



Five Ways the Institute for Clinical Economic Review FAILS Patients & People with Disabilities

The Institute for Clinical and Economic Review (ICER) is a private research organization that conducts cost-effectiveness assessments of medicines and health care services. Health insurers and policy-makers use these assessments to guide decisions that impact patient access, which is concerning to the patient and disability community, as their research fails them in multiple ways.

1. Reliance on Discriminatory Methods

Cost-effectiveness analyses rely on the use of discriminatory quality-adjusted life years (QALYs) and similar one-size-fits-all summary metrics. These metrics have long been prohibited from use in public health care programs because they discriminate against patients and people with disabilities by placing a lower value on their lives and treating them as averages rather than individuals. Despite the widely acknowledged ethical problems related to using QALYs in health care decision-making, this metric continues to underpin ICER's assessments.

***Recommendation:** ICER should halt its use of QALY-based value assessments and develop measures of value that do not discriminate against patients and people with disabilities.*

2. Failure to Meaningfully Engage Expert Stakeholders

ICER chooses to leave patients, caregivers and clinicians who have firsthand experience with the condition under review out of the deliberation and voting process. Their failure to include experts who can provide relevant and meaningful insight about the impact of specific conditions demonstrates how little ICER respects the value of patient and clinician voices.

***Recommendation:** ICER should include stakeholders who have firsthand experience with the topic being discussed, either as a patient, caregiver, or clinician, should have an equal voice and vote in all future assessments.*

3. Failure to Consider Outcomes that Matter to Patients and People with Disabilities

Rather than prioritizing outcomes that matter to patients and people with disabilities when determining the value-based price, ICER values a treatment strictly from the health system and insurer perspectives. This can lead to situations where it is more "valuable" not to provide care for some patients because to do so would not be "cost-effective." Placing payers' perspectives over patients' needs is wrong.

***Recommendation:** ICER must incorporate a range of patient-relevant outcomes in their determinations of value for treatments and acknowledge how value may vary among diverse patients and people with disabilities.*

4. Premature Assessments

ICER's rush to deliver payers and policymakers value assessments immediately upon FDA approval has led to hasty reviews based on early assumptions, oversimplified models, and incomplete data. By prioritizing speed over quality, ICER provides payers and policymakers with flawed information based on limited evidence, which leads to decisions that are similarly flawed. ICER should not prioritize swift service to its payer customers over scientific rigor.

***Recommendation:** ICER should refrain from publishing a value-based price until they are able to determine the 'impact on net health benefit' with 'high certainty.' They should also submit their assessments for peer review prior to releasing them to ensure consistency and accuracy in their methodology.*

5. Lack of Transparency to Patients and People with Disabilities

ICER's assessment process is a black box, leaving patients and people with disabilities in the dark on the assumptions used and important limitations that may have impacted the results. It is imperative that all stakeholders have access to the models used so they can assess their validity and understand the implications of alternative methodologies.

***Recommendation:** ICER's models should be open-source, transparent, and available to all patients and researchers to fully understand and replicate findings.*