



Patients Rising Now Fly-In QALY Issue Paper

Background

The Quality Adjust Life Year (the QALY) is a measurement used by some policymakers, insurers, and independent researchers to assess the value of healthcare treatments. QALYs appraise a patient's life by scoring a patient's health for each year of a life expectancy, ranging from a score of 1 for a year of perfect health to 0 if deceased. Policymakers assign a dollar value to an improvement in QALY to determine what group of patients to treat or which conditions to prioritize in allocating health care resources.

Cost effectiveness analyses based on the QALY are used by insurers and payers to inform the treatments and services that may or may not be covered. QALYs limit the care given to those most in need of it. Because people with disabilities, seniors, and patients with chronic conditions may never achieve a year of perfect health, a treatment that extends or improves their life will result in fewer QALYs and therefore given less value. When applied to coverage and reimbursement decisions, the result is discrimination against these patient populations.

Proponents of the QALY claim it is "the gold standard for measuring how well a medical treatment improves patients' lives." Yet, the QALY favors people with conditions that are relatively inexpensive to treat. The QALY systematically discriminates against people with hard-to-treat or advanced conditions and prefers healthier patients at the expense of others. Indeed, the Institute for Clinical and Economic Review (ICER), a privately funded non-governmental agency that markets its QALY-based tool to Medicaid, commercial health plans, and pharmacy benefit managers, admittedly favors allocating resources to more well-known and easily treatable illnesses, claiming, "[t]he opportunity cost of supporting the use of ultra-orphan drugs necessitates that patients with a more common disease, for which a cost-effective treatment is available, are denied treatment." This is simply untrue. Allocating resources to care for rare and chronic diseases does not necessarily limit treatments for more widespread conditions.

The problems associated with QALY-based pricing models are well documented. Chiefly, **the QALY is a deliberate discriminatory tool that intentionally shifts resources away from the most vulnerable.** The value of human life (each of whom is a mother, father, son, daughter, husband, wife and friend) should not be weighed on whether it is cheap to preserve.

Status

Both Congress and the Department of Health and Human Services (HHS) have recognized this fact and enacted a statutory ban on using QALYs in Medicare and by the Patient-Centered Outcomes Research Institute (PCORI) to determine coverage, reimbursement, and incentive programs. Yet the Institute for Clinical and Economic Review (ICER), a privately funded, unauthorized, unregulated, non-governmental, private organization continues to market QALYs as a useful tool for Medicaid, commercial health plans and pharmacy benefit managers.



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Members of Congress on both sides of the aisle have expressed opposition to using the QALY in public programs. Patient advocates have long pushed for the consideration of better metrics by payers that reflect the priorities of patients and people with disabilities, hoping to reduce hurdles to appropriate and timely care.

The Protecting Health Care for All Patients Act of 2023 (H.R. 485) will prevent discrimination against Americans with disabilities by ensuring that federal agencies cannot determine that extending the life of an elderly, disabled, or terminally ill person is of less value and prohibits the use of other forms of adjusted-life-year metrics and pricing methods as a “threshold to establish what type of healthcare is cost-effective or recommended.”

H.R. 485 was marked up and advanced out of the House Energy and Commerce Committee on March 23rd of this year, with a commitment from both sides of the aisle to continue working towards a bipartisan bill. It is not yet clear when it will be brought to the House Floor for a full Chamber vote. There is currently no companion legislation in the Senate.

Action Requested

House Representatives vote for the Protecting Health Care for All Patients Act of 2023 (H.R. 485) when it reaches the House Floor. Senators should work with their colleagues on a companion bill to H.R. 485.