

## Letter

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# Patient Perspectives: An Integral Part of Health Technology Assessment Methodology

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Dear Editor:

The article *Patient-centered health technology assessment: a perspective on engagement in health technology assessment by three patient organizations and a health technology assessment body* (20 October 2022) brings forth important considerations of vital patient engagement during health technology assessment (HTA), and specifically, with the value assessment review by the Institute for Clinical and Economic Review (ICER) of two lupus therapies.

The Innovation and Value Initiative (IVI) commends some of the practical learnings and applauds the patient representatives' and ICER's commitment to engagement throughout this review.

However, this commitment needs to go beyond eliciting patient-important factors merely as inputs for "contextual considerations." As one example, the authors noted the importance of factors such as "patients' and caregivers' career goals," but our field does not currently have good approaches for measuring and incorporating these impacts into economic models. Existing HTA approaches fall short by not actively updating our methodology or data collection to truly incorporate lived experience into economic models.

Looking to different experiences with ICER reviews can provide additional insight. Sick Cells, an organization dedicated to elevating the voices of those with sickle cell disease, recently detailed their experience on a review in the white paper, *Finding Equity in Value*.<sup>(1)</sup> As with the lupus review, ICER identified patient-important concerns, but merely considered these as contextual considerations rather than part of their base-case analysis. Sick Cells writes that "ICER, as the ultimate decision authority, chose to proceed with the evaluation despite known limitations in evidence and clear input from BIPOC stakeholders concerned about the equity implications of the decisions."

This article also states that: "Although ICER's methodology and consideration of cost would be standard in most countries with public HTA institutions, it is less known and accepted in the United States." While ICER's methodology indeed reflects the status quo for HTA, there is growing recognition that existing process and methods do not adequately capture patient perspectives. In our experience, decision makers, especially employers, health systems, and payors, understand the importance of patient experience as a driver of value. Nevertheless, we still lack consistent processes and methods to measure and incorporate this essential ingredient into HTA. Fundamental change is needed now – HTA organizations must invest in the hard work to ensure decision makers have a complete view of that value. Thus, more effort is needed to partner with patient communities to build patient perspectives and lived experience into core HTA methods.

It is essential to develop and test better processes and methods to achieve this, and it is being done. As one example, IVI is testing and improving systematic approaches to elicit qualitative and quantitative patient input that can then be incorporated into methods to inform HTA.<sup>(2;3)</sup> We have actively changed our approach and scope of our value assessment models based on the extensive patient feedback we received.

We challenge the HTA community to continue advancing research to make patient perspectives an integral part of HTA methodology so that we no longer relegate this valuable input to "contextual considerations."

**Conflicts of Interest.** The authors declare none.

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