

1. What are value assessments?

Patients aren't just a number or a calculation. They have value as human beings regardless of what chronic condition or disability they may have. Decisions about treatment courses and costs must always be made with a patient's best interest at heart, but some don't see it this way.

For-profit companies are trying to change our healthcare system and discriminate against patients who have the greatest needs by using value assessments to control what drugs to make available and at what cost.

Value assessments put a numerical value on improvements in a patient's quality of life from any given treatment. Based on the calculation of a Quality Adjusted Life Year (QALY), these assessments claim to determine the cost-effectiveness of treatments, but don't take into account the therapeutic benefits patients may receive and the improvements patients may feel.

2. How do QALYs work?

QALYs are a tool that ultimately discriminates against drug therapies that are used to treat but not cure disabilities and chronic conditions. QALYs place a price on the value of living a full year of life in "perfect health," and then insurance companies use QALYs to determine which drugs to cover. Drugs that do not offer a full year of life, or that offer less-than-full quality of life, are rated lower on the QALY scale.

3. How are value assessments discriminatory?

QALYs disadvantage the disabled, or those with chronic conditions, who seek treatments to extend or improve the quality of their lives but will never be fully cured, causing these treatments to be priced beyond what patients can afford or simply left off of their formularies. Value assessments unfairly favor treatments that are able to return a patient to "perfect health," which undervalues treatments for vulnerable populations who may see great improvements to their quality of life but never return to "perfect health."

4. Do value assessments include the patient perspective?

Patients and those with disabilities have been left out when value assessments are calculated. Instead, cost rankings are done by for-profit groups like the Institute for Clinical and Economic Review (ICER) for insurance companies and the government. QALYs are calculated by surveying the general population and asking them how much life they would be willing to sacrifice to avoid acquiring a disability. They don't include how patients feel about the health decisions they make for themselves and their loved ones. This isn't an appropriate method to determine what medicines a patient should or shouldn't have access to or how much it should cost. Those with disabilities or chronic diseases know that a full and happy life can be lived with a disability.

5. Are the calculations of QALYs transparent?

The development of these cost ratios is deliberately not transparent. These calculations do not involve input from patients, caregivers or their doctors, but are completely created and controlled by for-profit groups who shouldn't have a say in a person's health.

6. Why did the Affordable Care Act ban the use of value assessments in Medicare?

Disability rights advocates successfully secured a prohibition on the use of QALYs in Medicare in the Affordable Care Act due to their discriminatory nature, and because of concerns about the impact upon older Americans, the disabled and the terminally ill.

7. Who is monitoring the use of QALYs in Medicare?

Centers for Medicare and Medicaid Services is in charge of the regulations for Medicare plans, and must ensure that those with disabilities and chronic diseases can access the healthcare they need without unnecessary hurdles. Congress banned the use of QALYs in Medicare, but has not for Medicaid or commercial health plans. As of yet, QALYs do not have widespread use in the United States.

8. Why are value assessments beginning to gain favor in the United States?

As affordability continues to be a challenge for too many patients, states are looking at QALYs to save money. Even though it has been banned by Congress, ICER, who calculates QALYs, continues to market them as a useful tool for state-run Medicaid programs, commercial health plans, and pharmacy benefit managers.

9. What is Your Voice, Your Value?

Your Voice, Your Value is a coalition of health advocates, community groups, caregivers and patients with disabilities, chronic conditions and illnesses who all agree that patients have value beyond costs. Our mission is to make our voices heard, making it clear that value assessments can't be used to deny access to treatment or stifle innovation.

10. What is Familia Unida and why did they launch Your Voice, Your Value?

Created in 1998, Familia Unida Living with Multiple Sclerosis serves over 15,000 individuals and families living with diverse disabilities in and around Los Angeles County. We launched Your Voice, Your Value as part of our mission to help diverse communities living with chronic conditions have access the resources they need to maximize their quality of life.

11. What can we do to protect healthcare access for those with disabilities and chronic diseases?

Your Voice, Your Value is fighting against these discriminatory practices and need you to stand with us. Sign our pledge today at: www.lovefamiliaunida.org/pledge to demand patient-centered solutions and to voice your support for patients and health advocates impacted by value assessments. Make your voice heard and let decision makers know you have value. *Join Your Voice, Your Value today!*

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