

# PIPC Patient Blog: Patient Perspectives on the Quality Adjusted Life Year

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The use of the quality adjusted life year, or QALY, is widespread in research, health economics, and value assessment. However, the QALY is not without controversy as has been noted many times in the PIPC blog. Health economics and outcomes researchers, policy makers, and advocates have long debated the appropriateness and ethics of the QALY. Governmental agencies, managed care organizations, and healthcare payers routinely utilize the QALY in their decision making. However, one voice that has been glaringly absent from this debate is the most important voice: patients.

[The Cancer Support Community \(CSC\)](#) was interested in [patient perspectives on the QALY](#)—particularly considering the wide-ranging impacts that the measure has on patients, especially those living with life-limiting illnesses such as cancer. The QALY combines morbidity (quality of life) with mortality (quantity of life) to estimate the value of specific health interventions. The QALY and cost-per-QALY inform discussions and policy decisions regarding the allocation of healthcare resources.

The QALY, however, has significant limitations. It does not allow for changing patient preferences over time or other objectives such as fairness, equity, or political goals. The QALY was never intended to be used as an individual decision-making tool. Although the QALY is based on patient preferences, these preferences are determined by surveying samples of various populations—not by those who are actually making real-time decision about care. The QALY also makes assumptions and places worth on varying states of quality of life—inherently discriminating against individuals living with disabilities or those in a disabled state.

However, most disturbing about the QALY is perhaps the fact that it is used broadly and with significant impact on the lives of patients, and many patients are unfamiliar with the

concept. As our recent study, "[Perspective of Patients with Cancer on the Quality-Adjusted Life Year as a Measure of Value in Healthcare](#)" found, the majority of patients, although largely highly educated and health literate, were not aware of, nor did they completely understand, the QALY. Once we presented participants with more information about the QALY, about half of participants indicated that the QALY made sense, however only about one-quarter of participants believed it was a good way to measure value in health care. Qualitative findings revealed that participants were open to using the QALY in their personal decision-making process, showing that the QALY has the potential to be a valuable decision aid for patients with cancer. Yet, participants were highly reticent of the use of the QALY by external decision makers, who would have the ability to impact their access to care.

Ultimately, patients believe strongly that they should maintain autonomy over treatment decisions, with input from their healthcare team and family. We know that patients look beyond cost and treatment outcomes to determine value. Patients are not numbers and don't wish to be treated as such. They need the freedom to make personal and nuanced healthcare decisions for themselves. Ultimately, our study illuminated the fact that patients with cancer believe that the QALY does not reflect the diversity of their experiences, needs, and beliefs.

As critical healthcare decisions are made that will have serious repercussions in the lives of patients with cancer, it is vital to consider their needs, preferences, and values. The QALY is not an appropriate measure to help us achieve these goals.