

Roadblocks to effective patient engagement in health technology assessment in Europe: A review of patient-perceived challenges

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Background

Encouraging patient engagement (PE) in the health technology assessment (HTA) process strengthens the equity, relevance, accountability, and credibility of the decision-making process.¹ Input from patients and patient representatives improves the understanding of unmet needs and the impact of the disease and therapy in question. In the presence of complex treatment outcomes and a lack of concrete clinical and economic evidence, integrating patient perspectives and experiences can help establish more informed recommendations.²

Objective

- To identify the barriers and challenges perceived by patients and patient organizations for their effective involvement in the HTA process in Europe
- To review the guidelines published by HTA organizations from the European Union (EU4) and the UK that address the challenges perceived by patients and patient organizations for effective participation in HTA activities in Europe

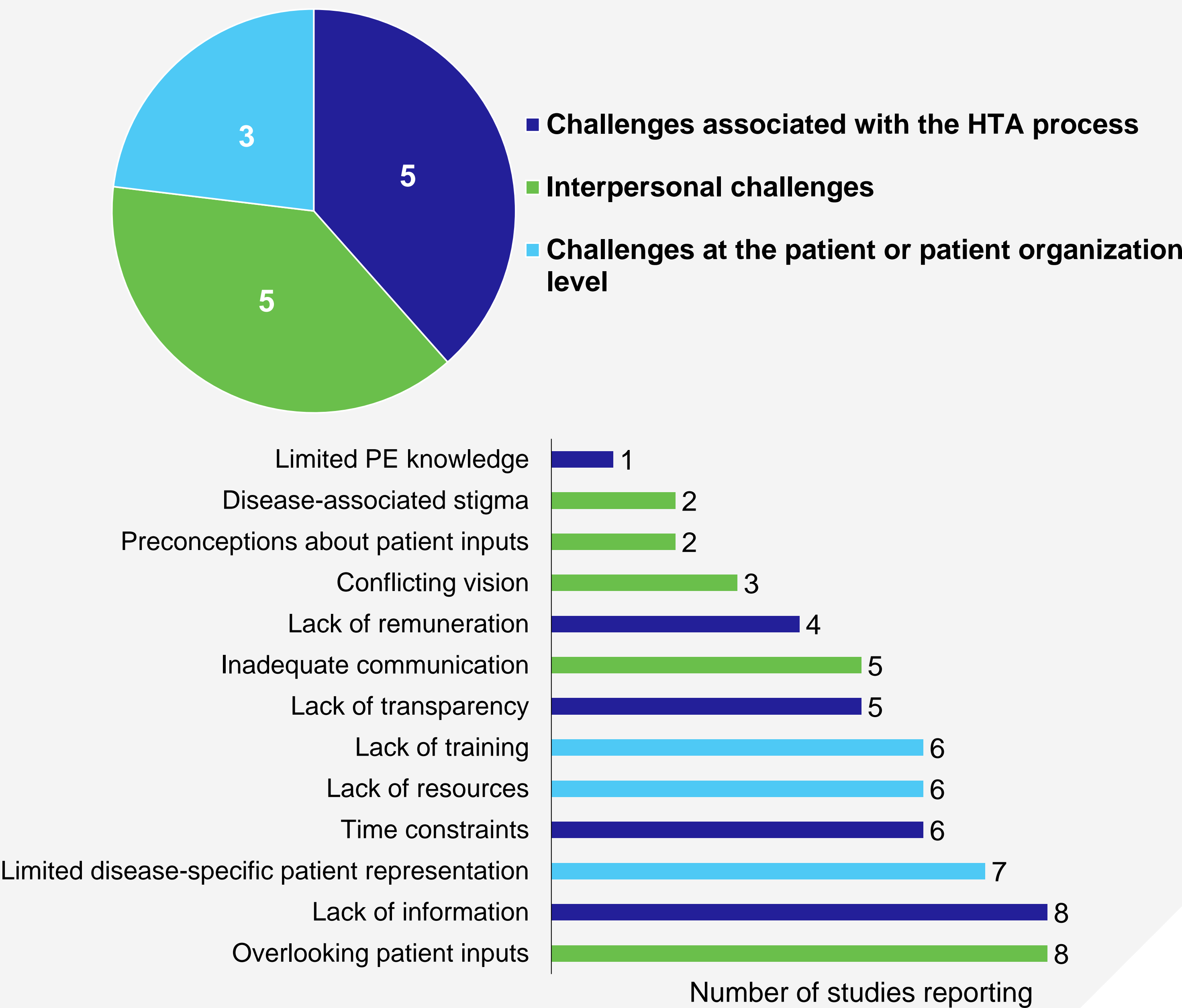
Methods

- We performed a targeted literature review in the PubMed database to identify observational studies published between January 2012 and April 2022. Narrative and systematic reviews, non-English studies, and studies with participants from non-European countries were excluded
- We also reviewed the guidance published by prominent HTA bodies in the EU4 and the UK, including the National Institute for Health and Care Excellence (NICE), the Haute Autorité de Santé (HAS), the Institute for Quality and Efficiency in Health Care (IQWiG), the Agenzia Italiana del Farmaco (AIFA), and the Agencia Española de Medicamentos y Productos Sanitarios (AEMPS) that address the identified challenges for active PE in the HTA process

Results

- The literature review identified 12 cross-sectional studies describing a total of 13 challenges reported by patients, caregivers, and patient organizations that affected their participation in HTA activities³⁻¹⁴
- These challenges can be classified as issues associated with the HTA process (n=5), interpersonal issues between the HTA agencies and the patients and/or patient organizations (n=5), and issues occurring at the patient or patient representative level (n=3) (Figure 1)
- HTA agencies overlooking the value of patient inputs and a lack of adequate information for the patient and/or patient organization regarding their participation in HTA activities were the most frequently reported challenges

Figure 1. Overview of the challenges reported by patients and/or patient organizations for participation in HTA activities in Europe³⁻¹⁴



HTA, health technology assessment; PE, patient engagement

Abbreviations

AEMPS, Agencia Española de Medicamentos y Productos Sanitarios; AIFA, Agenzia Italiana del Farmaco; EU, European Union; EUnetHTA, the European network for HTA; EUPATI, European Patients' Academy on Therapeutic Innovation; HAS, Haute Autorité de Santé; HTA, health technology assessment; IQWiG, Institute for Quality and Efficiency in Health Care; NICE, National Institute for Health and Care Excellence; PE, patient engagement; UK, United Kingdom












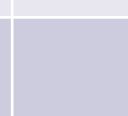


Disclosures: None

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Do the existing guidelines address these challenges?

- NICE guidelines for the HTA process specify involving patients and their representatives at various levels and ensuring the inclusion of patient experience and the day-to-day impact of the technology being assessed. Trained professionals identify and provide the necessary support for adequate patient participation throughout the HTA process¹⁵
- IQWiG incorporates patient experiences in the HTA process through oral and written consultations and encourages patients' comments on HTA reports¹⁶
- PE in HTA is still in the early stages in France and is limited to proposing topics for assessment to HAS¹⁷

Table 1. Guidelines addressing the challenges for PE in the HTA process in Europe¹⁵⁻¹⁹

Guidelines	NICE 	IQWiG 	AEMPS 	AIFA 	HAS 
PE in the HTA assessment process			-	-	-
PE in report review process			-	-	-
Encourage patient comments			-	-	
Recommend patient education		-	-	-	-
HTA actions outlined for increasing PE		-	-	-	-

AEMPS, Agencia Española de Medicamentos y Productos Sanitarios; AIFA, Agenzia Italiana del Farmaco; HAS, Haute Autorité de Santé; HTA, health technology assessment; IQWiG, Institute for Quality and Efficiency in Health Care; NICE, National Institute for Health and Care Excellence; PE, patient engagement

Conclusion

Despite the European network for HTA (EUnetHTA) recognizing patients as an important source of evidence, there is significant variability in PE among HTA bodies in Europe.²⁰ Although patient-led organizations like the European Patients' Academy on Therapeutic Innovation (EUPATI) provide education and training to patient advocates and healthcare policymakers to accelerate effective PE in Europe,¹ it is the responsibility of HTA bodies to provide adequate opportunities and resources to optimize patient participation and work together with patients to address these barriers.

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