



INNOVATION AND
VALUE INITIATIVE



Putting Patients and Caregivers at the Center of Understanding Economic Impacts

Economic Impacts Framework: Executive Summary

May 2023

About IVI

The Innovation and Value Initiative (IVI) is a 501(c)(3) tax-exempt, non-profit research organization dedicated to advancing the science and improving the practice of health technology assessment through development of novel methods and creation and application of enhanced health technology assessment models to support local decision-making needs in healthcare.

About AcademyHealth

AcademyHealth, a 501(c)(3) non-profit organization, is a national professional organization serving the fields of health services and policy research and the professionals who produce and use this important work. Together with their members, they offer programs and services that support the development and use of rigorous, relevant, and timely evidence to increase the quality, accessibility, and value of healthcare, to promote equity, and to improve health.

Economic Impacts Framework: Executive Summary

When people encounter the healthcare system – either through a medical emergency, management of a chronic health condition, or through acute care, for a serious disease – they often experience significant economic impacts in addition to the physical and emotional impact of the disease(s). These economic impacts can range from medical costs not covered by insurance to other costs that result from medical debt, transportation, and accessing care – child or family respite care. These are rarely evaluated in research, even when using a patient-centered or societal perspective.

The **Innovation and Value Initiative (IVI)** and **AcademyHealth** partnered to develop consensus around a common Economic Impacts Framework (the Framework) that identifies the scope of economic impacts affecting patients¹ and caregivers (see Figure 1). The Framework offers structure and an initial map to guide researchers, research funders, and other decision-makers to consider what economic impacts are important to include in research design. It also offers a reference point to evaluate the adequacy of research and evidence generation and can guide further consensus development about how to incorporate such data in comparative effectiveness, outcomes research, and health technology assessment.

We developed the Framework through an iterative process informed by the guidance and insights from over 20 hours of multi-stakeholder engagement activities. We are deeply grateful

¹ Throughout this document, we use the term “patient” or “patient advocate” to refer to a person who has had a significant encounter with the healthcare system and has lived expertise in the healthcare system. We do not suggest that a person is their disease or that is a person’s only area of experience or expertise. We use this term in recognition of their lived experience and the importance of this experience to improving the healthcare system.

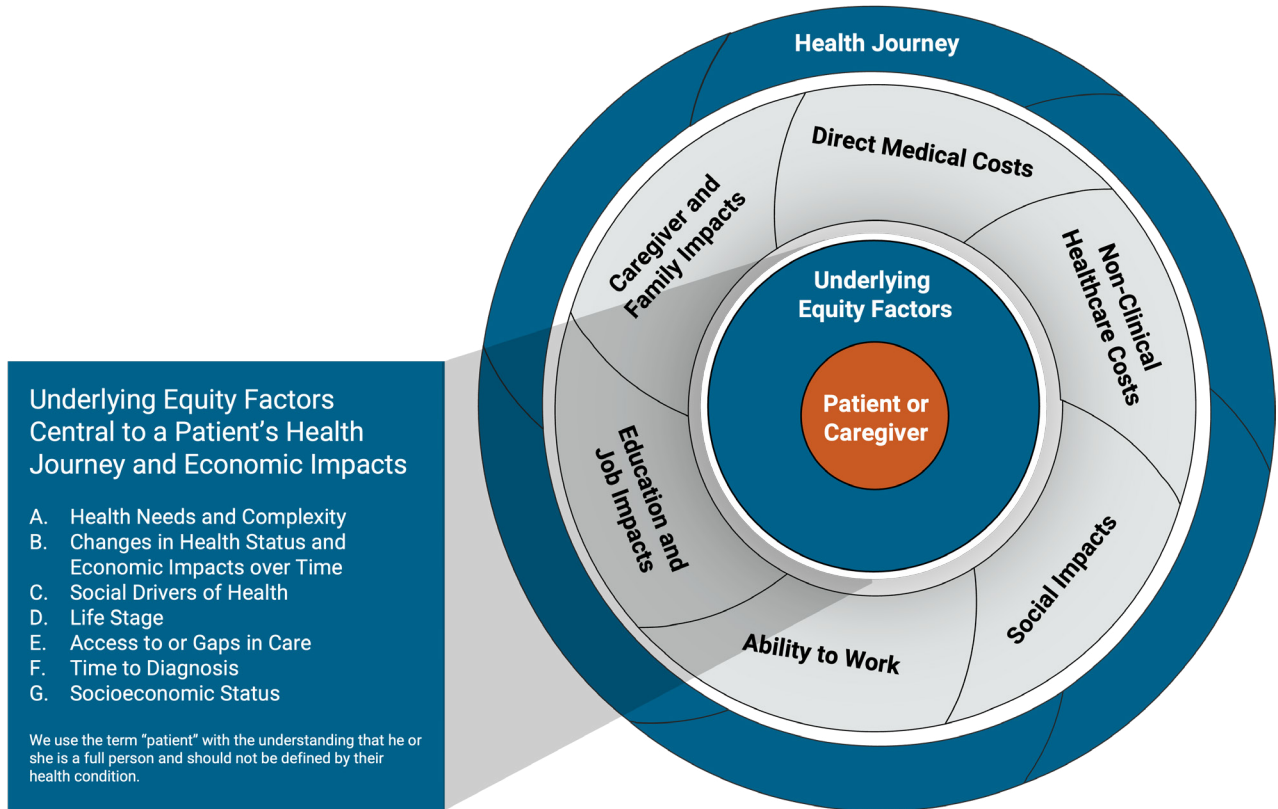
for the ongoing support and partnership from the participants in this initiative². Three overarching themes emerged:

1. Put patients, caregivers, and families at the center of understanding economic impacts.
2. Include a wider set of impacts that reflect lived experience, access to care, and affordability to improve understanding of issues around health equity and economic impacts.
3. While complex and challenging, adapt approaches and methods to build a better understanding of how the full range of economic impacts shape health behaviors, care delivery, and outcomes.

Participants identified six main areas of economic impacts: direct medical costs, non-clinical healthcare costs, caregiver and family impacts, social impacts, ability to work, and education and job impacts.

² This project is funded through a Patient-Centered Outcomes Research Institute® (PCORI) Eugene Washington PCORI Engagement Award (EASCS-24274) and members of the Innovation and Value Initiative.

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



The patient or caregiver is at the center of the Framework, and the patient's health journey is the foundation for understanding, prioritizing, and interpreting the economic impacts. The full report outlines the detailed inputs for each of the six areas, and provides guidance on how researchers, patients, payers, and others can use the framework.

This project is the first phase exploring needed change in defining, measuring, and applying a full range of patient-centered economic impacts in research and decision-making. Project participants recommend that researchers and decision-makers establish ongoing partnerships with patients and caregivers to provide context for the complexities of people's lived experience and inform research priorities. Future priorities

and collaboration opportunities that derive from this work include:

- Growing multi-stakeholder partnerships needed to expand data collection on a broader range of economic impacts,
- Driving culture change to orient researchers and decision-makers to patient-centered economic outcomes that are outside of traditional measures,
- Collaborating to identify measures and data points that reflect economic outcomes that reflect the full range of economic impacts, and
- Engaging underserved and underrepresented communities as leaders to identify priorities and solutions.

This Framework and the Principles (see below) that guide it are intended to encourage partnerships between the patient and caregiver community and researchers, and to broaden

how we understand and measure the economic impacts on patients and caregivers. Please see the full report to review the detailed inputs for the Framework and potential applications.

FRAMEWORK PRINCIPLES

- **Invite patients, caregivers, and family members to serve as advisors, partners, and/or co-authors.** Connect with people representing the health areas of focus and people representing diverse perspectives.
- **Start with the whole person.** Patients and caregivers often feel dehumanized by the healthcare system. Authentic engagement should guide research question development, increase the specificity of research goals, and build ongoing partnerships with the patient community – especially from underrepresented groups.
- **Acknowledge the complexity of the health journey.** Any research study or project will not be able to fully capture all relevant economic impacts, but it can incorporate those that patients identify as most important. Consider using mixed methods research approaches to help fill these gaps.
- **Incorporate health equity throughout.** As IVI wrote in its recent report, there is [“no value without equity.”](#) Design research goals or measurement strategies with a health equity lens. Incorporate an intentional health equity focus when planning the research, partnering with patients and caregivers, and identifying the research measures.
- **Clarify research goals.** Use patient and caregiver insights and the Framework to define research goals. Acknowledge the changing nature of the data and of the economic impacts over time.
- **Use the Framework and patient journeys to identify priorities.** In partnership with patients and caregivers, use the Framework to prioritize which economic impacts to include.

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