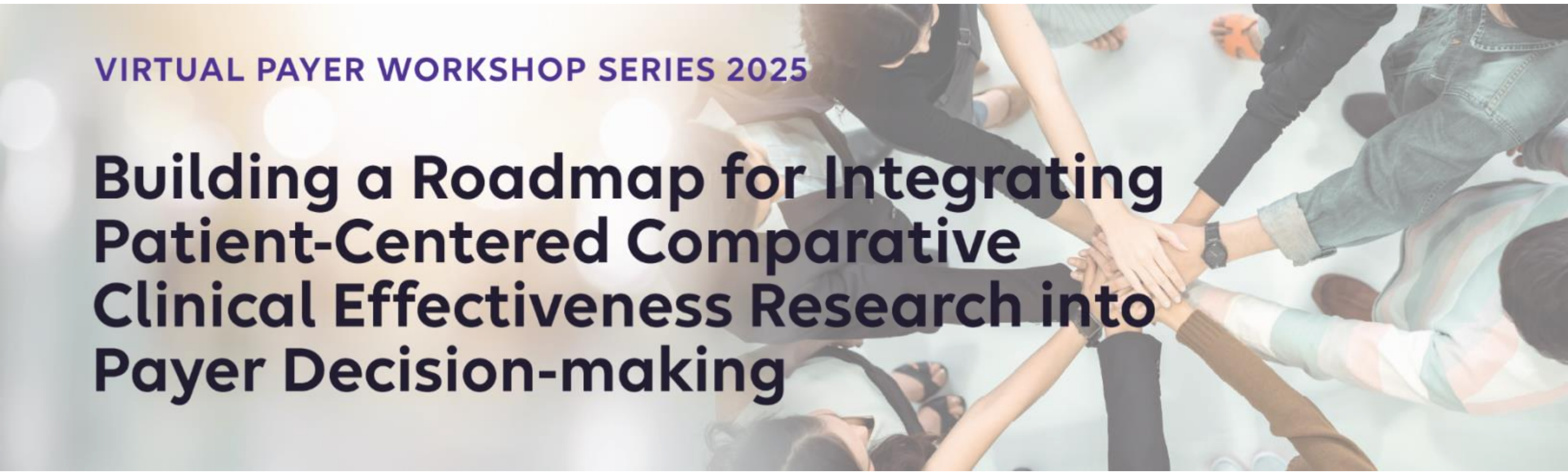

VIRTUAL PAYER WORKSHOP SERIES 2025

# Building a Roadmap for Integrating Patient-Centered Comparative Clinical Effectiveness Research into Payer Decision-making

# Workshop 1: Building Capacity in Patient-Centered CER

## Summary Report

May 29th, 2025

11:00 am - 12:30 pm EST

This project was conducted by Carelon Research, with funding through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASCS-39048).

# Background

In Workshop 1, participants gained a foundational understanding of patient-centered comparative effectiveness research (CER); its key components and quality indicators, while exploring the potential impact on value assessment, medical and pharmacy coverage decisions, and care management with a multi-stakeholder panel. The learning objectives for Workshop 1 were to:

- Define patient-centered CER and describe types of patient-centered CER study designs
- Learn about current frameworks and resources that integrate patient-centered CER to evaluate the value of medical and pharmacy products, care delivery and benefit design
- Consider challenges and opportunities for incorporating patient-centered CER into payer decision making from a multi-stakeholder perspective
- Articulate how patient-centered CER could add value to payer decision-making in the future

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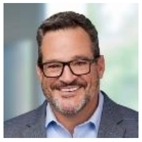
# Conference Summary

## Introduction to Workshop Series

- The next frontier of patient-centered research is to support the growing interest among payers who want to incorporate patient-centered CER and patient perspective into payer decision-making.
- Payers can leverage existing patient engagement tools and best practices as they develop their own policies and processes.
- This series of workshops is intended to build capacity among payers while also revisiting knowledge gaps, resource limitations, and process improvements.
- Participants are asked to consider the key decision points in payer decision-making and what is needed at those points to support the generation and optimal integration of patient-centered CER.



Mark Cziraky
*President*
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Carelon Research

## Foundational Aspects of Patient-Centered CER in Payer Decision-Making

Harv Feldman
*Deputy Executive Director for Patient-Center*
*Research Programs*
Patient-Centered Outcomes Research Institu

- CER is research that compares benefits and harms of two or more healthcare options delivered within real-world settings across heterogeneous study populations.
- Patient-centered CER addresses concerns that matter to patients and is achieved through a broad set of engagement activities and practices to generate evidence that stakeholder communities find meaningful and useful.
- The rapidly changing set of healthcare options with varying levels of evidence to support their use creates an inherent tension between speed and rigor. Payers often operate on a rapid timeline and to meet their needs a variety of evidentiary products need to be produced.
- PCORI produces a horizon scanning tool that systematically identifies, monitors, and reports on technologies and innovations that are emerging with a focus on the interventions that have a high potential for disrupting clinical care.
- High quality patient-centered CER has many characteristics, and two prominent ones are 1) the provenance of the research questions and identification of evidence needs come from genuine broad-based patient and stakeholder community engagement 2) the use of rigorous design and statistical approaches

to generate trustworthy evidence.

- The Center of Innovation and Value Research, formerly known as the Innovation and Value Initiative, is a nonprofit organization seeking to test new methods and approaches to patient-centered value research of which CER is a part.
- When using patient engagement as a methodology, real-world priorities are highlighted and outcomes that matter to stakeholders will be elevated. These outcomes may help influence satisfaction and people's ability to follow treatment recommendations.
- The Center has built a patient-centered economic impact framework considering co-payments, social impacts, caregiver impacts, education and job impacts.
- Lessons learned from engaging patients in the development of the economic framework include 1) the importance of continuous engagement throughout the process 2) patients want to know how their participation and input made a difference 3) provide compensation for patient advisors. One tool available to estimate compensation is the National Health Council Fair Market Calculator

Erica Malik
*Chief Operating Officer*
Center for Innovation & Value Research

Sarah Emond
*President and Chief Executive Officer*
Institute for Clinical and Economic Review

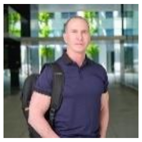
The Institute for Clinical and Economic Review (ICER) is an independent nonprofit that conducts value and health technology assessment. ICER synthesizes evidence on new technologies to determine their comparative clinical effectiveness and their cost effectiveness.

- The ICER mission supports a multi stakeholder approach to ensuring that patients have access to the care they need at an affordable price.
- ICER initiated a patient engagement program about 10 years ago that engages patients in 1) scoping calls to decide on research questions and identify outcomes that matter to patients 2) providing feedback on model analysis plans and draft reports 3) public meetings
- Sometimes patient-centered outcomes aren't in the clinical trial for a new technology being evaluated, so ICER will partner with the patient community to produce data to fill that gap, which in some cases has increased the recommendation of a value-based price.
- One lesson learned from ICER's patient engagement program was to not assume there is one patient perspective – consider ways to represent diversity by being flexible when and how you offer engagements, partner with patient advocacy organizations to diversify the patient voice represented, consider using social media to learn about different perspectives

*Q:* How do we improve the data pipeline so we know we're using data that really reflects what's important to patients?
*A:* "Patients express frustration when trial data do not incorporate outcomes that are important to them, and because of that lack of data, are not considered part of the value model. We have been hearing fewer frustrations over the last five or six years, so the data is getting better. This is a credit to the patient-focused drug development program at the FDA which really focused at the right point, which is upstream talking to patients and their families about what outcomes matter to them, so it is in the clinical trial data set, and manufacturers have the best case to make the value proposition for their medicine." – Sarah Emond

## Current and Future State of Patient-Centered CER in Payer Decision-Making

- A multi-stakeholder panel was assembled consisting of self-identified patients, caregivers, patient advocates, payers, researchers, industry representatives, and non-profit executives.
- Culture (paternalism and comfort level engaging individuals who have health challenges), communication (understanding what works and what doesn't), and clarity (providing internal and external guidance on patient engagement) were identified as challenges encountered when considering how to incorporate patient engagement in the patient-focused drug development program.
- Building capacity is important including knowing how to do patient engagement and understanding the organization within which that engagement is done.
- Process integration and impact measurement are important building blocks. Consider the range of processes that could benefit from patient engagement and measure outputs or actions taken because of patient engagement.
- The business case needs to be clearly defined across the entire set of payer processes, while continuously evaluating and measuring where engagement makes sense/has impact and where it doesn't.
- Define and measure short, medium, and long-term outcomes. Business decisions may need to be made quickly and may not be able to wait 5-6 years for a CER study to be completed. Identify what can be learned early on with short-term outcomes and consider how the organization can pivot as evidence grows.
- Payers need to be engaged in a two-way conversation with their members, providing education and outreach while receiving feedback on care and programming.
- Integrating patient engagement early on into aspects of payment models may make it more likely patients engage in the program and allow the program to be more effective. Consider components of payment models and how patient engagement may add value including quality measures, attribution methodologies, patient incentives, care models, clinical requirements, and how the organization communicates about these programs.



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*Senior Director of Research*
UPMC Center for High-Value Health Care

> "It turns out they are just what human beings want from healthcare because in health care, we have trained ourselves to try to solve problems for what we consider the median patient. When in fact, if you design the system and your processes for the length of the bell curve, you end up serving everyone better. Think of it as designing the health care equivalent of curb cuts, right? Designed for people in wheelchairs turns out also great for parents with strollers and travelers with luggage, and that's what you get out of authentic engagement."
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> – Mai Pham