Patient Voices in HTA:
Integrated Evidence and Policy Pathways for Strengthening Patient Involvement

Marta Bragagnolo[1] *, Vittoria Ardito[2], Monica Otto[2,3], Rosanna Tarricone[2,3], Neil Johnson[1]

[1] Global Heart Hub

[2] Center for Research on Health and Social Care Management (CERGAS), Government, Health and Not-for-Profit (GHNP), SDA Bocconi School of Management

[3] Department of Social and Political Sciences, Bocconi University

*Presenting author: marta@globalhearthub.org

INTRODUCTION & OBJECTIVES

- Health Technology Assessment (HTA) decisions have major implications for patients' outcomes, daily functioning and access to care, making inclusion of patient perspectives critical for legitimacy and relevance.
- Internationally, patient involvement in HTA is acknowledged as valuable but remains heterogeneous and often ad hoc, with engagement concentrated in assessment and appraisal rather than earlier scoping or post-access review.
- Patients and patient organisations contribute unique experiential knowledge on disease burden, unmet needs and real-world trade-offs that are not fully captured by clinical and economic evidence alone.

The objectives of this research were:

1. **To synthesise evidence from a literature review, a global survey and stakeholder interviews to build a holistic picture of patient involvement in HTA.**
2. **To identify barriers and facilitators of meaningful patient engagement from the perspectives of patients/patient representatives and other HTA stakeholders.**
3. **To generate an empirical basis for future strategies and policy options to strengthen systematic, patient-centred engagement in HTA, with particular attention to CVD.**

METHODS

Literature review:

- Scoping and synthesis of scientific and grey literature on patient and public involvement in HTA, focusing on 13 established HTA agencies and mapping who is involved, purposes, mechanisms, timing and depth of engagement across the HTA lifecycle (2010–2025).

Global online survey:

- International survey of patients and patient representatives disseminated through Global Heart Hub and partner networks (153 valid responses from 39+ countries; ~70% active in CVD), fielded between August and November 2025.

Qualitative interviews:

- Semi-structured interviews with key informants from patient organisations, HTA agencies, industry and other public bodies conducted in late 2025 to contextualize quantitative findings and explore perceived barriers, enablers and examples of emerging good practice.

RESULTS – Key Survey Insights

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, etc.

For what purposes:
Patients can be engaged to inform policy-making, to contribute to organisational governance within HTA bodies, to shape the commissioning and prioritisation 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.

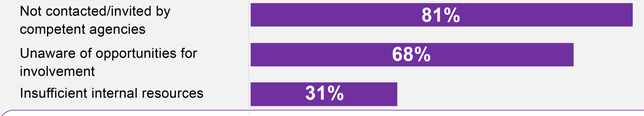
What mechanisms are used for involvement:
Refers to formal and informal methods to engage patients, such as advisory committees, public consultations, citizens' juries, workshops, interviews, etc.

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.

CVD respondents are less likely to have prior HTA involvement than peers in other disease areas.

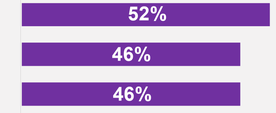
Prior involvement in HTA?	Overall	CVD respondents	Any other disease areas
Yes	50	28	22
No	83	62	21
I am not sure	20	16	4
Total	**153**	**106**	**47**
Yes	33%	26.5%	47%
No	54%	58.5%	44.5%
I am not sure	13%	15%	8.5%
Total	**100%**	**100%**	**100%**

Top three barriers for those with no prior involvement in HTA

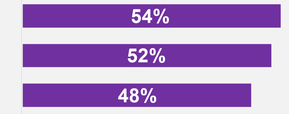


Limited participation in HTA is driven primarily by gaps in outreach and communication, rather than by disengagement or opposition. Capacity and knowledge constraints are present but secondary **83%** of respondents with no prior involvement are **very to extremely interested to being involved in HTA.**

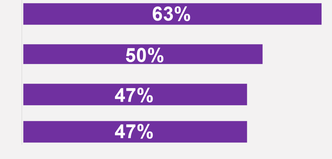
Top three barriers for those with some forms of prior involvement in HTA



Top three facilitators for those with some forms of prior involvement in HTA



Top four enablers rated as major facilitators for those with some forms of prior involvement in HTA



Effective HTA participation is facilitated by early engagement, clear guidance and supportive infrastructures, complemented by training and collaboration opportunities. This suggest that **well designed processes can significantly enhance the accessibility and effectiveness of patient engagement in HTA.**

CONSLUSIONS AND IMPLICATIONS FOR PRACTICE

- Survey findings indicate that cardiovascular disease (CVD) groups, despite forming the majority of respondents, report comparatively lower levels of prior HTA involvement, suggesting a specific engagement gap in this disease area
- The findings suggest that limited participation is driven less by lack of interest and more by weak outreach, unclear entry points, complex processes and insufficient support, in contrast with consistently high willingness to engage among patient organisations and advocates.
- This work underpins future efforts to co-design more consistent, transparent and adequately resourced approaches to patient engagement across the HTA lifecycle, while avoiding one-size-fits-all solutions and allowing adaptation to local contexts and system maturity.
- For the CVD community, addressing gaps in proactive contact, HTA literacy support and feedback mechanisms will be essential to ensure that health technology decisions better reflect the outcomes, burdens and trade-offs that matter most to patients and their families.

ACKNOWLEDGEMENT

Steering Committee (SC)

Key informants and experts from multiple perspectives

The authors thank the SC members (in alphabetic order by surname):

- **Hussain Al Omar** *(King Saud University)*
- **Neil Bertelsen** *(independent patient advocate)*
- **Fernanda Carvalho** *(Lado a Lado pela Vida)*
- **Pietro Erba** *(European Commission)*
- **Mandy Sandkuhler** *(Mended Hearts)*
- **Joe Vandigo** *(Applied Patient Experience)*

DECLARATION OF INTEREST

This independent research initiative is led by Global Heart Hub and SDA Bocconi School of Management, Milan, and it has been made possible with financial support from Bayer and Edwards Lifesciences.

The financial supporters have no influence over the study design, data analysis, interpretation of results or reporting.