

INTRODUCTION

Patients and caregivers experience economic burdens as a result of illness and encounters with the healthcare system. Researchers and decisionmakers increasingly recognize the importance of considering the full range of economic impacts on patients and caregivers at different stages of the patient journey.






However, significant questions remain as to what, how, and when to include a more extensive range of economic impacts in patient-centered research to inform decision-making.

The purpose of this project is to develop a framework that offers guidance on how to incorporate full range of economic impacts on patients and caregivers into comparative effectiveness research and patient-centered value assessment.

METHODS

A 13-person multi-stakeholder steering committee was established to guide the development of the overall research initiative. We then conducted an environmental scan to identify existing approaches to define economic impacts in health-related research. Based on the findings from the environmental scan, an iterative stakeholder engagement approach was adopted to develop a draft framework (see Table 1). During each engagement activity, participants were asked questions about their experience in capturing economic impacts, recommendations to improve the framework, and potential applications of the framework.

Table 1. Engagement Activities: Participants and Purpose

	 Steering Committee	 Key Informant Interviews	 Roundtable	 Consensus Meeting	 Public Webinar
Date	5 Meetings	Fall 2022	February 2023	March 2023	March 2023
Purpose	Provide ongoing expertise, guidance, and insight	Help define the framework and expand the list of inputs	Validate the framework and begin to explore when economic data should be collected	Prioritize principles to guide the framework and identify steps needed to put the framework into practice	Demonstrate the need for a better approach to economic impact and highlight early lessons learned
Participants	13 Members	9 Interviews	14 Participants	15 Participants	115 Registrants
Stakeholder Perspectives*	4 Patient/Caregiver 4 Researcher 2 HTA Researcher 2 Policy 1 Payer 1 Payer 1 Employer	6 Patient/Caregiver 3 Researcher 2 Policy 1 Payer 1 Employer	6 Patient/Caregiver 4 Researcher 1 Payer/Researcher 1 Employer 2 Industry	8 Patient/Caregiver 5 Researcher 2 Industry	28 Patient/Caregiver 36 Industry 21 Researchers 30 Other (payer, employer, not reported)

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RESULTS

Based on documented stakeholder input, a visual aid to represent the framework was developed (see Figure 1 and Tables 2a and 2b). Engagement insights resulted in increased inputs (30 to 67) and domains (5 to 6), more person-centered language, and creation of principles to guide Framework application . Emphasis on the intersectionality of economic impacts and health equity resulted in additional visual representations in the framework. Framework categories are overlapping and bi-directional.

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

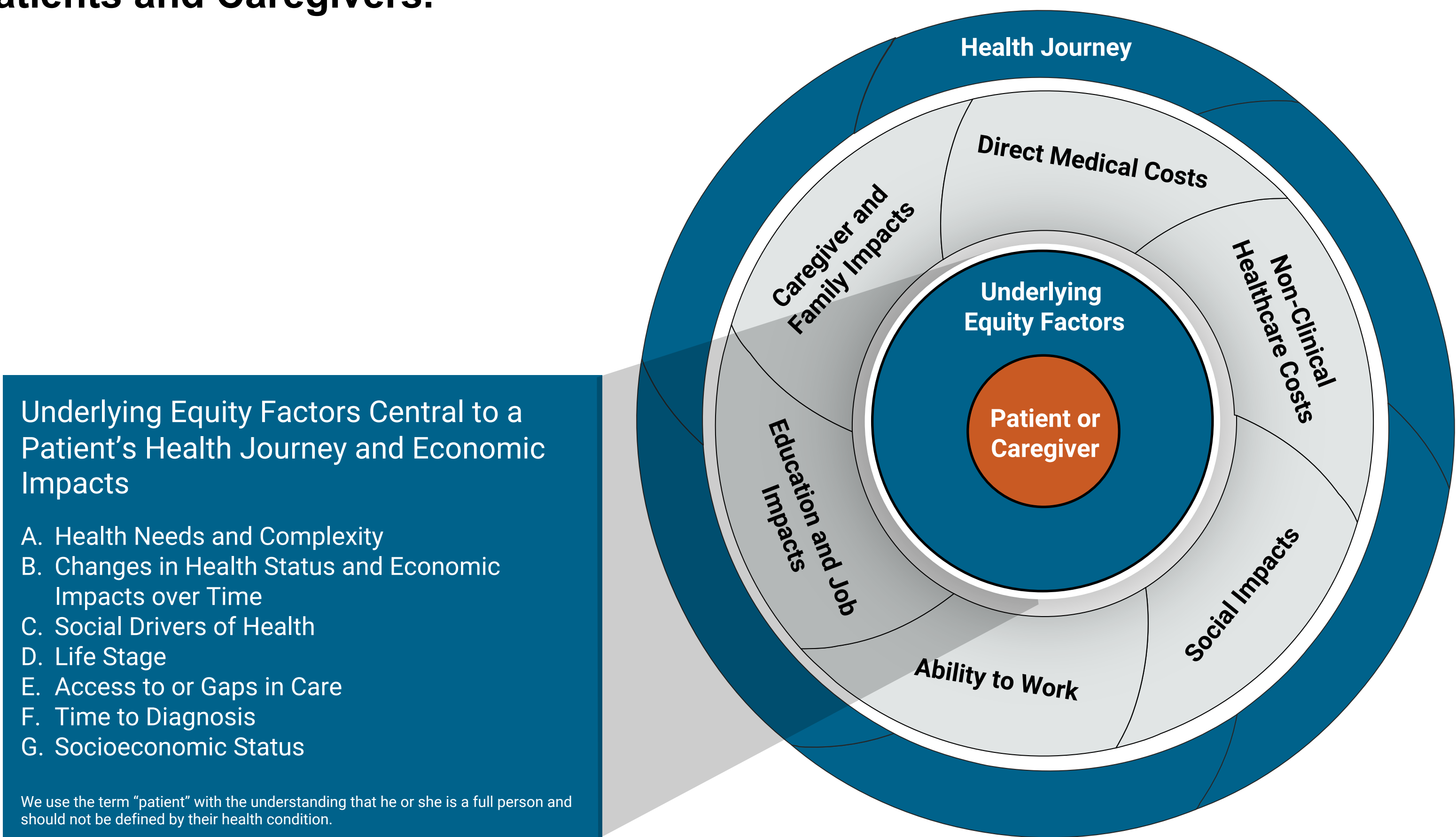


Table 2a. Detailed Inputs for each Domain

The Person's Health Journey		
Direct Medical Costs	Non-Clinical Healthcare Costs	Social Impacts
<ul style="list-style-type: none">Insurance Costs<ul style="list-style-type: none">– Co-insurance & co-payments (medications, doctor visits, emergency costs, hospital stays, ambulance, etc.)– Insurance premiums– DeductiblesDevice Costs (stints, needles, etc.)Durable Medical Equipment and Medical Supports (wheelchairs, walking aids, prosthetics, assistive clothing, etc.)Care Navigation AssistanceNon-covered Medical Costs (new healthcare innovations and tests, out-of-network costs, etc.)Downstream/Domino Healthcare Costs<ul style="list-style-type: none">• Misdiagnosis/diagnostic journey• Side effect costs• Co-occurring health conditions• Cost of delayed care	<ul style="list-style-type: none">Transportation (gas, parking, public transit, airfare, etc.)Housing/Vehicle ModificationsAssistive Technology/Devices/ClothingChildcare/Elder CareNon-traditional Healthcare (CBD, acupuncture, medical foods, meditation, fitness services, etc.)Clinical Trial Costs (cost of participating in trial)Quality of Network/Access to ProvidersAbility to maintain treatment regimen	<ul style="list-style-type: none">Access to Social Services (food, housing, transportation, prescription drug programs)Domino Financial Impacts<ul style="list-style-type: none">– Loss of savings, bankruptcy, dependent care costs, legal fees– Ability/Inability to obtain life insurance– Ability to pay for rent/mortgage/utilities– Ability to pay for food, clothingTime<ul style="list-style-type: none">– Care coordination time– Insurance navigation time– Travel timePsychosocial Impacts<ul style="list-style-type: none">– Psychosocial a result of health condition– Financial stressSocial Costs<ul style="list-style-type: none">– Lack of social capital– Social isolation– Relationship loss– Quality of life

PRINCIPLES TO GUIDE FRAMEWORK USE

- > Invite patients, caregivers, and family members to serve as advisers, partners, and/or co-authors
- > Start with the whole person
- > Acknowledge the complexity of the health journey
- > Incorporate health equity throughout
- > Clarify research goals
- > Use the Framework and patient health journeys to identify priorities

CONCLUSIONS

Engagement with diverse stakeholders in the US yielded a Framework that focuses on patient and caregiver economic impacts. Participants emphasized the overlapping and bi-directional nature of these impacts and recommended a new approach to capturing this information. Researchers and decision makers can use the framework to:

- > Partner with patients and caregivers from the outset of a research study to better incorporate the complexity of lived experience.
- > Raise attention to the underlying factors that should be addressed when capturing economic impacts, especially health equity issues.
- > Ensure that a more robust range of economic impacts are included in health technology assessment and research study designs.
- > Encourage data collection that captures this broader range of impacts.
- > Increase efforts to use mixed-methods research designs to understand these economic impacts.

Table 2b. Detailed Inputs for each Domain

The Person's Health Journey		
Ability to Work	Education and Job Impacts	Caregiver and Family Impacts
<ul style="list-style-type: none">Lost WagesSick DaysDisabilityProductivityPresenteeismAdequacy of Health Insurance CoverageUnemployment BenefitsSocial Security BenefitsJob Retaliation	<ul style="list-style-type: none">Educational Attainment (high school, two-year college, trade school, military, college, graduate school)Early RetirementJob ChoiceEmployment OptionsJob Re-TrainingRetirement SavingsLimitations on Employment ChoiceForced Retirement	<ul style="list-style-type: none">Insurance/Care Navigation TimeTravel/TransportationCost of Delaying or Forgoing CareAbility to WorkSick DaysLost WagesForced Early RetirementJob ChoiceJob RetaliationSibling Educational AttainmentPsychosocial ImpactsInjury or Illness as a Result of Providing Care