INTRODUCTION

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.

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.

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.

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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.