

Patient Involvement in Health Technology Assessment: A Global Survey of Patients & Patient Organizations' Practices and Pathways

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BACKGROUND

- Patient perspectives are increasingly recognized in HTA, but engagement methods are inconsistent.
- This study mapped practices of patient engagement in HTA through a **global survey** directed at patient organizations and independent patient representatives.
- **Conducted in partnership** with Global Heart Hub.
- A multidisciplinary **Steering Committee** which included patient representatives informed the research.

METHODS

- Survey development informed by a prior **literature review**.
- Target respondents included a purposive sample drawn primarily from the GHH community.
- Questionnaire consisted of up to 25 questions, structured into up to three sections: **Respondents profiles**; **Modalities for patient engagement**; **Barriers**.
- **Ethics approval** from Bocconi's Ethical Committee.

CONCLUSIONS

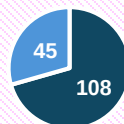
- **First large, global survey** targeting patient organizations and patient representatives.
- Findings highlight need for **clearer communication** channels, more **systematic outreach** from HTA bodies, and **targeted capacity-building** initiatives to support meaningful patient involvement.

RESULTS

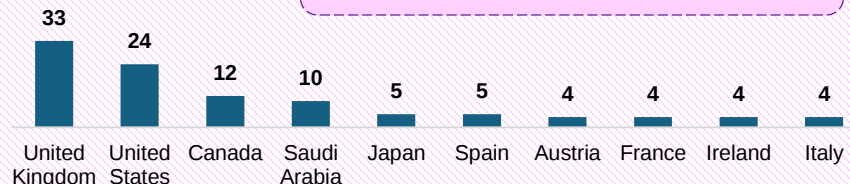
- A total of **153 valid responses** from a range of countries and disease areas were collected.

Respondents profiles (N=153)

Are you affiliated with a patient organization? In which country are you based? (top 10)



■ Yes
■ No



Have you ever been involved in a formal HTA?
50 Yes
83 No; 20 Not sure

Modalities for patient engagement (N=50)

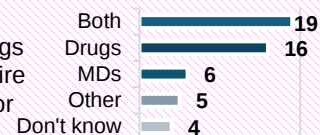
Invitations to contribute to HTA (top 3)

- 32%** Invitation received through an umbrella org.
- 28%** Invitation received from a doctor or a nurse actively involved in patient care
- 28%** Invitation received from a contact person at a pharmaceutical company

Modalities for providing input (top 3)

- 54%** Workshops or meetings
- 40%** Survey or questionnaire
- 36%** Written submissions or topic proposals

Technologies assessed



Perceived or experienced barriers

Top 3 perceived barriers (N=103)

- 81% Not being contacted or invited by HTA agencies
- 68% Unaware of opportunities for involvement
- 31% Lack of, or insufficient, internal resources

Top 3 experienced barriers (N=50)

- 52% No information on how input was used
- 46% Limited staff/time in the organization
- 46% Lack of funding or compensation