both ICER’s Value Assessment Framework and the Second National Panel on Cost-Effectiveness endorse the use of QALYs in valuing healthcare interventions. However, neither of these organizations explicitly endorses the use of QALYs to determine individual patient coverage or access to care. In fact, ICER acknowledges that their value framework is targeted towards population-level discussions, and is not intended to guide clinical decision-making. Yet, ICER’s governing Board consists mainly of insurers that look to this information for coverage decisions that impact clinical decision-making (Institute for Clinical and Economic Review, 2016). Thus, while ICER dodges the limitations of QALYs by espousing their use for population-level value assessment rather than individual, patient-level decision-making, it is unrealistic to think that value assessments derived from QALYs will not filter down to impact individual patients and coverage decisions. While application of the QALY should be limited to

While there is widespread acceptance that a healthcare intervention that comes under the \$100,000 per QALY threshold is considered to be a “good value,” more updated research indicates that in the United States a threshold between \$200,000 - \$300,000 may be more appropriate. The commonly cited \$50,000 per QALY threshold was not based on any rigorous willingness to pay or utility studies, but rather “the field settled on \$50,000 per QALY as an arbitrary but convenient round number...[which then] congealed into conventional wisdom.”

- Neumann, Cohen, & Weinstein, Updating Cost-Effectiveness - The Curious Resilience of the \$50,000-per-QALY Threshold, 2014.

theoretical discussions, we know that policymakers and payers use the results of a QALY-driven analysis for decision-making.

USING QALYS FOR DECISION-MAKING: THE OREGON EXPERIENCE

In 1990, the Oregon Health Services Commission developed a prioritized list that ranked the relative value of healthcare condition-treatment pairs to determine what services would be covered by their Medicaid program. Healthcare interventions were then categorized into “essential” services, “very important,” and interventions that were only “valuable to certain individuals” (Kaplan, 1993). In order to ensure that the prioritized list reflected the true preferences of the community, just over one thousand Oregonians were surveyed to develop the preference weights required by the selected quality assessment tool.

Although the State of Oregon used best practices to assess and rank the value of healthcare interventions, the use of community-based weights and a preference for distributive benefits resulted in some seemingly illogical results. For example, the final recommendation from the Health Service Commission ranked tooth capping higher than emergency appendectomy and recommended against life support for very low birth-weight babies (Hadorn, 1991; Kaplan, 1994). These results are incongruous or contradictory to most commonly held values. Eventually, in 1992, the U.S. Department of Health and Human Services (DHHS) rejected the state of Oregon’s request to proceed with their prioritized list based on explicit cost-effectiveness ratios derived from QALYs. Among other objections, one of the major concerns that DHHS cited was the potential for the Oregon prioritized list to discriminate against people with disabilities. In fact, the Secretary of the U.S. Department of Health and Human Services wrote an opinion to the *New York Times* stating clearly, “Our principal concern is that Oregon's plan in substantial part values the life of a person with a disability less than the life of a person without a disability. This premise is discriminatory and inconsistent with the Americans with Disabilities Act” (Sullivan, 1992).

The difficulties in applying a theoretical measure to practical applications where real lives are at stake are demonstrated by Oregon’s failed prioritized list experiment. Yet, while DHHS and CMS have prohibited the explicit use of QALYs in coverage and reimbursement decisions, many HTA organizations still consider cost and cost-effectiveness in their analyses. In fact, although DHHS denied Oregon’s request to use QALYs for coverage decisions, Oregon continues to use a modified prioritized list that does take cost and cost-effectiveness into consideration (Oregon Health Authority, 2013). The use of broad population-based cost and cost-effectiveness analyses in coverage decisions rather than metrics that take into account specific patient needs and heterogeneity have resulted in continued discrimination against people with disabilities. For example, there is a long history of individuals with intellectual and developmental disabilities being denied organ transplants because of the misguided notion that their lives are somehow less valuable (Autistic Self Advocacy Network, 2013).

Part Five

Alternatives to the QALY for Assessing Treatment Value

Measuring, calculating, and using the QALY to place a value on healthcare interventions and guide treatment or coverage decisions has significant limitations due to its reliance on the “average patient.” As PIPC Chairman Tony Coelho often says, “No patient is average.” While providers, patients, payers, and manufacturers must acknowledge the increasing costs and concurrent pressures, it is important not to be seduced by the simplicity of the QALY as a cure-all for an extremely complex issue. Using the QALY to address the cost-value conundrum does not recognize the range of issues facing patients and people with disabilities and the conflicting, more patient-centered, drive toward personalized medicine.

While some researchers believe that the QALY does have a place in theoretical discussions comparing the relative impact of one treatment against another, it is difficult to justify using it as a metric for coverage and payment policies because it averages the variegated preferences of multiple patients, populations, and conditions against a single absolute cost effectiveness threshold and is therefore not going to capture individual patient needs, preferences and outcomes. In fact, when the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) convened an expert panel to examine the use of the QALY, one of the participants concluded that developing “experience-based utility in the assessment of health states...is not going to happen with the quality-adjusted life-year... [because] a technique that is essentially built on the denial of inconsistencies has a problem” (Kahneman, 2009).

While some argue it may be premature to scrap the concept of the QALY in its entirety, in recognition of the limits of the QALY as a single metric, the Second National Panel on Cost Effectiveness recommended adding a second reference case in any cost effectiveness analysis (CEA) to explicitly acknowledge the fact that one single number cannot capture the heterogeneity of individual preferences across the entire patient spectrum (Neumann, Sanders, Russell, Siegel, & Ganiats, 2017). Thus, the use of a “range of estimates” rather than a single point estimate is beginning to gain acceptance; QALYs could also potentially be calculated as a range of scenarios to better characterize diverging patient preferences. Indeed, as noted earlier, the utilities calculated for specific health states depend heavily on the survey instrument being used and the method used to score the results. This argues for the use of multiple instruments, resulting in a range of estimates rather than a single numeric output. Yet, the information is still most useful academically, and continues to have limits for policy use.

Researchers have also started to develop alternatives to the traditional QALY that move away from generic population-based surveys to more explicitly patient-centered measures. Some advocate for quantifying the value that patients place on a particular intervention and their health to be done using measurement tools developed and deployed specifically for and in populations with the condition

under question. While this may improve the methodology, it does not resolve the heterogeneity even within populations of people with disabilities and patients with chronic conditions where QALYs are universally acknowledged to misjudge the value that affected individuals place on their health and livelihood. As discussed, the traditional methods of assessing QALYs are unable to account for improvements in health from different baseline health statuses, which can result in discrimination against people with disabilities (Nord, Enge, & Gundersen, 2010). At a minimum, QALYs should be constructed using condition-specific survey instruments within the patient population of interest, yet they will still have limitations for determining the most valuable care to the individual. Thankfully, there are better methodologies on the horizon.

There is also a growing body of research showing that patient preference methods can serve as an alternative, and more patient-centered, method of assessing value than the traditional methods used to determine QALYs (Bridges, 2003). Patient preference methods measure the value that patients assign to health status across domains, and can provide a more comprehensive picture that is more flexible and adaptable to numerous health conditions. While not without shortcomings, patient preference methods as well as health-related quality of life valuations such as multiattribute utility instruments (MAU) can account for patient heterogeneity and provide an alternative to either replace or supplement values determined by the conventional QALY framework (Nord, 2001). These flexible tools have been developed by researchers and can assess the marginal impacts of a healthcare intervention or the total value of the same intervention, providing a way to value incremental benefits of improvements in health from differing baseline values, one of the major shortcomings of the traditional QALY (Bridges, 2003).

The growing threat of increased use of QALYs has become an incentive for organizations representing patients and people with disabilities to engage in efforts to promote patient engagement in the development of value frameworks and assessments of treatment value. For example, the National Health Council engaged patient stakeholders and others to create a Patient-Centered Value Model Rubric to help evaluate the patient-centeredness of value models and to guide value model developers on the meaningful incorporation of patient engagement throughout their processes (National Health Council, 2016). Additionally, *FasterCures*, a non-partisan and non-profit think tank, has partnered with Avalere Health to develop the Patient Perspective Value Framework (PPVF) incorporating measures of benefits and costs in the context of patients' personal goals and preferences to assess the value of different health-care treatment options. The PPVF has five broad domains of value, each of which contributes different types of information important to patient decision-making (FasterCures, 2017). These efforts represent a growing emphasis on the development and use of patient-centered outcome measures as indicators of improving quality in health care programs (Centers for Medicare & Medicaid Services, 2016). The goal of these and many other ongoing efforts is to develop and implement a new paradigm for value assessment that prioritizes the delivery of care that is most valuable to the individual patient and, in many cases, that incorporates cost concerns that go beyond the scope of purely medical costs to also consider personal, family and societal costs associated with the condition being treated such as transportation needs, caregiving, loss of productivity and work, or increased risk of future disability.

Part Six

Conclusion

Placing value on individuals' lives, preferences, and health is an inherently difficult and complex proposition. There is increasing recognition of the increasing ability for providers to target treatments and care to patients based on their unique characteristics, i.e. personalized medicine, and thereby achieve care that patients value and lower overall costs by avoiding unnecessary care, decrease costly adverse events and increase treatment adherence. Yet this drive to a more patient-centered health system is also perceived to be at odds with the “tacit collusion between researchers and the decision-makers that the researchers will provide decision-makers with a number that is simple” (Kahneman, 2009).

The cost pressures facing stakeholders are real – from patients who are expected to dedicate a greater share of their income to cost sharing, to providers who are facing lower margins and decreasing reimbursements – and there is a need to develop better tools to help each sector in the healthcare puzzle better determine which treatments provide true value and benefit to patients and society. However, the first step in appropriately valuing healthcare interventions, treatments, and the lives of the patients is to acknowledge that this is a complex and multidimensional question that may not be best answered with a single number.

While the QALY metric may have a place in theoretical, population-based discussions, it fails to adequately account for the wide heterogeneity of patient preferences even within impacted patient communities, and should not be used in a manner that may impact clinical decision-making. Emerging research in patient preference methods, a movement towards more patient-centered outcome measures, incorporation of patient perspectives in value assessment, and other alternatives to assessing value in health deserve more attention in the cost-value debate. While the traditional way of assessing cost, value, and cost-effectiveness may not be the best way forward, the idea of “value” in healthcare is an important one that should not be abandoned because of methodological difficulties. Rather, the difficulties and heterogeneity of patient preferences and outcomes should be embraced, and explicitly acknowledged in any value assessment. It is an opportunity for researchers to partner with patients, people with disabilities and providers to advance new methodologies that are aligned with the drive to personalized medicine and the delivery of targeted therapies.

PIPC strongly believes in providing patients with high-value healthcare. Every person has different health needs, preferences, and quirks that make them a unique individual. Thus, while traditional QALYs are particularly discriminatory to people with disabilities and serious chronic conditions, methodologies that support a more patient-centered value system would benefit everyone, regardless of their health status. PIPC has, and continues to advocate for advancing the use of patient-centered tools and measures to transform the healthcare system. Policymakers, payers and others have an opportunity to promote the use of new tools and methods that recognize and accommodate

for patient heterogeneity and preferences, thereby supporting patients on a path to a truly value-based healthcare system. We look forward to embarking on this path together with all stakeholders to achieve care that patients' value.

Part Seven

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