

A Research Framework to Understand the Full Range of Economic Impacts on Patients and Caregivers

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PROJECT DESCRIPTION

Patients and caregivers experience economic burdens as a result of illness and encounters with the healthcare system. Researchers and decision-makers 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.

APPROACH

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 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)

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

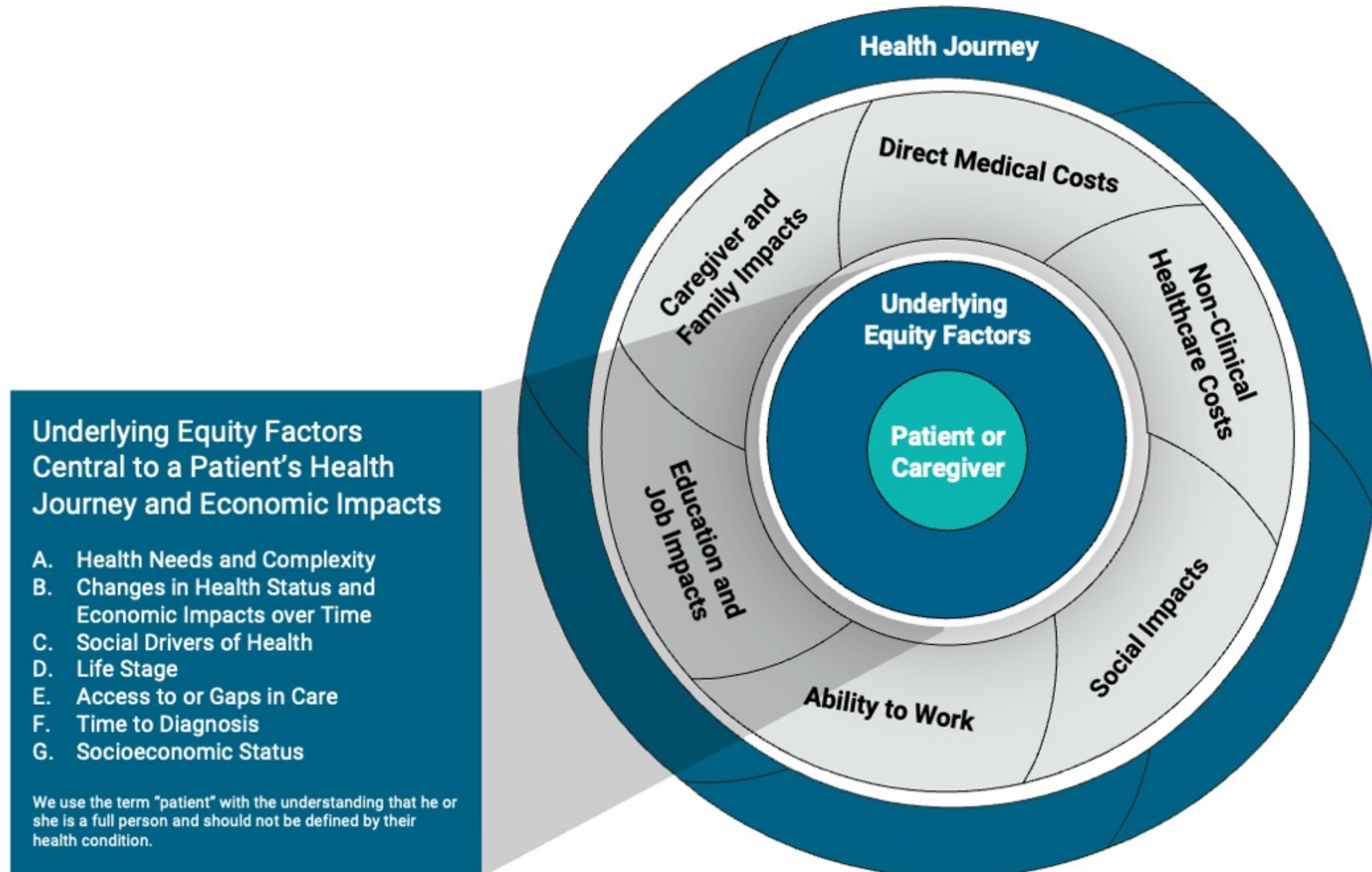


Table 2. Examples of Inputs for Each Domain

The Person's Health Journey		
Direct Medical Costs <ul style="list-style-type: none"> Insurance Costs Device Costs Non-Covered Medical Costs Downstream/Domino Healthcare Costs 	Non-Clinical Healthcare Costs <ul style="list-style-type: none"> Transportation Housing/Vehicle Modifications Assistive Technology/Devices/Clothing Childcare/Elder Care 	Social Impacts <ul style="list-style-type: none"> Access to Social Services Domino Financial Impacts Time Psychosocial Impacts Social Costs
Ability to Work <ul style="list-style-type: none"> Lost Wages Sick Days Disability Productivity Unemployment Benefits 	Education and Job Impacts <ul style="list-style-type: none"> Educational Attainment Early Retirement Job Choice Employment Options Retirement Savings 	Caregiver and Family Impacts <ul style="list-style-type: none"> Insurance/Care Navigation Time Travel/Transportation Ability to Work Lost Wages Forced Retirement

ENGAGEMENT IMPACT

Based on findings from the environmental scan and stakeholder input, engagement led to a revised framework with 68 specific impacts across 6 domains: direct medical costs, non-clinical healthcare costs, social impacts, ability to work, education and job impacts, and caregiver and family impacts (see Table 2 for sample inputs). The final convening and steering committee meeting yielded six principles to inform the use and application of the framework.

PRINCIPLES GUIDING FRAMEWORK USE

- Invite patients, caregivers, and family members to serve as advisors, 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

APPLICATIONS

This framework, and the principles that inform it, offers a guidepost to improve how research is incentivized to partner with people with lived experience, and prioritized to capture a more robust range of economic impacts for use in patient-centered outcomes research and health technology assessment.

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.

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