



INSTITUTE FOR CLINICAL
AND ECONOMIC REVIEW

GUIDE TO OPEN INPUT

We want to hear from you

When starting a new report, we have a lot of questions. What treatments should we include? What outcomes should we consider? What are we missing? We need help answering these questions. We look to all kinds of groups- doctors, drug makers, insurance companies, and, importantly, patients—to help us fill in the gaps.

That’s where you come in. By providing us with information about how patients experience their disease and what is most important to them, you help us to make sure we’re thinking about these issues from the very beginning. It’s important to us that we know what matters to you—the patient—to make sure our reports can support policies and guidelines that help make sure patients can access, and afford, the most effective treatments.

Sending your input

The questions below can help give you an idea of what kinds of information are most helpful to our reports. You can answer as many or as few of the questions as you’d like. There are no page limits to Open Input submissions. Anything you can tell us about your experience is very helpful and important in helping us create a useful report.

- To give us time to consider your input, we’ll need to receive your answers by the deadline. Open Input lasts for three weeks. You can find the deadline on the “Meeting” page of the specific topic you’d like to comment on.
- Email your responses, and any other information or documents, to publiccomments@icer-review.org. We’ll confirm that we’ve received it.

8) What are the outcomes that we should consider, but may not be part of the clinical trial literature?

9) Are there new/emerging treatments that the patient community is anticipating?

If so,

10) Are newer treatment options expected to have fewer side effects? Are the side effects more tolerable than side effects of current treatment?

11) Are new treatment options expected to be more or less convenient to take?

12) Are there other pros or cons of new treatment options?

13) Would new treatments help a particularly vulnerable population, or a subgroup of patients for whom other treatments haven't been as effective?

14) Do patients have trouble getting insurance coverage for treatment? If so, please describe the most common challenges that patients face.

- 15) Do patients have difficulty affording treatments? How do they deal with these challenges?

- 16) Are patients concerned about the potential costs of new therapies?

- 17) Do you know of any relevant, unpublished information that helps describe patient needs, preferences, or issues? Does your organization collect patient-related data, or do you know of a group that does this?

- 18) Are there any other patient groups working in this disease area that we should include in outreach efforts?

- 19) Please share any other information that you think is important for us to know from a patient perspective.

Thank you for taking the time to share your experiences with us.

We look forward to working with you as the process continues.