# Patient Involvement in Health Technology Assessment: A Global Review of Practices, Purposes, and Pathways

**PCR171**

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## INTRODUCTION & OBJECTIVES

- Over recent years, there has been **increasing emphasis** on the need for **patients to be engaged** in health technology assessment (HTA) processes.
- For HTA bodies, patients bring **detailed knowledge of a disease**, standards of care in practice, and an understanding of their priorities and needs.
- Patients expect to have access to the best standards of care and to have the opportunity to contribute and participate as an **equal stakeholder**.
- However, there is still an imbalance in the level of patient engagement in HTA activities, with HTA agencies often lacking tools, processes or resources, and patients not always being familiar with the role of HTA in healthcare decision-making.

**The objectives of this research – a joint initiative of Bocconi University and Global Heart Hub – were:**

1. **To update the state of the art on the practices of patients' involvement in HTA by running a literature review**
2. **To run a patient survey to investigate barriers, facilitators and progress towards incorporating patient views in HTA**

## METHODS

### 1 Scoping review of the scientific and grey literature

- Sources:
  - Scientific literature: PubMed, Web of Science
  - Grey literature: HTA agencies websites, documents, reports, white papers
- Search strategy: i) Patient involvement; ii) Health Technology Assessment
- Time horizon: 2010-2025
- Search restricted by title/abstract search

### 2 Global survey directed at patients or patient organizations

- Approved by Bocconi University Ethical Committee (ID: RA001018)
- Survey co-developed with feedback from key informants from multiple jurisdictions and backgrounds (Steering Committee)
- Field stayed open between August and October 2025
- Dissemination via Global Heart Hub network (affiliates), and both Global Heart Hub and SDA Bocconi social media channels (e.g., LinkedIn, website)

## RESULTS

### *Dimensions of analysis*

**Whom to involve:**
Considers the different stakeholders who may be engaged in HTA processes: patients (disease-experts), users of technologies (actual or potential), members of the general public, etc.

**For what purposes:**
Patients can be engaged to inform policy-making, to contribute to organizational governance within HTA bodies, to shape the commissioning and prioritization of HTA research, etc.

**Depth of involvement:**
The depth of engagement can vary, ranging from simple information-sharing, to consultation, to active participation in decision-making processes and committee work.

**What mechanisms are used for involvement:**
Refers to formal and informal methods to engage patients, such as advisory committees, public consultations, citizens' juries, workshops, interviews, etc.

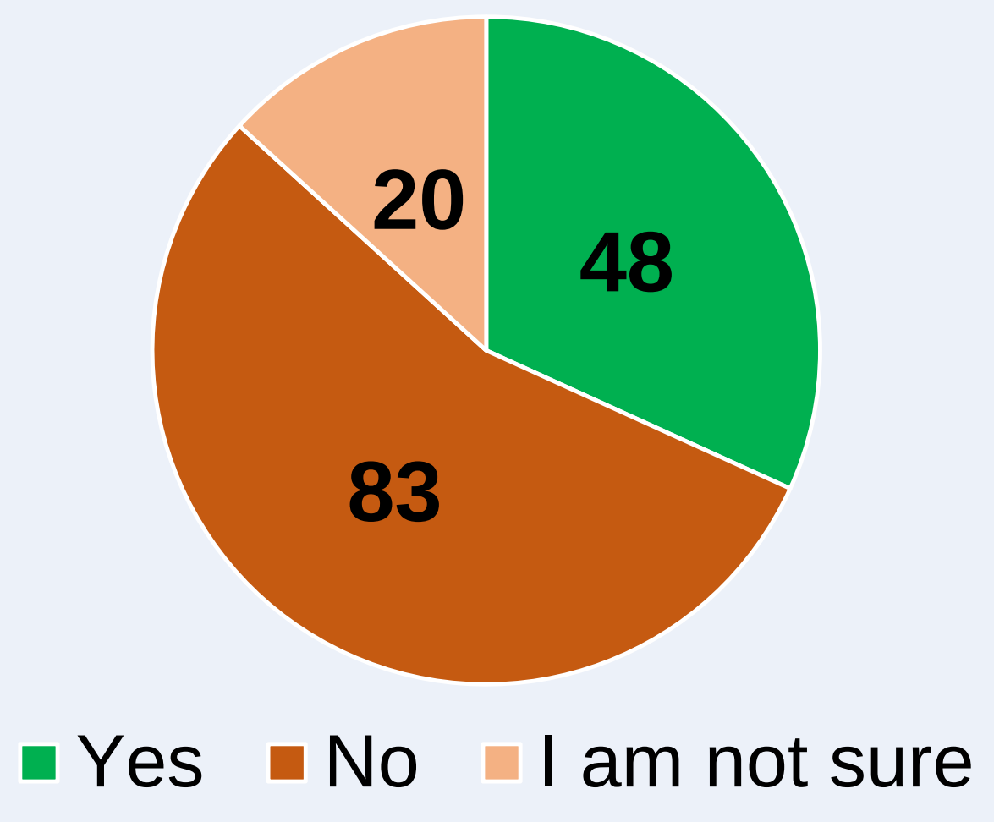
**Which timing of involvement:**
Patient involvement may occur at different stages of the HTA process, from early scoping and topic selection to evidence appraisal, deliberation, and final decision-making.

### ***Key survey insights*** *(selection)*

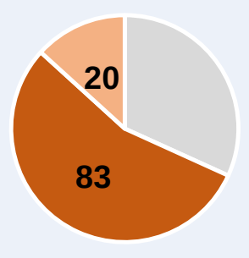
#### Key numbers on respondents

- 151 valid responses
- 70% from patient organizations (of which, 57% in governance roles); 30% independent patient advocates or patients/caregivers
- 42 countries represented (top 10 countries account for 70% of the responses collected)
- ~70% active in cardiovascular diseases
- Organizations of different sizes represented

#### Prior involvement in HTA?



#### Top three barriers for respondents with no prior HTA involvement



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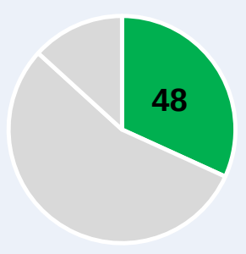
|---|---|---|
| **Not contacted or invited by competent agencies**: You or your organization have not been formally approached, invited, or informed of opportunities by competent agencies, like HTA bodies, to participate in their processes. | **83** | **81%** |
| **Unaware of opportunities for involvement:** You or your organization did not know that there were opportunities to engage in decisions around access to health technologies, such as HTA, or were not informed about when and how participation could occur. | **70** | **68%** |
| **Insufficient internal resources**: You or your organization did not have enough capacity, such as staff time, funding, or administrative support, to take part in HTA activities. | **32** | **31%** |

#### Top three facilitators for respondents with prior HTA involvement



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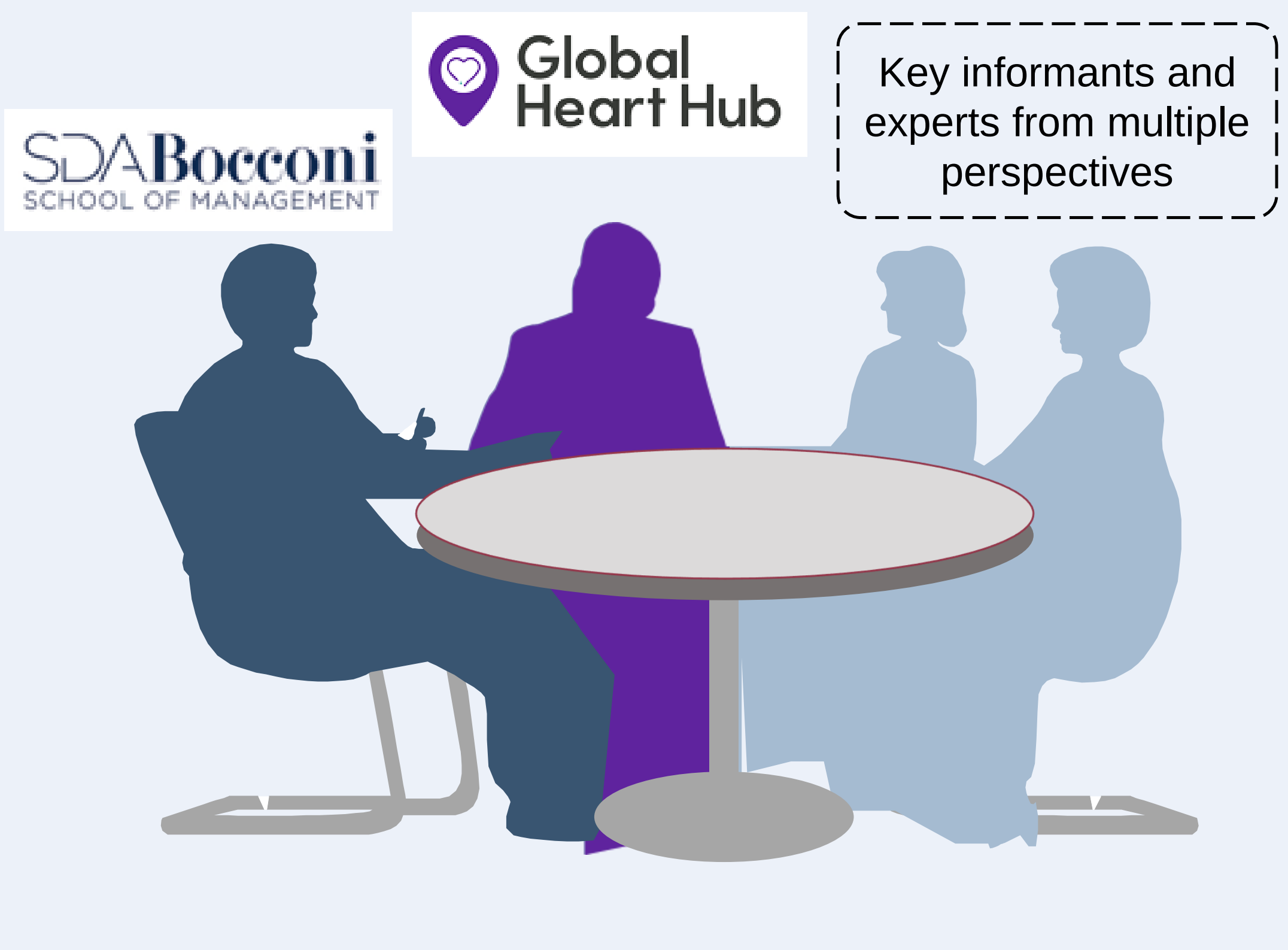
|---|---|---|
| **Early engagement and reasonable timelines**: You were involved with sufficient advance notice and adequate time to prepare and participate effectively. | **25** | **52%** |
| **Clear guidance documents**: The HTA agency gave you well-structured, easy-to-follow materials that explained the process, roles, expectations, and ways to contribute. | **25** | **52%** |
| **Collaboration with other patient groups**: You had the opportunity to connect with and learn from other patient organizations, strengthening your contributions and advocacy. | **22** | **46%** |

## DISCUSSION

- There are **multiple factors and levels of maturity** influencing the inclusion of the patient perspective in HTA.
- The key takeaway is that **a one-size-fits-all approach cannot work for patient engagement in HTA**; instead, various context-specific factors are likely to determine the extent, methods, and outcomes of such involvement.
- The research is ongoing, with **interviews currently being conducted** to gather qualitative insights from multiple stakeholders (patient organizations, industry representatives, public bodies).
- **Policy recommendations will ultimately be developed** to guide the future integration of patients' perspectives into healthcare decision-making and HTA.
- The **findings will be published** in a scientific journal and further disseminated through presentations at scientific conferences.

## ACKNOWLEDGEMENT



Steering Committee (SC)

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