

*Recommendations to Guide Adoption of Patient-Centered Outcomes and Impacts for Decision-Making**

Developing A Framework for Capturing Economic Impacts on People Living with Serious Health Conditions

Background

Traditionally, when healthcare researchers measure patient economic impacts, they focus on the medical costs defined by healthcare payers (e.g., co-pays, deductibles). However, patients *and* caregivers experience a much wider range of economic impacts because of their health conditions and healthcare. These might include the costs of transportation to receive care, their ability to work, or behavioral health concerns that may affect their overall health and economic status.

Researchers and decision makers have begun to recognize that the economic impacts of serious health conditions reach far beyond these traditional measures. Our hope is that by asking questions about economic impacts that are important to patients and caregivers, more robust measures can be included from the outset in research that will better inform healthcare decision making.

The [Innovation and Value Initiative](#) (IVI) and [AcademyHealth](#) have partnered to develop a framework for researchers, value assessors, and other decisionmakers to ensure we are addressing the full range of economic impacts in research studies and decision-making. The goals for the project are to:

- Define “economic impacts on patients and caregivers” and what cost areas should be a priority.
- Acknowledge barriers to collecting economic impact data.
- Identify when economic impact data should be collected and for what purpose.
- Identify promising approaches and actions needed to collect economic impact data.
- Offer insight to ensure sustained action.

Steering Committee Members

- Jennifer Bright, MA, IVI
- Richard Chapman, PhD, IVI
- Elizabeth Cope, PhD, MPH, AcademyHealth
- Gwen Darien, National Patient Advocate Foundation
- Kathryn Davidson, MSW, CMMI
- Margo Edmunds, PhD, FAMIA, AcademyHealth
- Omar Escontrias, Dr.PH., MPH, National Health Council
- Juan Marcos Gonzalez, PhD, MS, Duke Clinical Research Institute
- Maureen Hensley-Quinn, National Association of State Health Policy (NASHP)
- Tom Hubbard, The Network for Excellence in Health Innovation (NEHI)
- Laura McClung, PhD, UCB, Inc.
- Sharon Phares, PhD, MPH, National Pharmaceutical Council (NPC)
- Laura Pizzi, MD, ISPOR
- Elridge Proctor, MPA, GO2 Foundation for Lung Cancer
- Abby Sears, OCHIN
- Cristie Upshaw Travis, HealthCareTN
- Gretchen Wartman, National Minority Quality Forum (NMQF)

IVI and AcademyHealth have invited thought leaders from across the industry to participate in a multi-stakeholder Steering Committee to provide insight and recommendations as we develop this framework. We held a series of key informant interviews in the fall of 2022, are planning a roundtable discussion on February 1, and a consensus meeting in the spring of 2023.

We are currently reaching out to thought leaders across the field to engage in the roundtable and consensus meeting stages of the project. If you or someone you know may be interested in learning more, please contact Erica Malik at erica.malik@thevalueinitiative.org.

* This project is partially funded through a Patient-Centered Outcomes Research Institute® (PCORI) Eugene Washington PCORI Engagement Award (EASCS-24272).