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A Patient Advocate Guide to ICER and Why They Matter



Dear Fellow Advocates:

July is the month where we as a nation commemorate the Declaration of Independence of our country. On July 4, 1776 the Continental Congress declared that the thirteen American Colonies were no longer subject to the monarch of Britain and were now united, free, and independent states.

What does this have to do with patient advocacy, you ask?

Absolutely nothing or everything. I know you thought the fight was over after you raised the funds for the innovation, engaged in the clinical trial process, and then fought to get approval from the FDA. But if an outside body is allowed to determine who will have access – then what was it all for?

Our battle has only just begun.

Today we are at a similar crossroads as a nation as we decide whether we go the way of the British and adopt their system – a socialized medicine system using the QALY as our metric in determining what treatments are worth and if those that need them are worth the price. Rather than patients and doctors, a national price control body will hold the fate of all future medical innovation and who will receive it.

The QALY has many critics here and abroad, and yet, we have a self-appointed institution called The Institute for Clinical and Economic Review (aka ICER) trying to import this system here. Their methodology is a direct threat to the independence that drives our medical innovation and provides hope for many patients, especially those in the rare disease community.

ICER is dangerous. You may read headlines where they claim they are the ‘mouse that roared’. As someone who founded the website ICERWatch.org and has been following ICER for more than three years ... they are not a mouse. ICER is a Trojan Horse and they have been given a war chest in excess of \$19,000,000 to spread their influence.

No matter what rare or chronic disease you represent, if you believe in a future without ICER calling the shots -- we must all join forces to RISE against them. Read on to learn more about ICER and how you can get involved. Here is a link to an [online advocate registration form](#).

A handwritten signature in black ink that reads "Terry M. Wilcox". The signature is written in a cursive, flowing style.

Terry M. Wilcox
Co-Founder and CEO, Patients Rising Now

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Who is ICER?

The Institute for Clinical and Economic Review and its controversial “one-size-fits-all” value framework is a **direct threat to rare disease patients.**

In its newly-released report, “[*Looming Challenges for ICER in Assessing the Value of Rare Disease Therapies*](#),” the independent Pioneer Institute identifies a troubling pattern of ICER ignoring the needs of patients living with rare diseases and details how the cost appraiser systematically undervalues innovative treatments for chronic and complex conditions.

“Patients with complex and rare diseases have much to be hopeful for as our knowledge expands and more innovative and specialty therapies come to market,” explains Dr. William Smith, the report’s author and a visiting fellow in life sciences at the Pioneer Institute. “Yet, ICER threatens to limit access to these life-changing treatments.”

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2014-2018: No High Value Ratings for Rare Disease Treatments

Among the report's major findings: Between 2014 and 2018, none of ICER's reviews of rare disease drugs resulted in a "high value" rating. Insurance companies commonly use ICER's ratings to justify treatment denials and barriers to accessing life-saving treatments.

"Health care is not an equation," says Dr. Smith. "Patients battling life-threatening diseases shouldn't be denied access to treatments because a little-known research group in Boston put an arbitrary dollar amount on their life."

The in-depth report also raises new questions about ICER's political agenda and whether its cost-cutting health care framework has any validity in assessing the effectiveness of treatments for rare diseases and conditions.

"ICER's methodology is, by definition, a "one-size-fits-all" approach that will inevitably fail to keep up with medical science's understanding of how and why different therapies work differently in different patients," the report states.

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Patient Advocates Must Create an ONGOING Public Assessment of ICER

The Pioneer Institute report offers independent proof that ICER is unfit to review treatments for rare diseases. Patients Rising Now believes it is about time someone assessed ICER's anti-patient framework.

ICER's assessments have gone unchallenged as they advance the interests of both insurers and pharmacy benefit managers.

ICER is funded by former hedge fund manager billionaire, John Arnold. Mr. Arnold has spread his influence far and wide, and in many respects he and his funders are driving health care conversations in this country.

ICER's use of the quality-adjusted life year, or QALYs, in its value framework, discriminate against both rare disease and chronic disease patients, many of them seniors. QALY is a complicated and controversial method of calculating the value of a patient's life. One QALY is equal to one additional year of life in perfect health or two additional years of life at 50 percent health.

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QALY Discriminates Against Patients with Rare Diseases, Chronic Conditions

Patients living with rare diseases or chronic conditions can never achieve full value under a system of quality-adjusted life years. If left unchecked, ICER would rollback vital patient protections included in the Affordable Care Act.

As part of the Affordable Care Act, Congress banned Medicare from using the QALY methodology out of concerns that it could hurt the ability for the elderly and people with disabilities to access to medical care. ICER has embraced a novel tactic to circumvent these patient protections. ICER's ambition is therefore to have state Medicaid programs (New York, California, Massachusetts) and commercial plans employ their reviews when making coverage decisions," the Pioneer Institute report cautions.

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