

## Co-Design in Practice: Lessons from Engaging People with Lived Experience in Economic Impact Research Workshops

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### Purpose

**We asked:**

*What if patients and caregivers helped define what counts?*

- Traditional economic impact measures often miss the broader costs that patients and caregivers experience.
- Through co-designed engagement and based on the Patient-Centered Economic Impacts Framework (See Figure 1), this project aims to improve how patient and caregiver costs are included in research and decision making.

### Project Methods

The project convened two advisory groups to inform the design of the workshops, identify topics, identify both workshop faculty and participants, and review workshop materials. All workshops were grounded in lived experience and focused on co-learning across perspectives. Learning reports following each workshop were designed as reference tools for participants (See Figure 2).

**Figure 2. Approach**



### Objectives

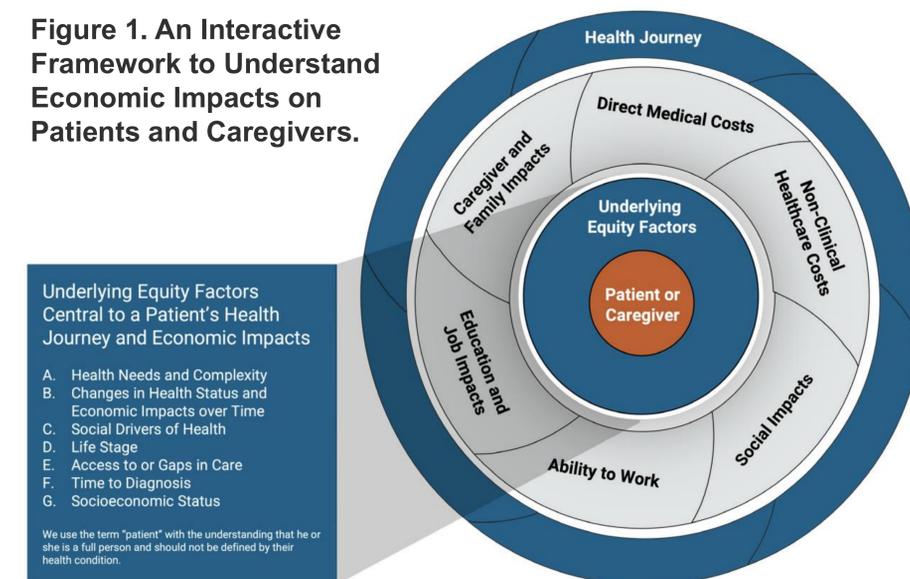
- Improve the definition, measurement, and communication of economic impacts to better reflect the real-world experiences and priorities of patients and caregivers.
- Equip researchers with practical tools to capture a broader spectrum of economic impacts and patient-centered burdens and economic outcomes in their comparative clinical effectiveness research studies.

### Lessons Learned

*“This was the first time I felt like my experience mattered to the research.”*  
- Workshop Participant

- Centering the patient voice grounds research in lived experience.
- Building trust and relationships is foundational to meaningful engagement.
- Inclusive language fosters respect and shared understanding.
- Co-develop goals enhances collaboration and alignment.
- Mixed methods strengthen findings by integrating narratives with quantitative data.

**Figure 1. An Interactive Framework to Understand Economic Impacts on Patients and Caregivers.**



### Project Findings

- **Process enhancements** included refined agendas, more interactive formats, and faculty selection informed by participant feedback.
- **Content updates** reflected advisory input and participant polling, ensuring workshops addressed the most relevant topics: patient journey, time costs, caregiving, and diagnostic delays
- **Advisory structure** was strengthened through joint Steering Committee–Community Advisory Board meetings, achieving a 3:1 patient/caregiver-to-researcher ratio in advisory roles.
- **Participant feedback** was overwhelmingly positive—attendees reported feeling respected, valued, and noted it was their first opportunity to define economic impact from their perspective.

