

VIRTUAL PAYER WORKSHOP SERIES 2025

A top-down photograph of a diverse group of people sitting on the floor with their hands stacked in the center, symbolizing teamwork and collaboration.

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

## Workshop 3: Building a Roadmap for Collective Action

### Summary Report

September 18th, 2025

11:00 am - 1:00 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

This capstone workshop brought together leaders from across stakeholder partners, including patients, industry, research, and payers to build a roadmap based on payer evidentiary needs in patient-centered CER. The workshop explored opportunities for collective action in a multi-stakeholder forum and a series of breakout sessions.

Workshop participants discussed:

- Payer unmet needs, multi-stakeholder priorities, and components of a draft roadmap for collective action.
- Actionable next steps and milestones that will indicate forward progress in the following areas:
  - Strategies for incentivizing patient-centered CER development and improving the patient-centered data ecology.
  - Multi-stakeholder investments that are needed to bridge evidence to action to address payer unmet needs.
  - Bi-directional resources and tools that support payer evidentiary needs and priorities in patient-centered CER.
  - Developing a communication strategy to raise awareness about payer evidentiary standards, priorities and needs in patient-centered CER.
- Promising practices and actionable next steps as part of the draft roadmap.

## Workshop Summary

Two breakout sessions were co-facilitated by a patient and payer representative. Each group prioritized the needs identified in Workshop 2 and discussed the following questions.

1. Are the needs presented representative of your experience?
2. What would you add or change?
3. How would you prioritize these unmet needs in terms of importance and feasibility.
4. What would you add or revise from the initial list of actions related to these needs?
5. Who are the key stakeholders responsible for these action items?
6. What resources are you aware of that might support progress in this area?
7. What resource gaps remain?
8. Who is curating the existing resources to support the payers and how do we bridge the gap between production of resources and action/implementation?

Below is a summary of some of the key points raised during the breakout discussions.

The discussion noted resources to raise awareness among payers including ICHOM core datasets and measures, some that are published and some that are not, and the National Core Indicators which focus on communities with disabilities and older adults, and the PFDD that has guidance and tools described on how to measure what is important to patients in a way that is useful to payers.

Patients and payers agree that condition-specific quality of life measures have more utility than generic or broad-based quality of life measures. Researchers, however, do not often collect condition-specific quality of life measures in their studies.

Participants noted that incorporating patient-reported outcomes into clinical trials is still 'formative' and the conversation about the type of data payers use needs to be expanded to include observational study designs and other types of real-world data post-market that represent the patient experience.

Participants noted the importance of layering patient representation during evidence synthesis in the payer review process including HBCU, Hispanic academic institutions, and community-based organizations. The importance of bi-directional communication was noted as well as the value of building trust within these underrepresented communities by providing feedback on reasons recommendations were or were not incorporated into payer decisions.

Some participants noted that stakeholder umbrella organizations (AHIP for the payers, NHC or others for patients) may be the best organizations to support transparency and education and organizing bi-directional forums where communication can happen among payers and patients.

One participant recommended that Carelon Research/Elevance Health consider ways to form a 'coalition of the willing' of like-minded payers to build momentum and support a deeper conversation with AHIP about patient-centered CER and payer decision-making. Additional venues where Carelon Research/Elevance Health may be able to elevate the dialogue is with MLTSS Association and MHPA.

Payers face hurdles on how to incorporate patient-centered CER, where to get good data and what does that data look like. Having answers to those questions when approaching AHIP would help. Conversations haven't happened with AHIP because payers don't know how to get past those hurdles. They can't tell when patient evidence is presented to them whether the evidence reflects the pharmaceutical manufacturer or the patients' needs.

Participants noted that payers may be able to access internal resources such as case managers and member outreach groups that work directly with members to bring additional perspective to the table.

Participants raised the possibility to use AI to support plain language summaries of guidelines or policies. Some participants warned that AI is often trained on claims data and not patient outcome data, so it may represent more what is DONE TO patients not what MATTERS TO patients. The group agreed that an expert would need to oversee the output of AI to ensure its intention and language is appropriate for the purpose of the summary.

Participants raised a concern about identifying additional resources and funding (beyond PCORI) that supports collective investments in what is important to patients.

One participant suggested we consider forming a dissemination committee to develop a dissemination plan that has specific goals, identifying audiences, what actionable results have been identified, and how audiences like to get their information.

Uptake of results and translating evidence into actual practice and implementation into local environments was identified as a challenge.