

## 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
5 meetings	Fall 2022	February 2023	February 2023	February 2023
Purpose: Provide Ongoing Expertise, Guidance, and Insight	Purpose: Help define the framework and expand the list of inputs	Purpose: Validate the framework and begin to explore when economic data should be collected	Purpose: Prioritize principles to guide the framework; and Identify steps needed to put framework into practice	Purpose: Demonstrate the need for a better approach to economic impact and highlight early lessons learned.
13 Members	9 interviews	14 Participants	15 Participants	115 Registrants
<b>Stakeholder Perspectives:*</b> 4 Patient/caregiver 4 Researcher 2 HTA researcher 2 Policy 1 Payer 1 Employer	<b>Stakeholder Perspectives:*</b> 6 Patient/caregiver 3 Researcher 2 Policy 1 Payer 1 Employer	<b>Stakeholder Perspectives:*</b> 6 patient/caregiver 4 researcher 1 payer/researcher 1 employer 2 Industry	<b>Stakeholder Perspectives:*</b> 8 Patient/caregiver 5 Researcher 2 Industry	<b>Stakeholder Perspectives:*</b> 28 Patient/Caregiver 36 Industry 21 Researchers 30 Other (payer, employer, not reported)

\* Some stakeholders brought multiple perspectives so there may be more perspectives than participants

### Contact

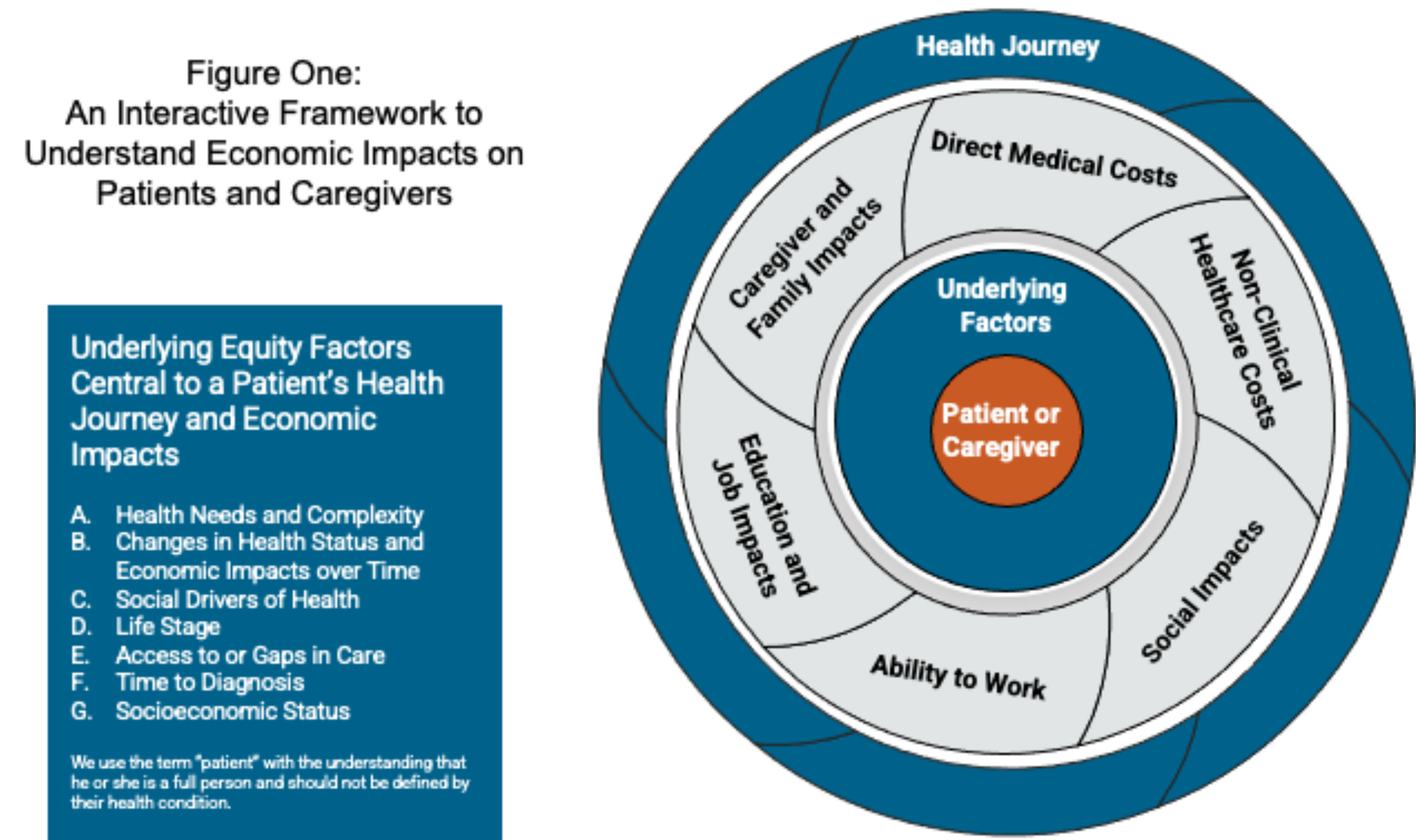
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## RESULTS

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 additional resources, such as patient journey map templates, vignettes, glossary, and an expanded resource list. 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.



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

“50% of patients who take hypertension medications are non-adherent. Instead of asking, what is wrong with what we’re asking patients to do, we keep asking, what is wrong with the patient. If McDonald’s releases a sandwich that only has a 50% uptake, versus what they expect, they’re not going to ask what is wrong with the customer. They are going to ask, “what is wrong with our sandwich?” I think this framework helps us move into that direction -- the decision to put a person in the middle of a framework speak volumes.” – Methods Summit Speaker



## CONCLUSIONS

Engagement with diverse stakeholders in the US yielded a framework that seeks to focus 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.

A final report will be available in June 2023.

**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"><li>Lost Wages</li><li>Sick Days</li><li>Disability</li><li>Productivity</li><li>Presenteeism</li><li>Adequacy of Health Insurance Coverage</li><li>Unemployment Benefits</li><li>Social Security Benefits</li><li>Job Retaliation</li></ul>	<ul style="list-style-type: none"><li>Educational Attainment (high school, two-year college, trade school, military, college, graduate school)</li><li>Early Retirement</li><li>Job Choice</li><li>Employment Options</li><li>Job Re-Training</li><li>Retirement Savings</li><li>Limitations on Employment Choice</li><li>Forced Retirement</li></ul>	<ul style="list-style-type: none"><li>Insurance/Care Navigation Time</li><li>Travel/Transportation</li><li>Cost of Delaying or Forgoing Care</li><li>Ability to Work</li><li>Sick Days</li><li>Lost Wages</li><li>Forced Early Retirement</li><li>Job Choice</li><li>Job Retaliation</li><li>Sibling Educational Attainment</li><li>Psychosocial Impacts</li><li>Injury or Illness as a Result of Providing Care</li></ul>