



Congress Should Support a Broad Ban on QALYs and Similar Metrics

As treatments are developed and approved for LGMD, it is imperative that LGMD patients are able to access them without barriers, like payers relying on discriminatory metrics to determine coverage and reimbursement.

Quality-adjusted life years (QALYs) are metrics commonly used to determine the value of a health care treatment. To calculate a QALY, researchers assign a value to a person's life. *Because the value assigned to seniors, the chronically ill, or people with disabilities is lower than that of a young, healthy person, QALYs could lead policymakers and payers to conclude that treatments for seniors, patients with chronic conditions, or people with disabilities are not worth covering.*

Currently, QALY-based cost effectiveness analyses are commonly referenced in the development of Preferred Drug Lists and benefit designs for services covered under Medicaid, allowing states to restrict coverage based on flawed determinations of clinical and cost effectiveness that inherently devalue people with disabilities or chronic conditions. Over the years, concerns about QALYs have been expressed by many Members of Congress on both sides of the aisle.

The Protecting Health Care for All Patients Act (H.R.3864), would advance the recommendation of the National Council on Disability calling for the bar on use of the QALY and similar metrics that discriminate to be extended to all federal programs, including Medicaid.

Congress should support this legislation as an important step forward to unambiguously bar QALYs and protect all people from health care discrimination.

QALY safeguards are bipartisan: This bill builds upon important safeguards in the Patient Protection and Affordable Care Act and the Inflation Reduction Act that protect against misuse of QALY standards in Medicare.

QALY prohibitions are broadly supported: The bill also advances recommendations from a broad range of stakeholders. The National Council on Disability, an independent federal agency advising Congress and the administration on disability policy, recommended as part of its Health Equity Framework that the bar be extended to all federal programs. Additionally, in its independent assessment, the Disability Rights Education and Defense Fund (DREDF) concluded that use of QALYs violates national disability nondiscrimination laws.

The bill would prevent efforts to use QALY metrics in federal health programs: In recent years, policymakers have pursued flawed policies that rely on QALY-based decisions—both directly and indirectly—at the federal and state level. This bill would protect against these or similar efforts, giving patients and people with disabilities greater assurance that policy will reflect their needs, instead of relying on discriminatory, one-size-fits-all standards that ignore individual differences.

The bill opens the door to giving a voice to patients and people with disabilities: By prohibiting the use of flawed standards that discriminate and ignore differences in patient needs, the bill sets the stage for ongoing work towards policies that include patient perspectives and considers individual needs and perspectives.

For Additional Information Regarding Limb Girdle Muscular Dystrophy Day on the Hill, Please Contact Kathryn Bryant Knudson at: Kathryn@TheSpeakFoundation.com.