

# Chairman's Corner: Congress Must Protect Health Care Access From Being Denied Based on Flawed Analysis

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In an op-ed for *The Hill*, PIPC Chairman Tony Coelho outlined his concerns with MedPAC's pursuit of cost-effective analysis to make coverage and reimbursement decisions. As he writes, "As policymakers encourage a transition towards value-based health care, I worry that more focus is being given to what is most cost-effective for the "average patient" than creating a system that works for each individual patient. I am not average. You are not average. We are the reason a health-care system exists — our health and well-being, our treatment, our recovery."

Chairman Coelho also states, "One thing I've learned over five decades as a patient advocate and public servant is that if patients don't stand up for themselves, nobody else will. The second is that when a policy-maker or academic tells us 'take your value-based care, it's good for you,' it's time for a second opinion. That's why I'm speaking out against the ideas being bandied around by an influential group of Medicare advisers that threatens to silence the voices of patients. At a recent public meeting, the Medicare Payment Advisory Commission (MedPAC) appeared eager to pursue an 'aggressive' approach that would encourage Medicare to rely on cost-effectiveness analysis to make Medicare coverage and reimbursement decisions."

***Congress must protect health care access from being denied based on flawed analysis***

*As chairman of the Partnership to Improve Patient Care (PIPC), I have strived to ensure that the voices of patients and people with disabilities have a meaningful impact on health-care system reforms. Too often, we are at the table as a token or nod to the perspectives of patients and people with disabilities, but our views are not incorporated into the final product or decision.*

*When given the chance to make our voices heard, patients are likely to emphasize the need to treat each person as an individual — not just a number. As policymakers encourage a transition towards value-based health care, I worry that more focus is being given to what is most cost-effective for the “average patient” than creating a system that works for each individual patient. I am not average. You are not average. We are the reason a health-care system exists — our health and well-being, our treatment, our recovery.*

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*That’s why I’m speaking out against the ideas being bandied around*

*by an influential group of Medicare advisers that threatens to silence the voices of patients. At a recent public meeting, the Medicare Payment Advisory Commission (MedPAC) appeared eager to pursue an “aggressive” approach that would encourage Medicare to rely on cost-effectiveness analysis to make Medicare coverage and reimbursement decisions.*

*These recommendations were followed by calls from academics to use cost-effectiveness thresholds to set Medicare policy.*

*Unfortunately for patients, these analyses typically rely on academic calculations that systematically disadvantage people with disabilities and patients with complex conditions when applied to coverage decisions.*

*For example, the most common method for determining incremental cost-effectiveness of health-care interventions is based on a calculation of quality-adjusted-life-years (QALYs).*

*While cost-effectiveness models that rely on QALYs have a basic appeal for making population-level decisions, in 1992 the Secretary of the U.S. Department of Health and Human Services (HHS) publicly recognized their discriminatory impact for people with disabilities when used to determine access to care.*

*As MedPAC considers whether cost-effectiveness has a place in*

*Medicare payment policy, there is good reason to be concerned about the implications of health-care coverage policy built on population-based value assessments.*

*For people with disabilities and patients with chronic conditions who may or may not be cured, access to treatments and health interventions can be essential in improving their quality of life. And because cost-effectiveness models systematically disadvantage the most complex patients, these communities have a long history opposing the use of QALYs as the benchmark to measure the value of health care interventions.*

*Commissioners acknowledged the political hurdles and previous resistance to implementing cost-effectiveness in Medicare when proposed and rescinded back in 1989 and 2000, but did not take much time to discuss the concerns that led to such opposition.*

*It is troubling to me that the “incremental approach” suggested by commissioners may be intended to impose cost effectiveness over time, thereby avoiding intense scrutiny despite its methodological flaws and long-term impact on patient access to care.*

*Thankfully, Congress did listen to patients back in 2010, and were concerned enough to ban use of the QALY metric used in cost effectiveness analyses in Medicare. Congress also barred the*

*research organization established in 2010 — known as the Patient-Centered Outcomes Research Institute (PCORI) — from using a cost-per-QALY in its assessments of comparative clinical effectiveness.*

*Simplistic average measures of value reinforce an outdated, paternalistic system of health care and work against the nation's efforts to achieve personalized medicine and to develop targeted, individualized therapies. They discriminate against those who don't fit the average.*

*There is more we can do together to advance these policies so that patients get high value care tailored to their unique characteristics, needs and individual response to treatment. Having authored the Americans With Disabilities Act (ADA), I am all too familiar with this fight. The medication I take for epilepsy isn't "high value" for every patient. But it's the only one that works for me.*

*After hearing MedPAC's plans for future recommendations, I hope that Congress and the administration will step in to ensure that the existing statute protecting patients from denied access to care based on flawed cost-effectiveness analyses is not circumvented.*

*Instead, work with patients and people with disabilities to advance policies that align the evidence of clinical effectiveness with the delivery of care through use of valid decision aids that clarify how*

*treatments work on different patients. To really put “patients first,” invest in the infrastructure and tools needed to determine what treatment works for that individual person, and pay for it.*