

Patient Engagement Guide: The Institute for Clinical & Economic Review (ICER)



Educational Guide: Engage With ICER & Raise Your Voice on Treatment Access & Medical Innovation Issues

Patient access and medical innovation are under threat. The Institute for Clinical and Economic Review (ICER) continues to rely on discriminatory practices that threaten vulnerable populations' access to innovative treatments. **Use this educational guide to learn how you can engage in the conversation with ICER and raise your voice to support innovation and Patient access.**

About ICER



What Is ICER? The Institute for Clinical and Economic Review (ICER) is an independent research group that uses a controversial approach to evaluate the value and cost-effectiveness of new drugs.



What Does ICER Do? ICER uses the "Quality Adjusted Life Years" (QALY) methodology in an effort to determine whether medical treatments for particular diseases and conditions such as cancer, cystic fibrosis, ulcerative colitis, and more are worth their cost.

Key Terms & Definitions



Health Technology Assessment (HTA): A multidisciplinary process that uses systematic and explicit methods to evaluate the properties and effects of a health technology.



Quality Adjusted Life Year (QALY): An arbitrary evaluation of the value of one year of perfect health. The QALY methodology is used to assess the value of medical interventions and often places a lower value on the lives of the disabled, the elderly, and Patients with a rare disease.



Value Assessment: A multidisciplinary field focused on the evaluation of health care interventions in an effort to accurately define and quantify their value.

Take Action



ICER's approach to drug value assessment may be discriminatory against vulnerable Patient groups, by placing a lower value on the lives of the disabled, the elderly, and Patients with a rare or chronic disease.

You can raise your voice around how the ICER value assessment model threatens Patient access to life-saving treatments. Here are some ways you can make your voice heard:

Participate in ICER's Public Meetings

- Eight months after the announcement of a drug value assessment, ICER holds a **public meeting to discuss the results of the assessment** and to vote on the effectiveness of the selected treatment.
- Every meeting is **fully virtual and open to the public**.
- **Patient advocates may nominate themselves or another Patient advocate to make an oral comment**; however, only a few are selected to speak at each meeting.
- Oral public comments are presented in front of ICER and other stakeholder experts and should **speak to the potential impact on access and Patient health outcomes**.
- To submit a nomination, email **publiccomments@icer.org** with the name, title, and organization of the speaker during the Draft Evidence Report's open comment period.

Share Your Story with ICER

- **Patients' unique lived experiences are vital** to helping ICER develop a comprehensive understanding of the impacts of a medicine.
- Sharing your story demonstrates **the diversity of Patient populations** and helps ICER to understand that **Patient experiences cannot be generalized**.
- ICER **uses this input anonymously** in reports about a treatment or disease.
- An ICER input form takes **approximately 10 minutes** to complete.
- You may answer **whichever questions you feel are relevant to your experience** in the form.
- Submit your story via form at **https://bit.ly/ShareStory_ICER**.

When evaluating a new drug, ICER releases **two draft reports** during the review process and invites Patients and other stakeholders to provide formal feedback over a 3-week period. **All comments must be written in 12 point, Times New Roman Font, and submitted to publiccomments@icer.org**. Public comments will always be published publicly on the ICER website.

Draft Scope 3 page maximum

The Draft Scope is a proposed outline for ICER's research report. The best written comments will focus on:

- Relevancy of the drug(s) and accuracy of the comparator under review
- Important health benefits and side effects
- Most heavily impacted Patient populations
- Outcomes that Patients value most

Strong comments will use personal experience to support all feedback.

Draft Evidence Report 5 page maximum

The Draft Evidence Report contains the results from ICER's clinical and economic analysis of a treatment's effectiveness. The best feedback will discuss potential areas of impact that ICER fails to address, including:

- Daily life and family
- Education or career
- Affordability and accessibility
- Existing health disparities
- Additional Patient populations

Effective comments will highlight personal experiences and emphasize how ICER's conclusions may exacerbate discriminatory health practices.

Best Practices

As you engage with ICER and other stakeholders around treatment value and Patient access issues, **keep the following best practices in mind:**



Your experience is your advantage. Share stories that highlight the personal impact of the issue that you are advocating around to help ICER staff and leadership understand the broad diversity of Patient experiences. Every Patient story is unique and critical to shaping individuals' understanding of an issue.



Remember your target audience. Whether you are sharing a letter directly with ICER leadership or meeting with members of staff, ensure that you are speaking directly to their ask and level of familiarity with the topic you are discussing.



Make your message specific. Keep your language and story straightforward and easily digestible so that the key messages and call to action are understood.



Lift up other Patient voices. While sharing your own story, drive awareness of the differences between Patient experiences and how those individual needs cannot be met with a one-size-fits-all approach value assessment framework like the one currently employed by ICER.



Include a clear and concise call to action. Clearly defining and conveying a single call to action will ensure that your audience has an actionable next step. A call to action could be reviewing new data or asking for a meeting with other advocates. Remember to restate the call to action at the end of your conversation, comment, or testimony!

Join Us

If ICER reports are used more broadly, it could limit incentives for future investments in the life sciences industry, threaten New Jersey's nearly 5,600 life sciences establishments, and ultimately prevent Patients from accessing breakthrough, often life-saving medicines.

Take Action to Protect Patients & Medical Innovation from ICER
BioNJ.org/Protect-Medical-Innovation