

# Integrating patient-reported outcome measures and patient experience into health technology assessment: A path towards patient-centred decision-making

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## Objectives

This research was undertaken to explore the application of patient-reported outcomes (PROs) and patient and public involvement (PPI) in national health technology assessment (HTA) in the USA, England, China, and Brazil.

## Introduction

In recent years, the integration of PROs and PPI into HTA has gained momentum as healthcare systems strive to become more patient centred.

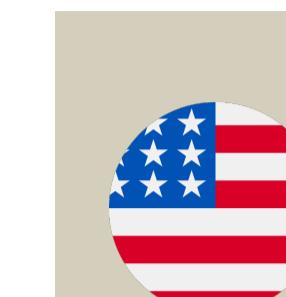
PROs offer direct insights into how patients experience their health and treatment, while PPI ensures that the values, preferences, and lived experiences of patients and the public are reflected in healthcare decision-making. Despite growing recognition of their importance, the extent to which and way in which PROs and PPI are embedded in HTA processes varies significantly across countries.

This research explores how four national HTA or stakeholder bodies incorporate PROs and PPI into their assessment frameworks. By examining these diverse systems, the study aims to identify global trends, highlight best practices, and uncover gaps in the adoption of patient-centred approaches. Understanding these differences is critical to advancing HTA methodologies that are not only scientifically rigorous but also meaningfully aligned with patient needs and societal values.

## Methodology

A targeted review was conducted across multiple HTA agency web portals to extract information on the role of PROs and PPI in the submission process. Additional information was gathered through desktop research of grey literature. Extracted data were synthesised to identify common practices and variations across agencies.

To support a quantitative analysis, each HTA body was assessed on a three-point scale at each stage of the HTA submission process. These individual scores were combined and used to classify HTA agencies into three categories based on their adoption of PROs and PPI into HTA frameworks: leaders (scores of 5–6), followers (scores of 3–4), and laggards (scores of 0–2).



**ICER:** Institute for Clinical and Economic Review



**NICE:** National Institute for Health and Care Excellence



**CDE:** Center for Drug Evaluation



**CONITEC:** National Committee for Technology Incorporation

## Results

	USA (ICER) <sup>1-5</sup>	England (NICE) <sup>6-9</sup>	China (CDE) <sup>10-13</sup>	Brazil (CONITEC) <sup>14-18</sup>
Pre-HTA submission	ICER's Value Assessment Framework encourages the inclusion of PROs; patients and advocacy groups contribute early via scoping consultations. ICER also set up a Patient Council (2023) and Patient Participation Guide to support engagement	NICE's HTA Manual mandates EQ-5D as the preferred health-related quality of life instrument; alternative PROs can be justified. Patient groups can submit evidence and nominate patient experts before committee deliberations	CDE has piloted "patient-centred" approaches in clinical trial design, especially in rare disease programmes	PROs can be included in manufacturer dossiers but are not required. A lay summary of each submission is prepared upfront
During HTA	PROs are considered in comparative effectiveness and cost-effectiveness models (e.g. PRO data inform "benefits beyond health"). Patients provide oral testimonies at public meetings, and anyone can submit written comments on draft evidence reports	Committees explicitly weigh PROs when judging quality of life and cost effectiveness. Patient experts sit on appraisal committees and contribute lived-experience insights during deliberations	PROs appear in some submissions for national reimbursement drug listing (NRDL) but remain secondary to clinical endpoints. There is minimal structured PPI. Engagement occurs mainly through public consultation on draft technical guidance	PROs are sometimes integrated into clinical effectiveness and cost-utility analyses, though not consistently. Formal public consultations (PCs) are held on every draft recommendation, and public hearings are convened for high-impact cases
Post-submission: Feedback and transparency	ICER publishes revised evidence reports that incorporate PRO evidence and public comments. Patient perspectives and comment summaries are transparently reported, with the Patient Council issuing periodic updates	NICE uses Managed Access Agreements and real-world evidence programmes, often collecting PROs to resolve uncertainty. Patients and carers may remain engaged in these schemes and future re-evaluations	PROs could feature in real-world data collection to support NRDL re-negotiations, but this is still rare. PPI after listing is limited to feedback during regulatory or guideline consultations	PCs and lay reports continue to facilitate engagement. PROs may be considered when evidence is revisited, though this remains inconsistent

Scoring

5



Leader

6



Leader

1



Laggard

3



Follower

## Conclusion

Across the HTA agencies in scope, there is a shift towards more patient-centred HTA practices, though pace and structure vary. NICE leads with a mature, formalised integration of PROs and PPI, where validated PROs are central to cost-effective analysis and patient voices are embedded throughout NICE's appraisal process. ICER shows growing interest in PROs, especially within value-based frameworks, but lacks consistent PPI mechanisms, relying more on voluntary engagement. CONITEC has made notable strides in public involvement through their stakeholder registry and PCs, and is expanding the use of qualitative PRO data to inform HTA decisions. Meanwhile, the CDE is in an earlier phase with limited application of PROs and PPI. Overall, the trend points to greater inclusion of patient perspectives, with digital health, international collaboration, and policy reform acting as key enablers in emerging markets.

Scan for references



### Abbreviations

CDE, Center for Drug Evaluation

NRDL, National Reimbursement Drug Listing

CONITEC, National Committee for Technology Incorporation

PC, public consultation

HTA, health technology assessment

PPI, patient and public involvement

ICER, Institute for Clinical and Economic Review

PRO, patient-reported outcome