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Making room for patients in economic evaluation: a commentary on current capacity and future directions

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Abstract
Patient engagement, in which patients and their caregivers work together with research teams, can enhance the relevance, quality, and applicability of health research findings. While patient engagement has been successfully integrated into many areas of health research, its application within health economic evaluations remains limited. This commentary explores interest and strategies for patient engagement in economic evaluation, based on our work with 5 patient partners and 12 research centres affiliated with the Ontario Strategy for Patient-Oriented Research SUPPORT Unit (OSSU). We also piloted a co-production approach to develop practical tools and strategies for meaningful engagement. Both patient partners and OSSU centre representatives emphasized the need for clear guidance, targeted training, and sustained investment to enable scalable and equitable engagement in this complex area of research. Key barriers identified included a lack of plain-language resources, limited institutional capacity for facilitating patient partnerships, and the absence of centralized supports across OSSU research centres. Through a series of virtual meetings between patient partners, we co-created a visual flow diagram and a patient activity matrix to support engagement across key stages of economic evaluation. The engagement process was grounded in shared learning, respect for lived experience, and responsiveness to evolving priorities. Our work supports the growing literature on patient engagement in health economics and offers early evidence that co-developed tools can support inclusive, patient-informed economic evaluations. Our findings lay the groundwork for future efforts to create targeted and practical guidance on when and how to embed patient perspectives throughout the economic evaluation process, thereby contributing to more transparent, collaborative, and equitable health policy decision-making.

Keywords Patient engagement, Patient and public involvement, Economic evaluation, Health technology assessment

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Plain English summary

Health economic evaluations are studies that help to decide how to use limited healthcare resources fairly and effectively. They compare the costs and benefits of different treatments or health technologies to identify which options provide the greatest value. Although people with lived experience, such as patients and caregivers, have valuable knowledge about living with illness and navigating healthcare, they are rarely involved in creating these studies. To better understand why patients are infrequently included, we held discussions with researchers specializing in patient engagement in Ontario, Canada, and five patient partners from across the country.

Both groups identified uncertainty about when and how to involve patients as a key barrier to meaningful collaboration. In response, researchers and patient partners worked together to develop two tools to support collaboration in economic evaluation projects. These include a visual diagram that explains the main steps of an economic evaluation in plain language and a table that offers suggestions on when and how patients should be involved at each step. These tools aim to make economic evaluations easier for patients to understand and encourage researchers to include patients in their work. Future work will build on this foundation to develop clearer guidance for researchers on how to collaborate effectively in economic evaluations.

Background

Health economic evaluations compare the costs and outcomes of two or more health interventions to assess their efficiency and support the allocation of limited healthcare resources. These evaluations are typically conducted by multidisciplinary teams who bring diverse forms of expertise. Health economists and modellers design and analyze the economic models. Subject-matter experts, including clinicians, epidemiologists, and other researchers, contribute knowledge on the condition, treatment pathways, and clinical evidence needed to populate model inputs. Healthcare payers or decision makers interpret and apply the results to inform funding and policy decisions. Although individuals with lived experience often contribute to health technology assessment (HTA) committee deliberations, they are not usually involved in producing the economic evaluations reviewed by these bodies [1–4]. Their experiential knowledge regarding care pathways, burden of illness, and real-world trade-offs could enhance the scope and validity of an economic model. Despite this, their perspectives have historically been overlooked in the production of health economic evidence.

In Canada, the Canadian Institutes of Health Research (CIHR) defines patients as “individuals with personal experience of a health issue and informal caregivers, including family and friends” [5]. Patients, as defined by CIHR, bring firsthand knowledge of living with health conditions and of receiving health interventions; these perspectives can help inform decision-makers about the potential costs, benefits, and risks of adding or removing health interventions [6, 7]. More broadly, patient engagement in health research reflects evolving conceptions of health and evidence that recognize experiential knowledge as a critical complement to scientific and professional expertise. Without patient input, an economic question may not align with patient priorities or reflect real-world care pathways [7, 8]. While patient engagement has been increasingly integrated across various fields of health research, its integration into health economic evaluations remains underdeveloped. Some studies have incorporated patient perspectives into economic evaluations of healthcare interventions, such as in setting research priorities [9–12], developing an economic model [13, 14] or study materials [11], identifying health states and relevant health events [9, 14, 15], and measuring and valuing quality of life improvements [1, 16]; however, these efforts are often scarce in how patient engagement is documented, operationalized, or sustained across the full economic evaluation process. Much of the published literature fails to describe engagement methods and explain how patient input influenced model structure, assumptions, outcomes, or decision-relevant results.

Work to bridge this gap has been underway in recent years. For example, the 2022 update to the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) advocated for the involvement of patients, the public, and other interest-holders in the conduct of economic evaluations [17]. In parallel, the CHEERS working group collaborated with members of the public to co-develop a patient-facing guide to understanding and interpreting health economic evaluations in support of patient involvement in health economic evaluation reporting [2]. This work provides an accessible entry point for patients interested in engaging in discussions about health economic evaluation. Despite these advancements, best practices for integrating patient perspectives into economic evaluations remain limited. Importantly, researchers have identified uncertainty about how to collaborate with patients within technically complex modelling processes as a key barrier to engagement [10]. Meaningful collaboration, therefore, requires complementary support: accessible resources for patients alongside guidance and tools for health economists and other interest-holders to adapt or innovate their research processes. Addressing both sides of this partnership is essential to advancing patient-informed, co-produced economic evaluations.

In our prior work examining the costs and benefits of a novel leukemia immunotherapy, patient engagement directly informed several components of the economic evaluation. Specifically, patient partners helped identify patient-relevant costs such as out-of-pocket expenses and caregiver time, refine assumptions about treatment pathways, and contextualize outcomes based on real-world care experiences [11]. Collaboration with patient partners provided a more comprehensive picture of leukemia and its treatment. Building on this experience [11], we observed that while patient contributions were highly valuable, decisions about when, where, and how to involve patient partners were largely driven by researchers, ad hoc, and dependent on individual researchers' familiarity with engagement practices. These challenges highlighted the need for structured guidance to support research teams in embedding patient engagement more intentionally and consistently across the economic evaluation process, while remaining responsive to patient partners' preferences and expertise [18].

To examine how these broader challenges and opportunities play out in practice, we situate this commentary within the Ontario context. Ontario offers a useful illustrative case, given its established patient-oriented research infrastructure and explicit investments in integrating patient engagement. Focusing on this context allows us to explore early, practice-based insights into how patient engagement in health economic evaluation is currently supported, where gaps remain, and how structured guidance might be developed. This commentary shares lessons learned from these initial collaborations and describes the co-development of tools and resources intended to support and expand meaningful patient engagement in this complex but important area of health research.

Patient engagement resources for researchers in economic evaluation in Ontario, Canada

Our initial efforts focused on understanding the current capacity for patient engagement and assessing the feasibility of developing a structured framework to support patient engagement in economic evaluation. This work began with preliminary discussions among methodologists with expertise in patient engagement, health economists, and one patient partner with extensive experience in Ontario SPOR Support Unit (OSSU)-funded research to scope feasibility and methodological considerations. This was followed by an iterative collaboration with patient partners to co-develop priorities, tools, and reflections.

In Canada, the CIHR has played a central role in advancing patient engagement in research through its Strategy for Patient-Oriented Research (SPOR) [5]. This national initiative has supported the development of infrastructure across provinces and territories, including the creation of SPOR Support Units that offer expertise and services to facilitate patient engagement in health research. In Ontario, which accounts for 40% of the Canadian population, the OSSU follows a hub-and-spoke model, with a central coordinating centre connected to 14 affiliated health research centres and programs [19]. These centres provide guidance and capacity-building support for patient-oriented research throughout the province.

Recognizing OSSU's central role in supporting patient engagement initiatives in Ontario, we held a discussion with representatives from 12 of the 14 OSSU research centres to better understand system-level capacity to support patient engagement in economic evaluations. Participants included 8 patient engagement specialists, 3 health economists, and 1 patient representative with extensive experience in OSSU-supported research. Consistent with OSSU's mandate to support researchers in designing and implementing patient-oriented research, the discussions focused on institutional perspectives, including existing supports available to researchers for engaging patients in economic evaluations, gaps in resources and training, past experiences with patient engagement in health economic evaluations, and views on appropriate levels of patient engagement.

These consultations revealed a strong interest in advancing patient engagement in health economics, but institutional capacity varied widely. Key enabling factors include access to in-house health economists, dedicated funding, and training resources. However, only one centre reported having specific support for patient engagement in health economic evaluations, including educational tools tailored to both patients and researchers. Moreover, centre representatives noted that while all centres operate under a shared mandate through OSSU, its hub-and-spoke model means that resources are largely within individual centres rather than centralized at the OSSU coordinating centre. As a result, access to resources, such as tools, training, and personnel is not uniformly available. Centre representatives emphasized the need for strategic investment and structured training to build consistent, province-wide capacity for patient engagement in health economic evaluation.

A patient perspective on patient engagement in economic evaluations

Building on the interest of researchers and OSSU representatives, we sought to explore patient perspectives on health economics and to co-develop preliminary guidance for engaging patients in health economic evaluations. Our interdisciplinary team collaborated with five patient partners (DW, LR, MH, SB, TH) who were recruited through the Patient Advisors Network, existing research connections, and current patient engagement initiatives. These partners brought diverse lived experiences with health conditions (e.g., mental health, cancer, and other chronic illnesses) and varied interactions with healthcare systems. Patient partners described a wide range of motivations for engagement, including a desire to ensure that economic evidence better reflects real-world care pathways, financial considerations, and long-term quality-of-life impacts. Many highlighted experiences related to access to care, out-of-pocket costs, and treatment delays as particularly important for contextualizing the value of health technologies, components that are often overlooked by traditional economic models.

During collaborative discussions, patient partners reflected on the importance of lived experience in shaping economic evidence used for decision-making. As one patient partner noted, "*It's important that the patient voice and patient lived experience become a credibly accepted practice in HTA economic evaluations, especially for increasingly expensive innovative therapies targeting rare diseases.*" Another patient partner reflected that "*collaborating with a diverse group of patient partners was invigorating and enhanced the credibility of the results.*" These reflections shared during exploratory, co-production discussions, rather than generated through formal qualitative data collection, illustrate how patient engagement can strengthen the perceived relevance, credibility, and legitimacy of economic evaluations for decision-making.

While acknowledging the technical complexity of economic evaluations, patient partners rejected the notion that this should be a barrier to their involvement. Instead, they emphasized that lived experience represents a distinct and essential form of expertise, complemented by transferable skills acquired through education, work, and caregiving. Patient partners stressed that meaningful engagement does not require oversimplifying economic methods but rather intentional design of supportive research systems that enable collaboration. This includes creating accessible entry points through plain-language communication, visual tools, and structured opportunities for collaboration throughout the research process. This perspective was echoed by researchers and patient partners in other collaborative efforts [1, 20, 21].

To support this vision, patient partners identified a need for educational resources tailored to both researchers and patients. Using the HTA process as a shared reference point, we worked with patient partners to map where economic evaluation fits within the broader decision-making process and to describe each stage in accessible terms. Through iterative discussions, we co-developed a visual flow diagram (Fig. 1) that breaks the economic evaluation process into four core stages: (1) defining the decision problem, (2) planning the study design, (3) identifying and valuing costs and outcomes, and (4) conducting data analysis and interpretation. For each stage, patient partners helped identify guiding questions intended to prompt reflection and dialogue about where patient input could be most valuable. In parallel, we developed a detailed table outlining patient engagement considerations and illustrative examples of involvement at each step of the economic evaluation (Table 1). These considerations were distilled from multiple discussions with patient partners and informed by system-level insights from OSSU representatives on common barriers and capacity gaps. These co-created tools provide a practical foundation for more inclusive and accessible engagement in economic evaluation and serve as a starting template for future initiatives.

Conclusions

Through our collaboration with OSSU and a team of patient partners, we explored interest, capacity, and practical strategies for advancing patient engagement in health economic evaluations. Our findings revealed that both researchers and patient partners recognized the value of involving patients in this complex field, particularly when evaluating high-cost, innovative therapies with significant access and affordability implications.

At the same time, our broader engagement with local interest-holders in Ontario revealed structural challenges that limit patient engagement in economic evaluations. While OSSU's hub-and-spoke model enables local innovation, it also leads to uneven access to tools, expertise, and training across centres compared with more centralized models in other Canadian provinces. These challenges are not unique to Ontario. Rather, they reflect broader system-level issues, such as variability in institutional capacity, fragmented supports, and unclear expectations for engagement, that are likely to arise across diverse health systems. Both patient partners and OSSU representatives highlighted the need for greater investment, clearer guidance, and more consistent infrastructure to enable meaningful and sustained engagement.

Realizing the full potential of economic evaluation, therefore, requires structured guidance that specifies who should be engaged, when engagement should occur throughout the evaluation process, and how to do

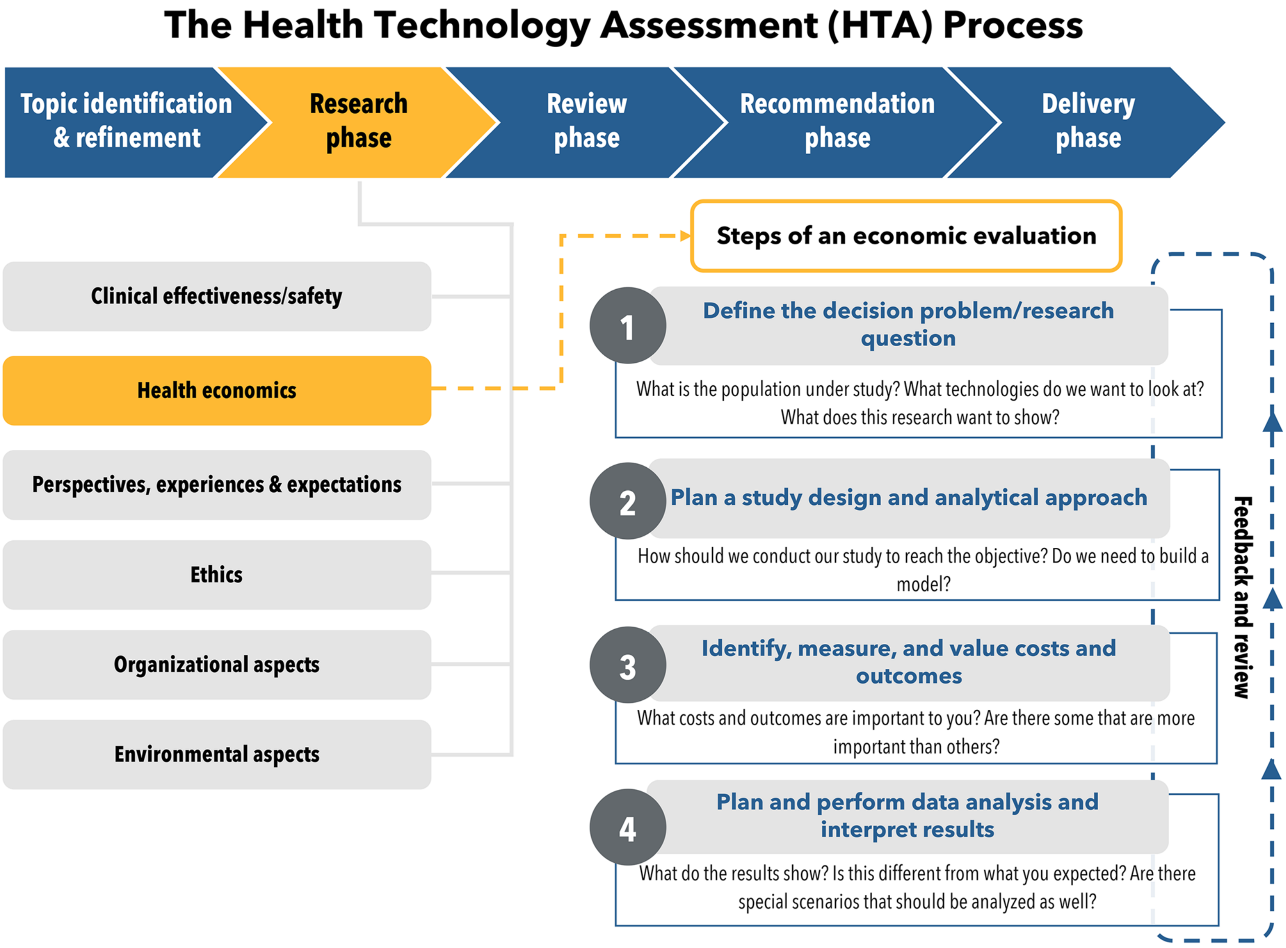

Fig. 1 Flow diagram of economic evaluation within the health technology assessment process

so effectively and ethically. Our co-created resources, including a visual flow diagram and an engagement activity matrix, address a gap not fully covered by existing patient engagement frameworks. Unlike broader frameworks that provide high-level principles applicable across research domains, these tools focus specifically on the stages of economic evaluation and offer concrete, stage-specific prompts to support collaboration within a technically complex workflow. In doing so, they provide a pragmatic bridge between established engagement principles and the day-to-day practice of economic evaluation.

However, these tools do not address the full range of considerations required for widespread and sustained adoption, such as approaches to patient partner recruitment and compensation, levels of engagement, and adaptation across diverse contexts and health technologies. Broader consensus-based frameworks are therefore needed to integrate these elements and ensure consistency, legitimacy, and scalability. Efforts to develop such guidance are already underway, which signals important progress toward standardizing patient engagement in economic evaluation [22]. Ultimately, our experience reinforces that patient engagement in economic evaluation is feasible and necessary. It also highlights the importance of designing economic evaluations that enable meaningful, context-rich patient input and produce evidence that genuinely reflects the lived experiences of those most affected by policy and funding decisions.

Table 1 Considerations for engaging patients across the health economic evaluation process

Phase	Patient engagement considerations	Activity examples
Defining a decision problem/research question	Engage patients from the start: Involve patient partners early in the project to shape goals, methods, and priorities. Offer early training and support "from day one": Provide orientation and resources at the outset to build shared understanding and confidence Include diverse perspectives: Where possible, engage multiple patient partners with varied lived experiences to capture a broader range of insights.	Develop and refine the research question (s) (choosing the patient population; treatment/health technology or intervention to evaluate; other treatment options, technologies or interventions to compare it to; and the different outcomes that should be considered).
Planning a study design and analytical approach	Provide patients with background material or past studies to support their understanding of the technology and language. Include lay language and mapping or diagrams to improve understanding, including of the model.	Assist in developing the research protocol. Decide on the type of model to use and what to include, such as describing the course of disease and disease states.
Identifying, measuring, and valuing costs and outcomes	Provide materials or literature on the types of costs and outcomes under study (e.g. quality adjusted life years, life years, direct vs indirect costs). Where possible, engage multiple patient partners with varied lived experiences to capture a broader range of insights.	Identify costs or outcomes important to patients, including overlooked sources of financial, physical, psychological, or emotional tolls. Establish a working group with other patients to better understand costs and outcomes of interest. Review literature for existing costs and outcomes, and identify and address gaps.
Planning and performing data analysis and interpreting results	Do not assume patient abilities; many have transferable skills that may be suited to data analysis, although possessing these skills should not preclude those who wish to be trained. Provide visual demonstrations to better illustrate the impact that variations in data can have on the analysis. Ask patients to interpret results in their own words to see where understanding or interpretation may vary.	Interpret results in lay language, distilling results into infographics where appropriate. Identify important scenarios or parameters for sensitivity analyses Verify and provide feedback on research assumptions.

Abbreviations

CHEERS	Consolidated Health Economic Evaluation Reporting Standards
CIHR	Canadian Institutes of Health Research
HTA	Health Technology Assessment
OSSU	Ontario SPOR Support Unit
SPOR	Strategy for Patient-Oriented Research

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Authors' contributions
ET contributed to investigation, original draft preparation, review and editing, and visualization. MW contributed to investigation, review and editing, and visualization. SN, DF, and ML contributed to conceptualization, funding acquisition, and review and editing. MS contributed to investigation and review and editing. TH contributed to conceptualization, funding acquisition, investigation, review and editing, and visualization. SB, MH, LR, and DW contributed to investigation, review and editing, and visualization. JP contributed to conceptualization, funding acquisition, investigation, and supervision. KT contributed to conceptualization, funding acquisition, visualization, supervision, original draft preparation, and review and editing. All authors read and approved the final manuscript.

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Data availability
Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
Ethics approval was obtained from the Ottawa Health Science Network Research Ethics Board (OHSN-REB 20200320-01HT). All procedures performed in studies involving human participants were in accordance with the Helsinki declaration as revised in 2013 and its later amendments.

Consent for publication
All authors have reviewed the manuscript and consent to publication.

Competing interests
The authors declare no competing interests.

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