

# Including Patient Experience Data in the HTA decision-making framework: a proposal based on HTA-stakeholder interviews

Isa Hemmer<sup>1</sup>, MSc, Marieke Krol<sup>2</sup>, PhD

<sup>1</sup>Erasmus University Rotterdam; <sup>2</sup>IQVIA, Netherlands

## Background and objectives

- Most Health Technology Assessment (HTA) decision-making frameworks include three pillars: Relative clinical effectiveness, Cost-effectiveness, and Budget impact.
- Although HTA decision-making bodies seem to acknowledge the importance of Patient Experience Data (PED) and patient representatives are regularly included in the HTA appraisal phase, PED seems to play a limited role in the traditional three pillars of the HTA decision-making frameworks. In the literature, HTA-frameworks are regularly criticized for not sufficiently incorporating patient experience (Drummond et al., 2020, Inotai et al., 2021, Sarri et al., 2021).
- This study aimed to explore how PED can be systematically and comprehensively incorporated into the assessment phase of HTA decision-making frameworks.

## Methods

- Semi-structured interviews lasting 60 minutes each were conducted with 10 HTA stakeholders (table 1). A purposive and snowball sampling approach was applied to select interview candidates. Interviews took place in May and June 2024.
- The interview guide included open questions asking the participants about how they defined PED, their views on the current inclusion of PED in HTA-frameworks, whether and which PED they thought should be included, and where PED could be best included.
- Interviews were transcribed ad verbatim. Transcripts were coded and analyzed in line with grounded theory. Saturation analysis was conducted to be confident that no important themes, or concepts were missed. A conceptual model was constructed including first order concepts, second order themes and aggregated dimensions (Figure 1).

## Results

- The 10 interviewed stakeholders came from six countries (table 1): three professors in HTA/PED, one HTA journal editor, three HTA/PED advisors, two patient representatives, one employee pharmaceutical company (two participants were ex-HTA-body employees, two were ex-pharmaceutical company employees). Concept saturation was achieved.
- The conceptual model that was developed based on the coded and themed data includes four dimensions (Figure 1): i) how PED is defined, ii) PED recognition in the current HTA assessment phase, iii) recommendations for PED incorporation in the HTA assessment phase, and iv) challenges for incorporating PED in the HTA assessment phase. Participants described PED as broad experiences related to disease/health, of qualitative and quantitative nature, described by patient, or others. All participants felt PED was currently not systematically and comprehensively included in HTA.
- Based on the HTA stakeholders' views two potential HTA decision-making frameworks are proposed (Figure 2 & 3) to better incorporate PED: 1) adding 'Patient benefits' as an additional pillar, 2) Changing the pillar 'Relative clinical effectiveness' into 'Relative effectiveness' with two buckets: 'Clinical effectiveness' and 'Patient effectiveness', which some proposed could be a part of Joint Clinical Assessment (JCA).

## Conclusions

All interviewed HTA-stakeholders stated that PED deserves a more prominent role in the HTA decision-making framework. Stakeholders suggest to include PED specifically and separately as 'Patient benefits', or 'Patient effectiveness', potentially as part of JCA. Two frameworks for including PED in the HTA decision-making framework are proposed

The proposed frameworks are a first step towards the systematic inclusion of patient experience in the HTA assessment phase. Further research should focus validating these finding in a broader sample and on the practicalities and implications of implementing a new framework. To advance the frameworks further, a task-force could be installed consisting of stakeholders from different bodies, such as EUnetHTA, EUPATI, the EMA, HTA bodies and pharmaceutical companies

Table 1. Background of interviewed respondents

	Gender	Experience with HTA/PED	Country
1	Male	Employee of pharmaceutical company with experience in HTA and PED	Germany
2	Female	HTA-advisor, experience with HTA and PED research	United Kingdom
3	Female	HTA-advisor and teacher, former employee of pharmaceutical company and experienced with HTA and PED research	The Netherlands
4	Female	HTA-advisor and former payer/HTA representative	The Netherlands
5	Male	Journal editor in the field of HTA	New Zealand
6	Female	HTA-researcher, professor	United States
7	Male	Former employee of pharmaceutical company with experience in HTA and PED	The Netherlands
8	Female	Employee of patient advocacy group and former payer/HTA representative	The Netherlands
9	Male	HTA-researcher, professor, clinician	France
10	Female	HTA-researcher, professor	The Netherlands

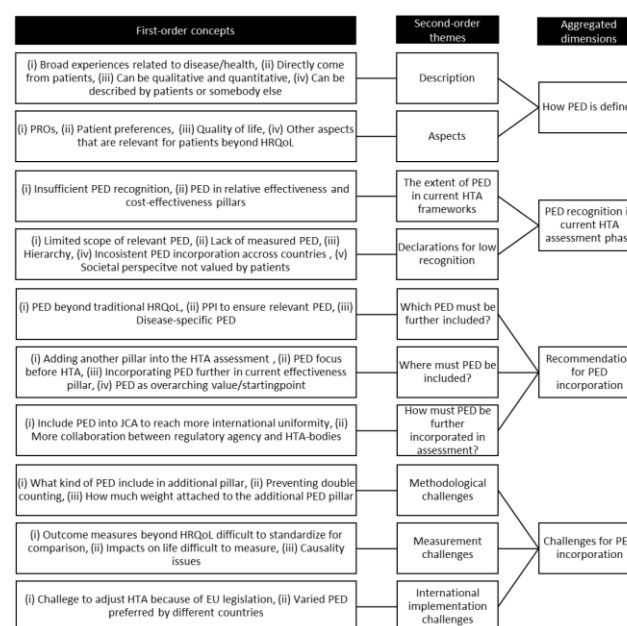


Figure 1: Conceptual model including first-order concepts, second-order themes and aggregated dimension based on the results

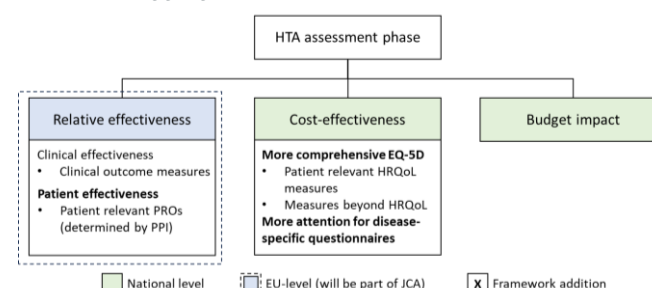


Figure 2: Proposed Framework 1 with patient effectiveness in the relative effectiveness pillar

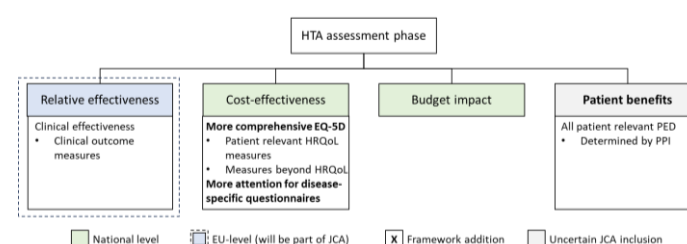


Figure 3: Proposed Framework 2 with an additional patient benefits pillar

- Drummond, M.F., Torbica, A., & Tarricone, R. (2020). Should health technology assessment be more patient-centric? If so, how?. The European Journal of Health Economics, 21, 1117-1120.
- Inotai, A., Jakab, I., Brixner, D., Campbell, J. D., Hawkins, N., Kristensen, L. E., & Kaló, Z. (2021). Proposal for capturing patient experience through extended value frameworks of health technologies. Journal of managed care & specialty pharmacy, 27(7), 936-947
- Sarri, G., Freitag, A., Szegvari, B., Moutian, I., Brixner, D., Bertelsen, N., Kaló, Z., & Upadhyaya, S. (2021). The Role of Patient Experience in the Value Assessment of Complex Technologies – Do HTA Bodies Need to Reconsider How Value is Assessed? Health Policy, 125(5), 593-601.

HTA = health technology assessment, JCA = joint clinical assessment, PED = patient experience data, PPI = patient preference information