

# Is the QALY Fit for Purpose?

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## ABSTRACT

Most value assessment research uses the quality-adjusted life-year (QALY) to measure health gain within a cost-utility framework. The many scientific and ethical flaws of the QALY have been described previously, but it continues to be used because it seems to provide a methodological bridge to a policy goal: resource allocation. Our aim in this paper is to assess whether the QALY is an adequate proxy measure of health value for the purposes of health care priority setting or whether the limitations inherent in how it is calculated and used in cost-utility analysis have the potential to be harmful. To do this we pose 3 questions. First, does the QALY accurately measure what it purports to measure? Second, does it value the health of all people equally and avoid the ethical and economic harms that arise when this is not the case? Third, does the QALY manage to fairly balance the needs of individuals and society as a whole? We argue that the QALY does not currently pass these 3 tests to an acceptable standard. We argue for methods to achieve incremental improvement in both the scientific and ethical standards used in constructing measures such as the QALY and for an end to the inertia in improving a measurement system that is widely considered inadequate. We point to solutions that are growing in popularity and highlight some of the key challenges that remain.

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Value assessment has been a part of priority setting in global health care for more than 40 years and is beginning to gain a stronger hold in the United States. One approach to value assessment uses the quality-adjusted life-year (QALY) to measure health gain within a cost-utility framework. The many scientific and ethical flaws of the QALY methodology have been described previously,<sup>1-5</sup> but it continues to be used because it seems to provide a bridge to a policy goal: resource allocation.

The key innovation of QALYs is the use of numeric “utilities” to quantify the value of different health states. The utility assigned to a given state of health is based upon the preferences of the general public as measured by large, country-specific surveys. The highest possible utility for a health state is 1, representing perfect health. Zero represents death. The calculation of a QALY for a specific patient requires them to complete a questionnaire such as the EuroQol 5-dimension instrument (EQ-5D). This assigns the patient to one of a limited set of health states. The utility associated with that health state is then multiplied by the years that the patient has lived in the health state. For example, a year lived in the hypothetical “perfect health” state is worth 1 QALY.

Costs can be combined with QALYs to compare the cost per QALY gained of various possible health care investments and guide funding decisions. The most extreme version of this approach is used in countries such as the United Kingdom and Australia, where an explicit cost-per-QALY threshold, above which interventions generally cannot be funded, is imposed by the single-payer public health care system.

Our aim in this paper is to assess whether the QALY is an adequate proxy measure of health value for the purposes of health care priority setting or whether the limitations inherent in how it is calculated and used in cost-utility analysis have

the potential to be harmful. To do this we pose 3 questions. First, does the QALY accurately measure what it purports to measure? Second, does it value the health of all people equally and avoid the ethical and economic harms that arise when this is not the case? Third, does the QALY manage to fairly balance the needs of individuals and society as a whole?

At the outset, we wish to be clear that we are not questioning the importance of efficient resource allocation. There is no need to repeat the obvious financial constraints on health systems and the growing pressures caused by technological innovation and population aging. What we are arguing for is incremental improvement in both the scientific and ethical standards used in constructing measures such as the QALY and an end to the inertia in improving a measurement system that is widely considered inadequate. We point to solutions that are growing in popularity and highlight some of the key challenges that remain.

## 1. THE QALY FAILS TO ACCURATELY MEASURE THE HEALTH OF PATIENTS

QALYs incorporate the health of patients through the use of generic patient-reported outcome (PRO) questionnaires. Clearly, if these questionnaires are to measure patients' health, it is vital that patients are engaged in the development of the dimensions in the questionnaires. This has been echoed by the FDA, which places great emphasis on this in its guidance to industry on the use of PROs<sup>6</sup>:

“PRO instrument item generation is incomplete without patient involvement. Item generation generally incorporates the input of a wide range of patients with the condition of interest to represent appropriate variations in severity and in population characteristics such as age or sex.”

As an aside, some may argue that the metric for measuring value at the patient level—the remit of the FDA—can be different from the metric used to determine value for money to a health system that would result from the drug's reimbursement. Yet other than the fact that the value to society should in essence simply be the sum value accrued to all patients in society who could benefit, what this argument really betrays is that for many single-payer tax-funded systems, the question being addressed is not one of value but of affordability.

We are not arguing that affordability is not important, but we would argue that in multipayer systems the relationship between funding and choices is more fluid compared with in single-payer systems. The resources available are a function of a myriad of payers that in turn have a myriad of coverage levels that are themselves a function of varying premium rates. This may be a less efficient system (in the utilitarian sense), but it is a system put—and kept—in place by a functioning democracy, so its goals deserve no less respect than those of single-payer systems.

The EQ-5D, which is the most commonly used PRO within QALY calculations, does not meet the FDA's standard for patient involvement and therefore does not have the legitimacy that is obtained by consulting with patients and the general public. The EQ-5D was developed in 1987 by a small group of researchers who aimed to identify “three or four key elements that most health status indexes contained” and explicitly stated that they were not aiming to be comprehensive.<sup>7</sup>

Given the limited pool of expertise and that the instrument developers were not aiming for a comprehensive measurement system, it is unsurprising that the result was an instrument with significant content validity problems. There are 5 dimensions within the EQ-5D: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. It does not directly measure many other dimensions that matter deeply to patient health and quality of life. Examples of these are visual impairment (eg, following cataract surgery), hearing impairment (eg, following cochlear implantation), body esteem (eg, following reconstruction after mastectomy), behavior and ideation difficulties (eg, with treatments for psychosis), cognitive ability (eg, with treatments for dementia), sexual functioning (eg, following prostate cancer surgery), incontinence (eg, following bowel surgery), social functioning (eg, with treatments for autism), energy/vitality (eg, following cancer treatment), and spirituality (eg, in end-of-life care).

This means that whole areas of health technology cannot be properly assessed using the EQ-5D because it does not cover the health issues that the technologies were designed to improve or are likely to damage through adverse effects. The consequence of poor content validity is poor sensitivity: The EQ-5D often underestimates the impact of health treatments compared with measures that were developed with those treatments and diseases in mind.<sup>8</sup> Studies have shown that the content of the EQ-5D is often poorly aligned with patient perceptions in diseases such as asthma,<sup>9</sup> mental health,<sup>10</sup> and cancer<sup>11</sup> and in whole population groups, such as older adults.<sup>12</sup> It can be argued that we should switch to a health utility measure with a broader range of content, such as the Health Utilities Index. However, it is uncertain whether the use of 8 (Health Utilities Index v3) vs 5 (EQ-5D) health dimensions is sufficient to provide content validity for the wide range of conditions to which health utility measures are applied.

It may be argued that some of the dimensions that are missed by traditional health utility measures are captured in a diluted form through secondary effects on the dimensions that are measured. For example, some of the harms associated with visual impairment might be captured by questions about mobility or anxiety and depression. This argument has some validity, but it seems an unnecessarily crude approach that sacrifices accurate measurement to the policy goal of having

a single measure that can be used to compare all possible health conditions. The alternative is to use condition-specific preference-based measures that produce QALYs at the level of condition group. For example, the ReQol Utility Index (ReQol-UI) is a tool designed specifically to value mental health conditions and measure the cost-effectiveness of different treatments in this area.<sup>10</sup> Measures such as the ReQol-UI are growing in popularity and contain questions that are sensitive to the concerns of the patient groups under scrutiny but retain the design features required to produce QALYs for cost-effectiveness analysis. The health states being valued are generated by consultation with the patient groups to whom the measures are applied (thus ensuring content validity), but valuations for these health states are still generated by the broader general public, and it is possible to derive a QALY-type metric that can be used in cost-effectiveness analysis.

A separate critique of the QALY method is that although it purports to represent “societal consensus” about the value of different health states, this is generally not the case. The surveys of the general public used to measure consensus about the value of different health states reveal enormous heterogeneity (ie, disagreement) within populations. For example, the EQ-5D health state 12213 (no problems with mobility or pain/discomfort, some problems with self-care and performing usual activities, extreme anxiety/depression) received a median rating of 0.5 (on a scale where, by convention, 0 represents death and 1 represents full health) in a Canadian survey, but the interquartile range of valuations was 0.338 to 0.725.<sup>13</sup> In other words, half of the Canadian general public rated the value of this health state outside an already wide range. This lack of societal consensus is apparent across life states<sup>13</sup> and is a function of the methods used to derive values for health states (eg, the “time trade-off” technique). The values produced by these methods are known to vary substantially across respondent characteristics such as age, sex, and marital status.<sup>14</sup> Because all existing health utility measures use these valuation techniques, the lack of societal consensus that we have described is apparent across measures and in the different contexts in which they are applied.

With such a level of disagreement, it is unclear that societal consensus really exists around the value of various health states. Averages are not the same as consensus: If the intention is to measure consensus, then an explicit criterion should be used to demonstrate that consensus has been achieved. For example, at least 50% of respondents should agree on the value of a specific health state within a prespecified interval that is considered to be clinically important, such as 0.1. As shown earlier, the current value sets used by the EQ-5D are often far from reaching this standard. This is likely because consensus is not a high priority within the current methods used to derive

societal preferences (eg, the time trade-off technique). It may be necessary to approach the elicitation of preferences in a completely different way in the future; for example, by using methods such as the Delphi technique, in which a prespecified level of consensus, achieved through deliberation and iterative consultations, is the ultimate goal.<sup>15</sup> It may be the case that consensus cannot be achieved, or is achieved with significant minority dissent, but this would not preclude the use of the derived valuations. It would, rather, make clear the extent to which dissent exists, and this would be an important consideration in future resource allocation exercises. For example, it could provide a legitimate basis for greater discretion around choices in conditions or demographic groups in which consensus has been difficult to achieve.

## 2. THE QALY DISCRIMINATES AGAINST SOME GROUPS

This leads us neatly to the question of whether the QALY equitably reflects the health of all individuals. The metric uses a definition of “perfect health” and longevity that implies a fit younger person with no underlying health concerns. This means that patients who currently have a hard ceiling on the amount of QALYs they can gain, because of age, incurable conditions, or permanent and unsolvable deficits in their capabilities due to disability, can never benefit to the same degree as the “ideal” patient. This has been highlighted as affecting numerous groups, from the disabled to the elderly<sup>16</sup> and those with greater severity of disease compared with those with milder disease.<sup>17</sup> The inevitable result of this is that the average QALY gains for interventions targeted at these groups will systematically produce lower estimates of overall health gain compared with similarly efficacious interventions targeted primarily at able-bodied or younger populations.

For example, a recent cost-utility model<sup>18</sup> was constructed with a utility of 0.21 for “early nonambulatory” Duchenne muscular dystrophy, and the highest possible utility achievable was just 0.73. In the event that a treatment was able to extend the life of someone in this health state without sufficiently improving their quality of life, that treatment would only be credited for a fraction of the life-years extended. In contrast, people whose conditions are curable have value attributed for a much larger percentage of the life-years that treatments provide them. Although people with lifelong and chronic conditions may face severe quality-of-life challenges, it would be ethically questionable to automatically assume that they desire life extension any less than their nondisabled counterparts.

This problem is so widely accepted that there have been a number of attempts to develop alternatives to the QALY, such as the Equal Value of Life (EVL)<sup>19</sup> and most recently the Health Years in Total (HYT).<sup>20</sup> Although both were successful

in reducing the impact of distributional inequity compared with the QALY, they both also had wider limitations, which make them poor substitutions for a broken measure. EVL limits the value of interventions that both extend life and improve quality of life,<sup>21</sup> whereas the HYT improves distributional probity but does not altogether fix it. Fortunately, there is an emergence of approaches that incorporate disparities and equity into the cost-effectiveness framework. Cookson and colleagues have developed methods that are being widely adopted around the world that use an equity impact plane to measure trade-offs between equity and efficiency.<sup>22</sup> This allows for the incorporation of equity directly into the quantitative analysis, not as an external “nuance” to be addressed qualitatively as a matter of choice.

Such problems could also be aided by an acceptance of the impracticality of the expected utility theory requirement for a linear utility function. There is no lack of evidence that expected utility theory fails to stand up to scrutiny in practice,<sup>23</sup> so perhaps loosening this constraint would allow us more flexibility in how we view—and calculate—changes in health ratings within a patient set and across a population.

### 3. THE STANDARD QALY FRAMEWORK DOES NOT REPRESENT HOW SOCIETY ACTUALLY VALUES HEALTH CARE

The acceptance of a cost-utility measure has traditionally assumed a purely rule-utilitarian framework, a concept that is sometimes described as “a QALY is a QALY.”<sup>24</sup> In other words, it matters not when, how, or for whom the QALY is gained—its value is equal in the eyes of society. The problem is that the utilitarian framework does not have widespread support. This has been seen in numerous studies asking people to quantify their preferences across various patients in specific contexts. These studies have shown a preference for helping the younger, the sicker, those suffering the most, or those most immediately in need of help.<sup>25-27</sup> The latter category provides an illustrative example of how the standard QALY framework does not represent our general approach to balancing the needs of individuals and society as a whole.

The concept that utilitarianism is inappropriate for comparing wider society with a subset of patients with immediate needs is sometimes called the “rule of rescue.” A number of papers have looked at the validity of the argument for a role of the rule of rescue in resource allocation decisions.<sup>28-30</sup> Arguments have been put forward both for and against by economists and clinicians, but unsurprisingly, as it is a moral question, philosophers have probably provided the most insight into this question.

Hope<sup>31</sup> and Sheehan<sup>32</sup> both highlight that the only argument with a strong moral or judicial foundation is the question of whether it is good to care about identifiable individuals over

and above our responsibility to care for society as a whole. The key here is that our obligations toward those with whom we have direct relationships or those who are close to us in terms of proximity (relative) are more pressing than our obligations to any random person (neutral). For example, we are more obligated to save a drowning child if we are nearest to the water or it is our child.

Agent-neutral obligations are less strong, but we have obligations inasmuch as we are part of humanity and we believe that the well-being of all people is something to aspire to.<sup>33</sup> The question is whether a policy maker has the same moral position as they would have as an individual. Here a policy maker is analogous to the head of a household; the role has both obligations to a constituency as a whole but also equally to each constituent as an individual.<sup>34</sup> Which of the many *prima facie* obligations is relevant depends on which is the most fitting in the context.

Even if we were to suggest that rule-utilitarianism is a comfortable fit with general economic theory—and we, among others, would say it is not<sup>35</sup>—it still does not sit comfortably within the reality of societal preferences and norms for how decisions on health care spending should be made.

We suggest a shift from a one-size-fits-all valuation of health states and toward methods that compensate vulnerable groups within the formula—whether that be in QALYs or an alternate measure. Work on such methods has begun,<sup>36</sup> but they will be widely adopted only if decision makers demand it, as has happened in some jurisdictions (eg, Sweden, Norway).<sup>37</sup>

### SUMMARY AND CONCLUSIONS

Let us return again to the questions we began with: Does the current version of the QALY adequately reflect a patient’s health, does it do so with consistency across all patients, and does the cost-per-QALY approach adequately balance the needs of individuals and society as a whole? We would suggest that the QALY could be substantially improved on all counts. It fails—as outlined as a basic requirement by the FDA—to account for the diverse health concerns of different patient groups. It fails on its own terms as a measure that reflects societal consensus on health valuation. It fails to treat diverse sets of people who can benefit from health care equitably. This is not to say that the overall purpose of the QALY framework—utility maximization—is always wrong, but that when it is activated without consideration and context, it can become a dangerously flawed tool.

In response to these flaws, we have identified ways to improve the QALY framework while maintaining a commitment to efficient resource allocation: (1) the use of health measures that are truly sensitive to the issues that arise in different conditions, (2) true deliberation and consensus

development on how different health states should be valued, and (3) more sophisticated QALY scales that account for variation in ability to benefit across patient and age groups.

We advocate for the greater use and development of condition-specific health utility tools in which patients define the health states to be valued. We propose a greater flexibility in how we compare the effectiveness of treatments across populations so that certain patient groups are not punished for the constraints imposed by their underlying condition. We need to describe and not hide the true heterogeneity of value in health states, if such a metric is to truly reflect societal consensus.

Some argue that value assessment cannot wait for a perfect tool, so an adequate one will have to do. That may be a reasonable answer for the present but not for the future. We argue for more urgency in improving the measurement of health benefit in economic evaluation.

In response to the argument that we need a policy tool that measures equally all interventions across all patients and all diseases, we would note that just because a policy maker asks a scientist to produce something does not mean that it can be produced. A health measurement tool must, above all else, measure health accurately, and condition-specific tools measure health much better than generic tools like the EQ-5D.<sup>38</sup> The only advantage of the EQ-5D is that it is capable of satisfying a practical purpose (distributing resources across diseases). Although it is true that science regularly compromises on method for practical reasons, it is important that the nature and scale of this compromise is transparent when the legitimacy of decisions based upon a controversial methodology is debated.

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