



Uncovering the True Cost of Healthcare

Advancing Patient- and Family-Centered Economic Impacts

Executive Summary

July 2026

This workshop and report was partially funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (#EACB-32695).

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Suggested Citation: Uncovering the True Cost of Healthcare: Advancing Patient- and Family-Centered Economic Impacts (Executive Summary). IVI, July 2026.

Overview

When facing a serious health condition, patients, caregivers, and families experience not just clinical impacts, but also financial and non-financial impacts—including direct medical costs, administrative costs, travel and childcare, mental health impacts, caregiving responsibilities, educational and employment impacts, and others. These burdens shape health outcomes, influence treatment decisions, and vary across families, especially for people with complex health conditions or from different backgrounds. Yet they remain inconsistently measured and are rarely integrated into research, policy, or decision-making.

“Economic burdens and health outcomes—not external financial issues—and patient experiences must guide how we measure and respond to them.”

– Workshop Participant

Purpose

To address this gap, IVI led *Uncovering the True Cost of Healthcare*, a six-part multi-stakeholder workshop series design to build capacity across research, policy, and patient communities to better understand, measure, and advance patient- and family- centered economic impacts. The series operationalized [*A Research Framework to Understand the Full Range of Economic Impacts on Patients and Caregivers*](#) (released by IVI and AcademyHealth in 2023), translating conceptual guidance into practical insights and actionable lessons.

The project sought to catalyze a shift in how healthcare stakeholders conceptualize “cost”—from a narrow, system-centric lens to a more comprehensive, patient- and family-centered understanding that reflects lived experience across the care journey.

Project Goals

The overarching goals of the project were to:

- Normalize patient- and family-centered economic impacts as essential outcomes in patient-centered outcomes research (PCOR) and comparative effectiveness research (CER);
- Equip researchers, funders, policymakers, and other stakeholders with practical approaches to identifying and prioritizing meaningful economic impacts; and
- Center lived experiences as a form of evidence that strengthens relevance, feasibility, and trust.

Participants and Engagement Approach

IVI brought together a diverse, cross sector group of stakeholders, including patients, caregivers, patient advocates, researchers, clinicians, payers, policymakers, employers, industry representatives, and funders. Two advisory groups, a Community Advisory Board composed of patients and caregivers with lived experience, and a multi-stakeholder Steering Committee representing research, policy, patient advocacy, and health system perspectives, helped co-develop the workshop series.

Over two years ago, IVI engaged nearly 300 participants, with strong representation from individuals with lived experience. Each workshop was intentionally co-designed with a patient or caregiver partner and a researcher, and every session began with a personal story to ground discussion in real-world experience. This approach fostered trust, openness, and deeper insight, as reflected by one advisory member who shared, “The sessions were grounded in lived experience, creating a space where individuals felt comfortable expressing vulnerability.”

The six-part workshop series explored priority domains within the Patient-Centered Economic Impacts Framework, including patient journey mapping, time costs, caregiving impacts, diagnostic delay, stress, and long-term educational and employment consequences. Workshops combined storytelling, research presentations, interactive polling, and facilitated small group discussions to surface both methodological challenges and practical solutions. These findings are presented in six publicly available learning reports, acknowledging all workshop participants.

Our Impact in Numbers



Overarching Takeaways

- **Economic burdens are inseparable from health outcomes.** Financial strain, time burden, stress, and caregiving responsibilities are not downstream consequences of care. They are integral to the patient experience and directly influence health outcomes, often compounding over time.
- **What is not measured is systematically undervalued.** Without shared approaches, these costs remain invisible in decision-making.
- **Lived experience is essential infrastructure for better research.** Meaningful patient partnership improves the relevance, feasibility, and interpretability of research. Co-design helps ensure that studies focus on outcomes that matter most to patients and caregivers and that findings can be translated into real-world action.

Key Takeaways by Workshop (Click on Workshop Number to View Full Learning Report)

WORKSHOP #1

Journey Mapping Patient-Centered Economic Impacts for Research

Patient journey mapping reveals that economic burdens vary across individuals and over time, challenging static notions of "the patient experience."

WORKSHOP #2

Time is Money: Capturing Time Effects of Economic Impacts

Time burden is a universal yet under-measured economic impact with significant implications for equity and treatment choice.

WORKSHOP #3

The Economic Realities of Caregiving

Caregiving costs extend beyond lost wages to include emotional labor, health decline, and long-term financial instability for families.

WORKSHOP #4

Incorporating Patient Costs into Research on Diagnostic Delays

Delayed diagnosis generates cascading economic consequences that persist even after treatment begins.

WORKSHOP #5

Quantifying the Cost of Stress for Patients and Caregivers

Chronic stress is both a cause and consequence of economic strain, with measurable health and financial impacts.

WORKSHOP #6

Beyond Productivity: Capturing Long-Term Educational and Job Impacts

Educational disruption, underemployment, and stalled career trajectories represent long-term economic costs that are poorly captured by traditional productivity metrics.

Project Impact

The Uncovering the True Cost of Healthcare workshop series advanced the field in meaningful and concrete ways. Over the course of the initiative, IVI and its partners:

- **Advanced the field’s understanding of patient-centered economic impacts** by moving beyond theoretical frameworks to surface practical, experience-grounded insights from nearly 300 cross-sector stakeholders over two years.
- **Produced six publicly available learning reports** that translate complex concepts into accessible, actionable guidance for researchers, funders, policymakers, and patient advocates.
- **Identified methodological priorities for future research**, including the need to standardize measurement of time costs, stress, caregiving impacts, and long-term trade-offs that are currently invisible in conventional analyses.
- **Built a cross-sector community aligned around this work**, bringing together patients, caregivers, clinicians, payers, employers, and policymakers in sustained dialogue—creating shared language and shared purpose across traditionally siloed groups.
- **Generated actionable insights that can inform future research, value assessment, and policy decisions**, laying the groundwork for integrating patient and family-centered economic impacts into study design, health technology assessment, and real-world decision-making.

“As a researcher and caregiver, these questions are important but ultimately will only be useful if we collect data and information to do something to make people’s lives better.”

– Workshop Participant

Looking Ahead: Applying and Advancing the Work

Findings from the workshop series underscore the need for coordinated action across research, funding, and policy. Patient journey and experience mapping, in particular, emerged as a practical tool for understanding how economic burdens—and especially time—shift across the life course.

IVI is now translating this momentum into concrete next steps, and with four priority action areas:

1. Standardize measurement of priority economic impacts—including time, stress, caregiving, and long-term trade-offs—to ensure these outcomes are consistently captured across research and evaluation contexts.
2. Embed patient and family partnership throughout research design, moving from consultation to true co-creation so that lived experience shapes study questions, methods, and interpretation from the start.

3. Apply insights beyond research into policy and payment, testing patient-centered economic impacts in real-world models and decision-making frameworks.
4. Translate findings into practical tools, publications, and partnerships that extend the reach of this work and support continued methodological development—particularly around time impacts, the unifying theme across all six workshops.

“One of the key approaches that we’ve used to elevate patient perspectives is patient journey mapping. This tool has been especially valuable in helping us move beyond a single static notion of the patient experience. Patient experience and the economic and non-economic burdens associated with care vary widely across individuals, and they change over the life course. Journey mapping really helps us to surface that variability to understand how patients values and burdens shift over time, and acknowledge the different realities that people are going to face at different points in their care journey.”

– Workshop Participant

Conclusion

Through Uncovering the True Cost of Healthcare, IVI demonstrated the value of sustained, equity-centered convening to advance patient- and family-centered economic impact research. The project has already influenced research planning, patient journey mapping, and policy thinking, and it has laid the groundwork for continued dissemination, partnership, and capacity-building. Understanding the true cost of healthcare requires listening to patients and caregivers—and acting on what they share. IVI remains committed to advancing this work and supporting stakeholders across the healthcare ecosystem in translating insight into impact.

Acknowledgments

IVI would like to extend a sincere thank you to our [members](#), as well as the following individuals who were integral to this project:

Steering Committee Members

- Elizabeth Cope, PhD, MPH, AcademyHealth
- Gwen Darien, Patient Advocate Foundation
- Vakaramoko Diaby, PhD, MSc, CRA, Otsuka
- Phyllis Foxworth, Huntington's Disease Society of America
- Juan Marcos González Sepúlveda, PhD, MS, Duke Clinical Research Institute
- Elisabeth Oehrlein, PhD, MS, Applied Patient Experience
- Alexis L. Estomin Malfesi, MSHS, Center for Medicare and Medicaid Innovation
- Mary Reed, DrPH, Kaiser Permanente
- Silke Schoch, MA, National Health Council
- Kevin Wake, CMR, CHW, MS, Uriel E. Owens Sickle Cell Disease Association of the Midwest

Community Advisory Board Members

- Jamal Brown
- Claudia Chahin, JD
- Elizabeth Cope, PhD, MPH (Steering Committee Liaison)
- Rodney Dawkins
- Brian Dawson, MLIS
- Christine Freund, CSW
- Beth Gore, PhD
- Gail Graham
- Jae Samuel (in memoriam)
- Dorothy Winningham

IVI gratefully acknowledges the Patient-Centered Outcomes Research Institute (PCORI) for supporting this work, with particular thanks to Senior Program Manager, Ivey Wohlfeld, and Senior Advisor for Patient-Centered Burdens and Economic Outcomes, Casey Quinn, for their guidance throughout the project.



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