

2025

Institute for Clinical and
Economic Review
(ICER)

ICER PATIENT COUNCIL

PROGRESS REPORT



“The 2024 Patient Council Summit was a unifying event, and an occasion to celebrate the great strides made in developing a robust suite of patient engagement materials for ICER. Upon this strong foundation, the Patient Council was able to dive deeper into strategic projects this past year, focused on patient education and accessibility. The success of ICER’s pilot project for patient-informed health economic modeling represents a key example of how the Patient Council’s guidance from project conception to conclusion paved the way to explore a potential patient-informed process enhancement.

--Cat Koola Fischer, MPH
ICER’s Director of Patient Engagement and
Co-Chair of the Patient Council

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Introduction to ICER

The Institute for Clinical and Economic Review (ICER) is a non-profit that conducts research on how well prescription drugs and other treatments work for patients and what a fair price should be.

ICER's Work ICER conducts health technology assessments – a research process that evaluates how much added benefit a new treatment brings to patients when compared to existing options.

ICER's Goal ICER wants the price of treatments to match the benefits that patients and families receive. Treatments that work really well should cost more, while treatments that don't work as well, should cost less. Treatments that are fairly priced should be easy for patients to access.

ICER's Public Process To do this, ICER works with patient groups, patients and caregivers, clinicians, insurers, and manufacturers to understand the added benefit of the new treatment. Our work is transparent and publicly available on our website, icer.org.

ICER's Independent Funding To remain independent, ICER receives the majority of our funding from non-profit foundations to ensure that our research is free from conflicts of interest. We list all our sources of funding [here](#).

ICER is working toward a health care system that can provide all patients access to the treatments they need at prices everyone can afford.

Background

In July 2023, ICER announced the creation of a [Patient Council](#) to advise on ICER's patient engagement strategy, outreach, and process for input into drug reviews and broader initiatives. The Council comprises patient representatives with a range of expertise on health technology assessment (HTA) and engaging with ICER, offering a variety of perspectives for evaluation of the ICER process.

Establishing the Patient Council's formal governance, role, and responsibilities were made in consultation with Jean Mossman, who has international expertise in HTA. Jean served as the independent facilitator between ICER and the Patient Council members in the early phase of Council development. Having a neutral facilitator was critical to allow the Council members and ICER to independently voice expectations and concerns, and co-create an action plan for the Patient Council that met the needs of both parties.

Meet the Patient Council



TIFFANY WESTRICH-ROBERTSON
Patient Council Co-Chair;
CEO, International Foundation for
Autoimmune & Autoinflammatory
Arthritis (AiArthritis)



REV. TAMMIE DENYSE
Cofounder & President,
Carrie's TOUCH Breast
Cancer Organization



ISIAH C. LINEBERRY
Former Executive Director,
Harrisburg Family Health Care



RICHARD PEZZILLO
Executive Director,
New England Hemophilia
Association



DINA THACHET
Board Member & Patient Advocate,
Lupus and Allied Diseases
Association (LADA)

Patient Council Objectives

The main objective of the Patient Council is to help patients and the public understand the value and impact of their involvement, and improve the diversity of people that are included and heard in the process of the evaluation of health treatments. The Council aims to achieve this in three key ways:



Process Evaluation

Evaluate ICER's current process of patient engagement to identify opportunities for improved communication and participation



Diversity & Inclusion

Ensure that the ICER HTA process includes a diversity of experiences



Accessibility

Review ICER's Patient Portal and public-facing documents to ensure accessibility and inclusivity



Measuring Progress: Process Evaluation

COMPLETE

IN
PROGRESS

Objective	Activity / Project	Impact
<p>Explore potential solution to address patient dissatisfaction with ICER's economic model development and results</p>	<p>Provide feedback on ICER's pilot project for patient-informed health economic modeling to add 3 focused sessions with patients during a drug review process:</p> <p>»»» Session 1: Introductory training on cost-effectiveness analysis</p> <p>Session 2: Semi-structured patient group interview to gather patient input and feedback on ICER's draft economic model approach</p> <p>Session 3: Presentation of draft economic model results to gather patient reactions and additional feedback</p>	<p>The approach to this process enhancement as well as the slide content used for the patient sessions were reviewed by the Patient Council and updated to reflect their feedback.</p> <p>The final outcome of the pilot project was patient satisfaction with the new process, a deeper understanding of cost-effectiveness analysis, and feedback that the content provided during the sessions was accessible and easy to follow.</p>

Patient Council Summary Report

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Meetings
Attended

Since the 2024 Patient Council Summit, Council members attended four virtual meetings (August 2024, November 2024, February 2025, May 2025) and one in-person meeting at the ICER Office in July 2025.

- A key highlight of the July 2025 meeting was hearing directly from patient participants about their experiences engaging with ICER within the last year, prompting ideas for future process improvement.

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Strategic
Project

The Patient Council advised and provided regular feedback on the following strategic project:

- ICER's pilot project on patient-informed health economic modeling

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Conference
Presentations

ICER's Director of Patient Engagement, Cat Koola Fischer, presented on the role & impact of the Patient Council at the conferences below:

- 2025 NEHA Consumer Medical Symposium
- Vital Voices Workshop hosted by FasterCures
- 2025 Patient Engagement Open Forum

Looking Forward

Patient Council's Action Plan for 2025-2026

Following the 2025 Patient Council Summit, all Council members identified new opportunities within ICER's Patient Engagement Program to further evaluate ICER's process and drive policy change in partnership with participating patient groups.

- The Patient Council aims to better understand how the patient-facing materials created to date (e.g., [Introduction to ICER](#), [How to Share Your Lived Experience](#), [How to Respond with Feedback to ICER's Work](#), and [How to Participate in ICER's Public Meeting](#)) are actually utilized by participating patient groups, and advise on how they can be strengthened to decrease the burden on patient groups to educate their respective communities about ICER.
- Patient Council members will explore opportunities to elevate the evidence and policy recommendations coming out of ICER's final reports to empower patients and patient groups to better advocate for policy change.

ICER would like to thank the following individuals and groups whose contributions and support have made the 2025 Progress Report possible:

- ICER's Patient Council members -- Tiffany Westrich-Robertson, Rev. Tammie Denyse, Isiah Lineberry, Richard Pezzillo, and Dina Thachet -- for their time, expertise, and strategic guidance on ICER's patient engagement program
- Patient participants from ICER's 2024-2025 reviews for their panel session participation during the 2025 Patient Council Summit and thoughtful feedback on how ICER can continue to improve its process for engaging patients
- The Patrick and Catherine Weldon Donaghue Medical Research Foundation for grant funding to support Patient Council activities
- Cat Koola Fischer, ICER's Director of Patient Engagement and Co-Chair of the Patient Council, for her leadership and facilitation of Patient Council activities, and for designing and authoring the 2025 Progress Report
- Sarah K. Emond (ICER's President and CEO), Ellie Adair (ICER's COO), Kelsey Gosselin (ICER's Program Director), Grace Ham (ICER's Senior Program and Events Coordinator), Marina Richardson (ICER's Associate Director of HTA Methods and Health Economics), and Madeline Booth (ICER's Program Manager) for their participation, guidance, and support during Patient Council meetings



Group photo from 2025 Patient Council Summit in Boston, MA

Left to right: Richard Pezzillo, Tiffany Westrich-Robertson, Dina Thachet, Cat Koola Fischer, Tammie Denyse, Isiah Lineberry

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