



How to Share Your Lived Experience with ICER

A Guide to ICER's Scoping Phase:
For patient groups, individual patients,
and caregivers.

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What is the Scoping Phase?

The scoping phase is the first two months of ICER's research process. During this time, the ICER team is trying to "scope" or figure out what is most important to include in our report about the treatment and patient population we are researching. We do this by speaking to different members of the patient community to better understand the diversity of patient lived experience.



What Happens During this Phase?

- ✓ ICER notifies the patient community about the review
- ✓ ICER offers introductory calls to meet with patient groups
- ✓ ICER offers scoping calls to figure out our research priorities
- ✓ ICER publicly announces the review & publishes the **Draft Scope**
- ✓ ICER asks for **public comments** on the Draft Scope
- ✓ ICER publishes the **Revised Scope**

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What is the Draft Scope?

The Draft Scope is the proposed outline for ICER's research report. The Scope includes information like the treatment(s) under review, the patient population of focus, and the outcomes most important to patients.

What is the Public Comment period?

Public comment is a period of time (usually 3-4 weeks) following the public posting of an ICER draft document. During this time, the patient community and the public are invited to provide written input on the draft document. We read and post all public comments on our website.

How to Submit a Public Comment?

- Email comments to publiccomments@icer.org
- Please submit as an attached Word document in the following format:
 - 12-point Times New Roman font
 - 3-page maximum for Draft Scope (not including references or appendices)

What is the Revised Scope?

The Revised Scope is the updated outline of ICER's research priorities. This version includes any changes to our thinking based on input we received during the scoping calls and public comments. We hope the patient community can help us focus our research on what outcomes are most important to patients.

How You Can Share with ICER

We want to hear from you! You can choose some or all of the options below, depending on how much time you want to spend.

1

Scoping Call

Scoping calls are 30-minute virtual calls with ICER's team. The goal of these calls is to better understand the patient experience with the disease and treatments. We will use this information to ensure the most important patient priorities are reflected in our report. Scoping calls are attended by about 10 members of ICER's clinical and economic teams.



2

Written Input

Once the Draft Scope is posted, we have a 3-week public comment period for the community to provide their feedback on anything the ICER team should change. The patient community can also provide written input at any time via email to the Program Manager or Patient Engagement Lead.

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3

Small Group Patient/Caregiver Discussions

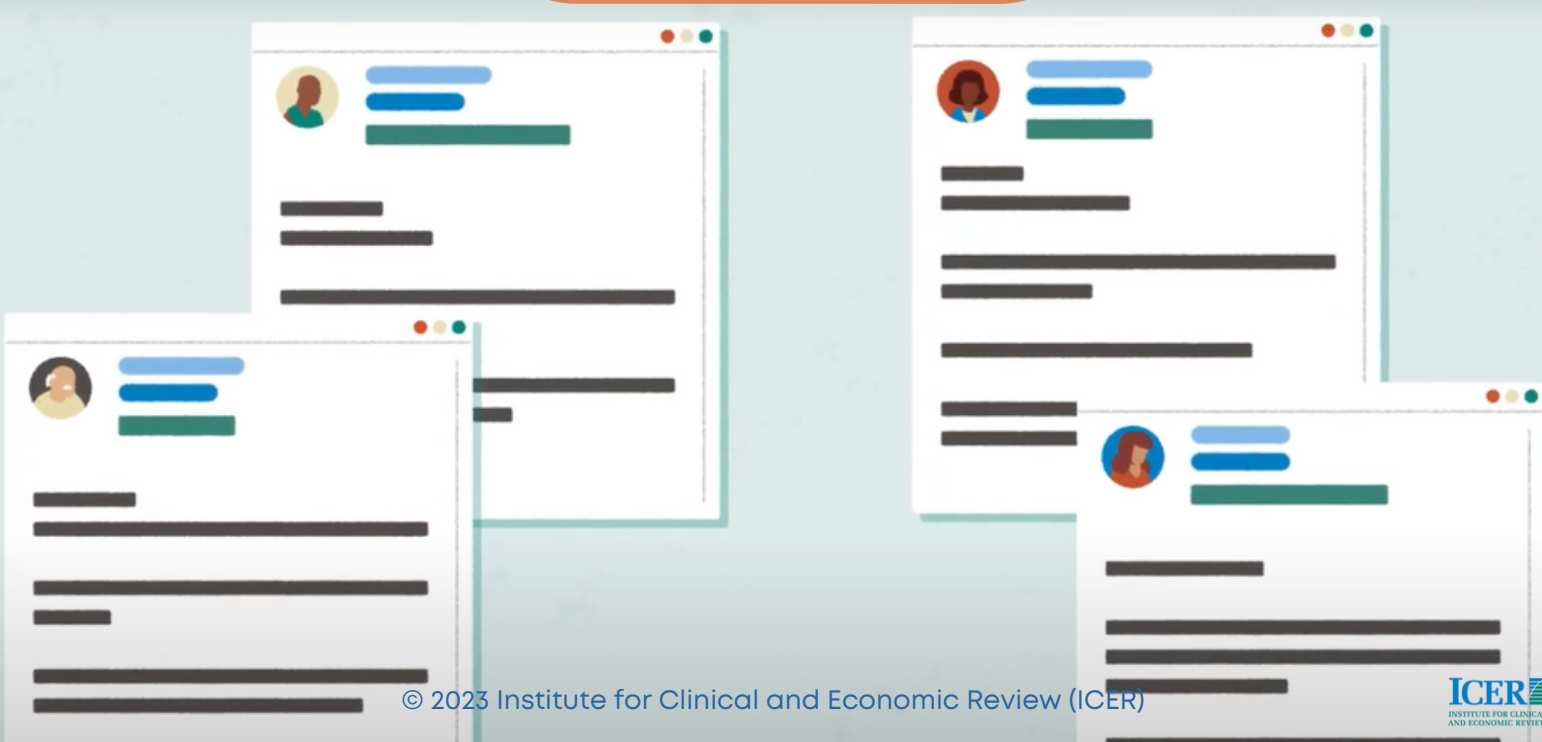
Once the ICER team has spoken with relevant patient groups, we request to be connected with individual patients and caregivers for a 1-hour small group discussion. These discussions help the ICER team learn about patient preferences, experiences, and hopes for new and existing treatments.

4

Share Your Story Form

The Share Your Story Form is a 5-question form meant to capture the diversity of lived experience with the disease and treatment. This is a short and simple option for those who are interested to share their story but unable to attend a scoping call. Submissions to the form are kept anonymous when summarized in the ICER report.

[Click here to check out the form!](#)



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What ICER Can Learn From You

- ? **What types of patients are most impacted by the disease?**
- ? **How does the patient community feel about the treatment?**
- ? **What are the pros/cons of existing treatments for this disease?**
- ? **What symptoms of the disease are most bothersome or difficult to manage?**
- ? **What is the patient community most hopeful that a new treatment can do for them?**
- ? **What are the biggest challenges for patients in getting the treatment or being able to afford it?**
- ? **What is the impact of the disease on family members or caregivers?**
- ? **Are there any important health disparities that impact this patient population?**



What haven't we asked that you think would be important for us to know about this disease or treatment?