

From Participation to Partnership: Advancing Patient-Centric, Inclusive and Equitable Evidence Generation in HEOR



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Introduction

- > Patients are increasingly interested in and calling for a more proactive role as partners with health technology developers. Understanding the burden and impact of disease as well as diagnosis and treatment pathways for patients is of paramount importance for developing health technologies.¹
- > Engaging patients in market access and health economics and outcomes research (HEOR) activities can help to ensure that findings are both relevant to patients, and of utility to healthcare decision makers.²⁻⁴
- > Health Technology Assessment (HTA) bodies such as the National Institute for Health and Care Excellence (NICE) and Canada’s Drug Agency (CDA) weave patient and public engagement throughout their appraisal and assessment processes, reflecting a shift towards shared decision making.⁵⁻⁸
- > Despite the recognised benefits, practical frameworks and solutions for meaningful patient and public engagement in HEOR remain underdeveloped and under recognised.⁹
- > Patient-centric approaches and the patient voice can only be integrated in market access and HEOR if multi-stakeholder literacy and capacity is built.
- > HTA bodies, payers, and researchers need to be aware of approaches and methodologies and be enabled to utilise them.
 - Furthermore, patients and members of the public need to feel empowered to be involved and trained to enable effective contribution.
- > We reviewed existing frameworks advocating for the inclusion of patients in both research and planning, and precedent methodologies enabling patients to participate in HEOR based studies and aimed to generate an illustrative roadmap consolidating appropriate approaches to support advancement of knowledge of patient-centric, inclusive, and equitable evidence generation practices in market access and HEOR.

Methods

- > A targeted evidence review was conducted to identify key published frameworks and established methodologies being used to capture the patient voice during evidence generation.
- > Our review sought to capture frameworks and established methodologies that capture the patient voice either by informing research design or via research participation.
 - We identified evidence from the United Kingdom (UK), EU4 (France, Germany, Italy and Spain), Canada and the United States (US) published between January 2010 – October 2025.
- > Following the evidence review, the frameworks and methodologies were collated into a roadmap highlighting the plausibility of patient-centric evidence generation throughout the product lifecycle.

Results

Our exploratory evidence review identified 18 key frameworks and 11 commonly used established qualitative methodologies that can generate patient-centric evidence in HEOR.

Published frameworks and guidance

- > In initial searches, we identified broad frameworks that were not specific to types of evidence generation and decision-making activities but outlined principles for the incorporation of the public and patient voice in health research¹⁰
- > However, we highlight a narrower range of 18 published frameworks and guidance that promote the incorporation of the public and patient voice within a range of activities most relevant to market access and HEOR. The commonalities between these frameworks illustrate key components that support public and patient engagement irrespective of the activity type.
- > Future frameworks for evidence generation and decision-making activities would add to those identified if:
 - tailored to specific populations
 - they promote approaches for accessibility
 - they outline appropriate ethical standards
 - they promote consideration of equity and inclusivity of an approach.

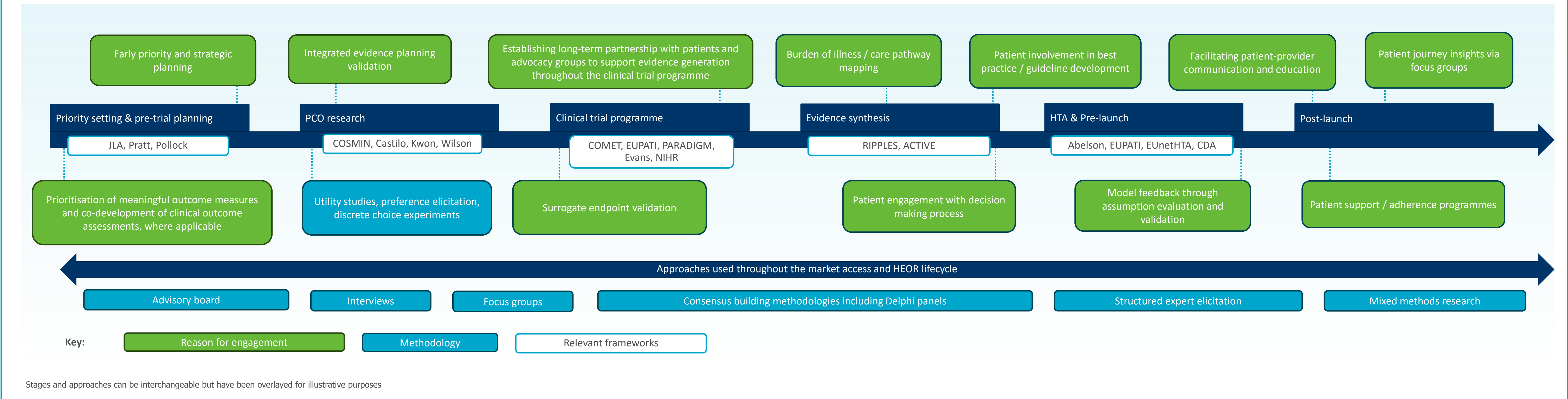
Figure 1. Overview of frameworks identified enabling patient involvement in evidence generation to decision making activities

| Categories of evidence generation | Priority setting | Patient-centred outcomes research | Clinical trials | Evidence syntheses | Health technology assessment |
|-----------------------------------|--|--|--|---|--|
| Examples | A: James Lind Alliance Priority Setting Partnership (PSP) Handbook ¹¹ B: Pratt, initial framework to construct power and dynamic balanced citizen engagement in priority-setting ¹² C: Pollock, New Model to Engage Patients and Clinicians in Setting Research Priorities ¹³ | D: Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) ¹⁴ E: Camello Castillo, A framework for culturally sensitive approaches in patient-centred outcome research ¹⁵ F: Kwon, how to translate common themes from community based participatory research into effective patient-centred outcomes research strategies ¹⁶ G: Wilson, A framework adapted from the Food and Drug Administration’s roadmap for patient-focused clinical outcome assessment ¹⁷ | H: Core Outcome Measures in Effectiveness Trials (COMET) Handbook ¹⁸ I: EUPATI Guidance for patient involvement in ethical review of clinical trials ¹⁹ J: Patients active in research and dialogues for an improved generation of medicines (PARADIGM) ²⁰ K: Evans, A framework for involving service users in trials L: NIHR, Good practice guidelines on the recruitment and involvement of public members on trial and study steering committees ²¹ | M: Johnson, Rapid Involvement of Patients and the Public in Evidence Synthesis (RIPPLES) ¹⁸ N: Pollock, ACTIVE ¹⁹ | O: Abelson, A framework for action P: EUPATI Guidance for Patient Involvement in Medicines Research and Development ²⁴ Q: EUnetHTA D7.2 guidance? R: CDA Framework for Patient Engagement in Health Technology Assessment ⁶ |
| Overview of purpose: | A: Step by step guide to the processes involved in a PSP with the aim of bringing patients, carers and clinicians together to identify uncertainties or unanswered questions for specific health issues B: Guidance on addressing ethical considerations and dimensions of power during priority-setting processes to accurately and equitably reflect patients’ health needs C: To facilitate involvement through targeted engagement and assisted involvement to gather research priorities from people affected by stroke | D: Guide to mechanisms for patient engagement whilst designing, evaluating and selecting measurement instruments including PROs E: Guidance to assist in including the perspectives of Latin American caregivers in patient-centred outcome research F: Guidance on how to apply the core principles of community-based participatory research whilst developing patient-centred outcomes research G: A methodological framework for engaging patients at various stages of developing clinical outcome assessments for medical product development | H: Outlines how to develop core outcome sets and engage patients within this process I: Practical recommendations for ground rules and options for involving patients in the work of ethics committees and in the overall clinical trial process from concept development to trial result reporting in lay summaries J: A sustainable framework for meaningful, structured, and effective patient engagement (PE) across the entire medicines research and development (R&D) lifecycle – particularly where patient input can have the greatest impact K: Guidance to help researchers involve service users successfully in developing and conducting clinical trials and creating a culture of actively involvement at all stages L: Guidance including definitions of public members roles in research oversight groups and good practice for recruitment and involvement of public members | M: A framework and toolkit to help researchers carrying out rapid evidence synthesis to embed patient and public involvement in their work N: A framework to enhance the relevance, quality, and applicability of systematic reviews by incorporating perspectives from various stakeholders, including patients, healthcare professionals, and the public | O: A comprehensive framework to involve patients and the public in the government’s HTA process P: Guidance on patient involvement in industry-led medicines research and development covering the interaction between patients and the pharmaceutical industry within all functions throughout the medicines R&D lifecycle in relation to medicines for human use Q: A framework for involving patients and healthcare professionals in the European Union (EU)’s Joint Scientific Consultations (JSC) and Joint Clinical Assessments (JCA) R: An overview of the values and standards for patient involvement in action at Canada’s Drug Agency |

Roadmap of approaches

- > Combining insights from both the frameworks and methodologies identified, we developed an illustrative roadmap that can be used to identify ways and means to capture the patient voice, including early and sustained patient engagement across the product lifecycle (Figure 2).
- > The appropriate approach to capturing the patient voice and involving patients as active participants in HEOR depends upon the objective and if patient perspectives are to inform study design, endpoint selection, model assumptions, or evidence interpretation.

Figure 2. Overview of frameworks identified enabling patient involvement in evidence generation to decision making activities



Conclusions

- > Insights from our review reiterated that capturing the patient voice and involving patients as active participants in HEOR is crucial for generating evidence that truly reflects real-world experiences and outcomes that matter most to those affected.
- > Published frameworks were identified that promote the incorporation of the public and patient voice in HEOR. However, frameworks were not specific to types of evidence generation and decision-making activities. Future frameworks should provide clear, practical guidance on how to involve patients in specific HEOR activities, including how to recruit and engage different groups and consider equity and inclusivity.
- > In addition to frameworks that enhance patient involvement in research planning and design, our review identified a range of methodologies that can be utilised for evidence generation in HEOR to enhance the patient voice in the evidence base for novel therapies.
 - Patient and public involvement in research planning and design helps to ensure that research questions reflect real patients’ concerns and addresses matters of importance to them.
 - Involvement in research planning also supports patient recruitment to and engagement with HEOR, which further enriches evidence generation, leading to more impactful and actionable insights.
- > Patient and public involvement can highlight outcomes that truly affect individuals moving beyond clinical markers of effect and ensuring incorporation of outcomes, preferences, and priorities that ensure research is meaningful and relevant to patients. It can also ensure findings are interpreted in an appropriate language and within a meaningful context for non-clinical audiences. It can also improve language of materials making them accessible to wider communities.
- > Our illustrative roadmap provides an overview of use cases whereby patient involvement could be considered across the product lifecycle, be that as participants or research planning and design partners. This roadmap aims to provide drug developers with an outline on where and how to incorporate the patient voice in HEOR and market access, including frameworks to use at each stage.
- > By leveraging existing frameworks and established methodologies, we can move toward a more inclusive and credible paradigm ensuring that HEOR evidence in decision-making reflects the needs and values of all stakeholders.

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