

Method

Cite this article: Itaborahy A, Morais Q, Frossard L, Mateus I, Leite B, Santos M (2025). Learning strategies for laypeople to participate in health technology assessment: a scoping review. *International Journal of Technology Assessment in Health Care*, **41**(1), e26, 1–8
<https://doi.org/10.1017/S0266462325000200>

Received: 26 June 2024
Revised: 24 February 2025
Accepted: 22 March 2025







Keywords:

laypeople; education; training; health technology assessment; HTA

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Learning strategies for laypeople to participate in health technology assessment: a scoping review

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Abstract

Objectives: To provide an overview of learning strategies that health technology assessment (HTA) agencies use worldwide to educate laypeople about HTA.

Methods: A scoping review focused on learning strategies to educate laypeople about HTA using the Joanna Briggs Institute frameworks was conducted across databases and gray literature. The study reviewed qualitative, quantitative, and mixed-methods studies from four databases, including practice documents from the HTA and health organization websites.

Results: Fifteen studies were included in this review. The United Kingdom, Spain, and Canada mainly contributed to knowledge about educating laypeople in HTA. The main strategies employed were conference-like events, educational materials, training, and plain language. International HTA and health agencies developed courses, online training, and guidance materials to increase laypeople's participation in the HTA process.

Conclusions: Efforts to improve public involvement in HTA focus on structured consultations, digital platforms, and capacity-building to enhance accessibility. Strategies like workshops and plain language aim to encourage lay participation, but challenges such as technical complexity and limited resources persist. Despite these challenges, incorporating patient perspectives has increased research relevance and public trust. Future studies should examine standardized frameworks for involvement, the impact of lay participation on policy, and solutions to barriers to a more equitable HTA process.

Introduction

Health technology assessment (HTA) has become vital in health care, where new technologies rapidly develop in a scenario with limited budgets (1). The International Network of Agencies for HTA (INAHTA) and HTA International (HTAi) define “HTA as a multidisciplinary process that uses explicit methods to determine the value of health technology at different points in its lifecycle. The purpose is to inform decision making to promote an equitable, efficient, high-quality health system” (2).

Patient values should be central in decisions about approval, utilization, reimbursement, and pricing (3). However, the involvement of laypeople in HTA is challenging, and several hurdles must be overcome. Patient group representatives believe that community involvement can be improved by using plain language and improving the process's transparency (4).

The INAHTA (5) and HTAi (6) have a strong position on the involvement of patients and the public in HTA (5;6). Both organizations recognize that incorporating these perspectives ensures that assessments meet the actual needs of the population and promote informed, democratic decision making. HTAi has notably invested in educational initiatives, offering resources, workshops, and conferences to empower patients and the public for effective participation in HTA processes.

In Europe, initiatives like the Involve Foundation (7) and the European Patients' Academy on Therapeutic Innovation (EUPATI) (8) are prominent. The Involve Foundation fosters public engagement in health, encouraging participatory and transparent decision-making practices. EUPATI provides education and training programs for patients and advocates, enabling significant contributions to developing and evaluating medicines and health technologies.

Patient-led associations also play a crucial role, even if HTA is not their primary focus. A notable example is EURORDIS (9), the European Organization for Rare Diseases, a nongovernmental alliance representing 988 patient organizations across 74 countries. EURORDIS aims to improve the quality of life for individuals with rare diseases in Europe by promoting research, policy development, and advocacy initiatives. Although not exclusively focused on HTA, EURORDIS significantly impacts the field by bringing patient perspectives into health policy

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development and evaluating new technologies and treatments for rare diseases. The organization empowers patients to effectively contribute to health decision-making processes, including participation in HTA-related committees and working groups.

Patient and public involvement (PPI) in the planning and development of healthcare services is becoming increasingly important in healthcare organizations and their delivery. This involvement is essential for making more informed, transparent, accountable, and legitimate decisions about health technologies (10–13).

Several initiatives within the UK's National Health System (NHS) give individuals and groups a stronger voice within the healthcare sector in planning and development and involve the public in empowering decision making and policy (12;14). Ontario is a PPI development leader in the Canadian HTA Area. The Ontario Health Technology Advisory Board (OHTAC) established a Public Engagement Subcommittee to guide early efforts. As one of its most significant efforts, the OHTAC has set up a public and professional consultation process for drafting OHTAC recommendations (13). However, the Canadian PPI context in HTA extends beyond OHTAC, reflecting diverse approaches and practices across provinces and institutions, highlighting the increasing recognition of PPI to enhance the relevance, transparency, and acceptability of HTA outcomes (10;15).

The establishment of PPI and the very nature of democracy are linked to particular historical situations. This is especially true in Latin America, where ongoing political instability and systemic inequalities make it challenging to develop and sustain policies allowing societal participation in decision-making processes (16). In Brazil, for example, community participation in health-related decisions has been enshrined in the Constitution since the introduction of the Unified Health System (SUS), regulated by National Health Conferences and Health Councils. The social participation guaranteed by law has helped to mitigate the effects of political instability on social participation, allowing PPI to become a subject of debate and actions to engage in health decision making (16).

A previous study (17) outlines strategies to enhance PPI in HTA processes. Key strategies include capacity-building through workshops, simplifying technical language, and encouraging active participation in consultations. These approaches aim to empower patients to provide evidence, co-develop training resources, and share information about consultations and decisions. Although designed for patients, these strategies also benefit the general public. According to Street et al., a layperson is defined as anyone without qualifications in health care (11). Thus, the main objective of this study was to map the strategies HTA agencies use worldwide to educate laypeople about HTA. The secondary purpose was to identify the challenges for training laypeople in HTA.

Methods

The scoping review protocol

An a priori protocol was developed and registered with the Open Science Framework (<https://www.doi.org/10.17605/OSF.IO/9ZC3F>) following established scoping review frameworks from the Joanna Briggs Institute Manual for Evidence Synthesis (18). This scoping review was based on Arksey and O'Malley (19), who followed the PRISMA Extension for Scoping Reviews (PRISMA ScR) guidance on conducting and reporting a scoping review (20;21). We employed a three-step approach to search for relevant papers. Initially, a preliminary search on MEDLINE was conducted with a general search strategy: The text words in the title and abstract were analyzed to identify the MeSH Terms. The final terms and synonyms were

selected after discussion with the other authors. EMBASE, LILACS, and Cochrane databases were used for the selected search terms in the second step.

Additionally, sources of gray literature, such as Google (with advanced search strategies), theses, conference proceedings, and abstracts, were verified. The third step was to search the reference list of all identified papers, followed by the screening phase using Rayyan screening software (22). The results were limited to English, Portuguese, and Spanish languages. No restriction on publication year was applied. Finally, a complementary manual search was conducted on the websites of HTA organizations worldwide. This nonstructured search aimed to find instructional materials and documents for laypeople that have not been published in academic journals. A total of 31 organizations, including HTA agencies, networks, and patient organizations, were examined. A list of the searched agencies can be provided upon reasonable request.

Study selection

Following the search, all identified citations were collated and uploaded into Rayyan software (22), and duplicates were removed. The titles and abstracts were then screened by two independent reviewers for assessment against the inclusion criteria for the review. Studies that meet the inclusion criteria were retrieved and assessed in detail against the inclusion criteria by two reviewers. Full-text studies that do not meet the inclusion criteria were excluded, and the reasons for exclusion were provided (Supplementary Material). The final report reported the research results in full and presented in a PRISMA for Scoping Reviews flow diagram (23). The disagreements between the reviewers were resolved in a consensual way (Figure 1).

Eligibility criteria

A scoping review has a broader “scope” with correspondingly less restrictive inclusion criteria. The following question was based on the population, concept, and context elements considering the inclusion criteria below.

Participants

Studies whose participants were laypeople could be eligible for inclusion in the review. As mentioned above, a layperson is anyone who does not have qualifications in health care. These individuals can include patients with a disease or condition using the healthcare system and potential consumers of preventive services like vaccines. It can also refer to the public, that is, community members with a public interest but no commercial, professional, or personal involvement in the HTA process.

Concept

The concept of interest was the use of learning approaches for laypeople. This included but was not limited to education or training approaches such as workshops and formal training, production of learning materials, the use of simplified forms, and technical reports in accessible language.

Context

This scoping review included studies whose educational strategies for training laypeople had as their context participation in HTA processes, whether at the national, regional, or local level.

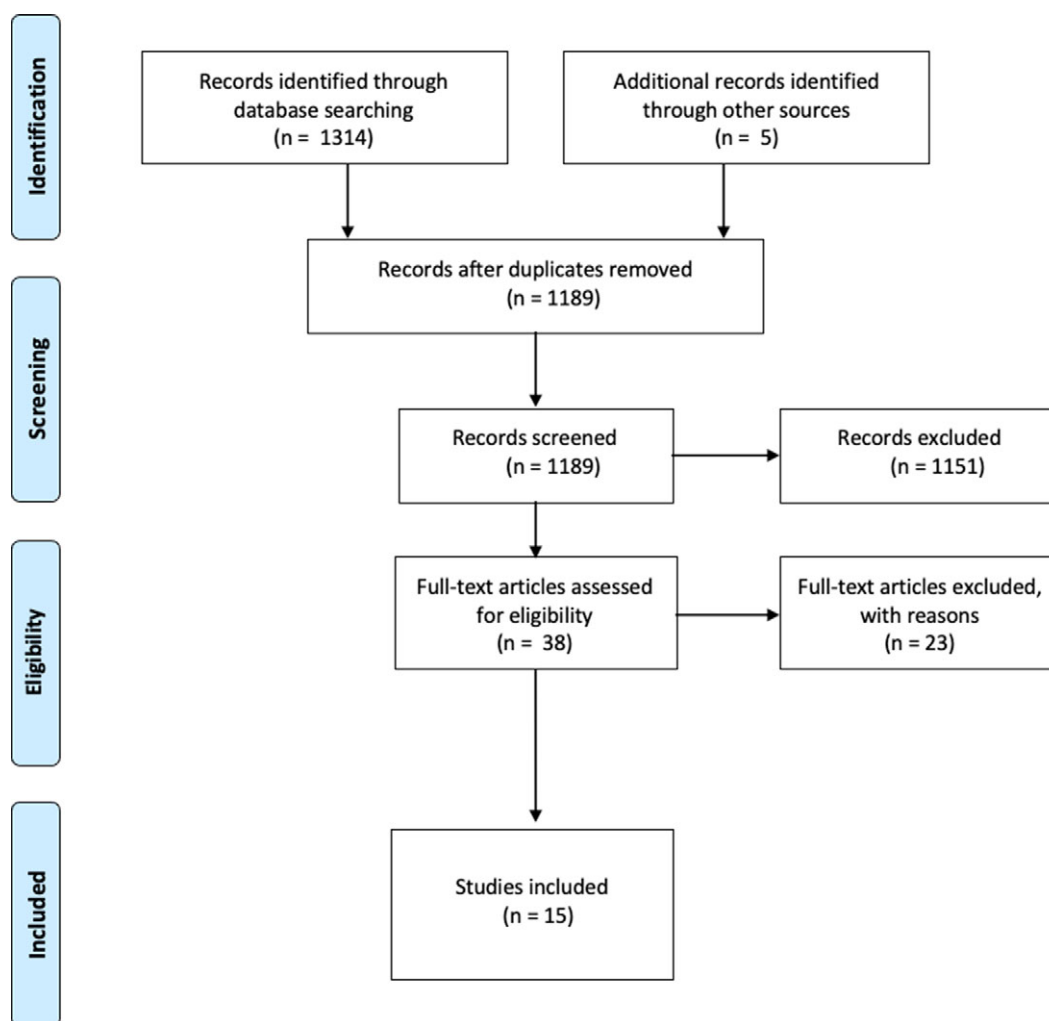


Figure 1. PRISMA flow diagram for the scoping review process.

Types of sources

This scoping review considered experimental and quasi-experimental study types, such as randomized controlled trials, nonrandomized controlled trials, before and after investigations, and interrupted time-series studies. Analytical observational research, such as prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies, was considered for evaluation. Descriptive observational study designs, such as case series, individual case reports, and descriptive cross-sectional studies, were also considered. Expert opinions, clinical guidelines, dissertations and theses, editorials, articles, and reports on practices in use by organizations were evaluated in a search of the gray literature.

Data extraction

Two independent, blinded reviewers extracted data from the papers using a predesigned extraction form. The extracted data included participant details, study methods, and key findings relevant to the review questions.

Results

The structured searches in electronic databases retrieved 1314 references, and the unstructured searches in additional sources

resulted in five references, totaling 1319. After removing 130 duplicates, 1189 references were analyzed based on their titles and abstracts, and 1151 were eliminated for not meeting the eligibility criteria. Thus, in the second stage of the selection process, the full texts of the 38 selected references were analyzed. Of these, 23 were excluded, and the reasons for exclusion are detailed ([Supplementary Table 1](#)). At the end of the selection process, this review included 15 studies (7 conference proceedings, 7 full-text articles, and 1 doctoral thesis).

The general characteristics of the studies included in this review are summarized in [Table 1](#). Most studies were published between 2015 and 2022. Of the 15 publications included, 7 were full-text journal articles. Four of them investigated the involvement of the patient (24–27), one looked at public participation (28), and two focused on consumer involvement (29;30) in HTA. One doctoral thesis addressing public involvement in HTA was also included (31). Another seven studies were conference abstracts that provided limited detail. However, five of those conference abstracts explored patient involvement (32–36), and two focused on patient and public engagement in HTA (37;38). This review included registries from various geographical contexts, but the representation is limited. Specifically, four studies focused on the healthcare system in the United Kingdom and three examined the healthcare setting in Spain. Additionally, there was one registry each from Canada, Finland, Switzerland, and Taiwan, which

Table 1. General characteristics of the included studies

Characteristics	Quantity (n = 15)	Percentage (%)
Publication year		
2000–2004	2	13.3
2005–2009	0	0.0
2010–2014	1	6.7
2015–2019	6	40.0
2020–2022	6	40.0
Publication type		
Conference proceeding	7	47.0
Journal article	7	47.0
Thesis dissertations	1	7.0
National contexts		
Multinational settings	4	27.0
United Kingdom	4	27.0
Spain	3	20.0
Canada	1	7.0
Finland	1	7.0
Switzerland	1	7.0
Taiwan	1	7.0
Definition of laypeople		
Patient	9	60.0
Consumer	2	13.3
Public	2	13.3
Patient and public	2	13.3

together represent a smaller proportion of the total studies reviewed. The remaining registries were about multinational settings (26;31). It is worth noting that full-paper journal articles were about the contexts of the United Kingdom (25;28;30); Europe (26); Canada (29); Finland (27); and Taiwan (24). The geographical distribution of the national contexts in which the included studies were applied is shown in [Supplementary Figure 1](#).

The main strategies identified in the included studies used to educate or train laypeople about HTA are depicted in [Figure 2](#).

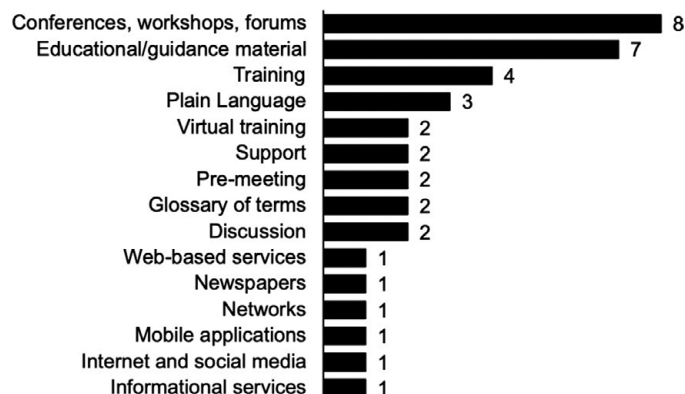
Conference-like events were the strategy most frequently used according to the present review, since 21 percent of the studies cited it, followed by the creation of educational or guidance materials (18 percent), training (11 percent), and using plain language (8 percent). Other strategies were cited by 5 percent or fewer studies. The strategies identified in each study included in this review are shown in [Supplementary Table 2](#).

Some barriers and challenges to educating laypeople on HTA were also identified in this review ([Figure 3](#)). Public involvement in HTA bumps in several types of constraints. The need for dedicated staff, time constraints, and regular feedback is challenging (28;31). Another barrier is the lack of financial compensation for the public's costs of displacement, feeding, and accommodation (26;28;31). Poor training and support (26;28–30;32;35), low general awareness of the processes (26;31), or poor communication (24;26;28;30) were also found as constraints in this review. Moreover, it was found that some HTA agencies do not encourage any patient involvement (26;31). Often, HTA is seen purely as a scientific process (26), so patient inputs can be considered anecdotal or biased (26), or they can occur in a tokenized fashion (29). Structured education initiatives should equip public contributors and researchers with the skills needed for effective PPI (39). Training must clarify roles and expectations, enhance communication for better engagement, and provide methodologies for assessing the impact of PPI activities to improve transparency and effectiveness (39).

The search on HTA agencies' websites retrieved the strategies they applied to encourage laypeople to participate in the HTA process. The primary strategy found is the production of guidance material followed by online courses, as seen in [Table 2](#).

Discussion

This review identified 15 studies that applied educational strategies to laypeople about HTA. The papers retrieved by this review abridged diverse contexts. However, most papers included the UK's NHS context (25;28;30;34), followed by publications in Spanish (32;33;35) and multicenter/international (31;37;38) settings. Pieces of information were found in other contexts like Finland (27), Switzerland (36), Europe (26), and Taiwan (24). The small sample of studies found worldwide that focused on strategies to educate the public to participate in HTA shows that, despite the work that HTA agencies have done, little has been published on this topic. Moreover, the number of publications has increased over

**Figure 2.** Teaching/training strategies for laypeople in HTA cited in the studies included in the scoping review.

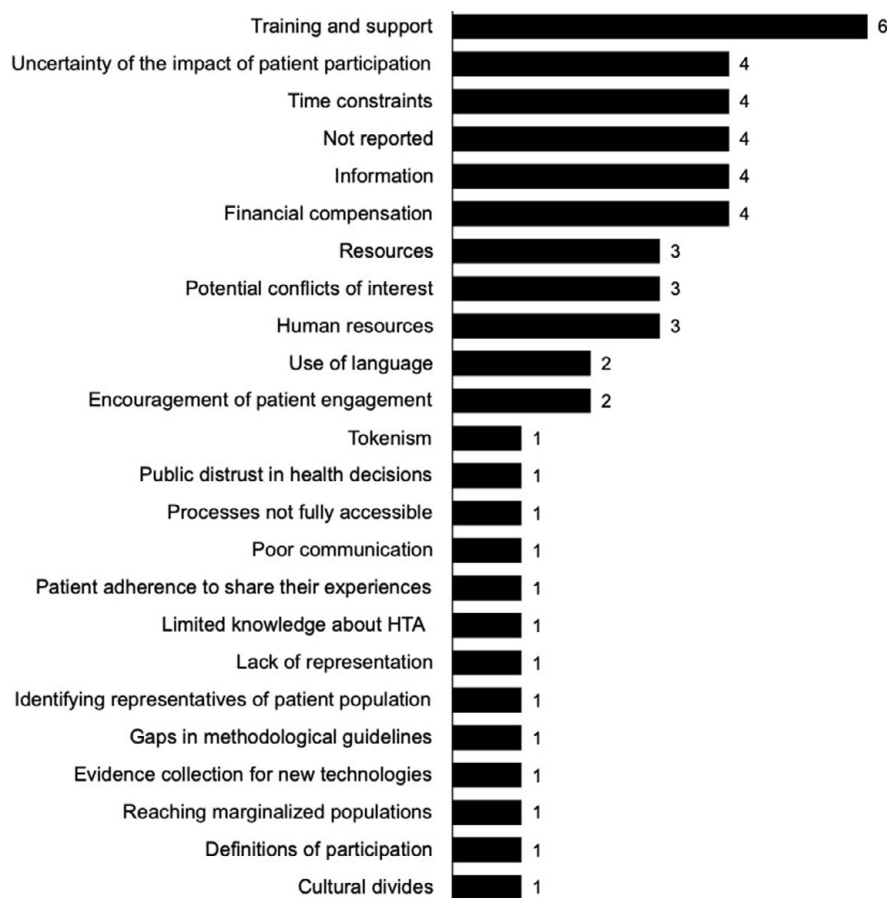


Figure 3. Challenges for teaching/training laypeople in HTA cited in the studies included in the scoping review.

time, indicating interest in this topic, but few full-text studies continue to be published on this topic.

Due to the limited information in congress abstracts, this discussion focuses on full-text material, considering study contexts, strategies, barriers, and the impact of lay participation in HTA presented in chronological order.

In the United Kingdom, consumer involvement in shaping HTA research has been emphasized through prioritization panels and research review discussions (30). In-person meetings proved more effective than literature reviews or formal consultations, helping to bridge communication gaps and address training deficiencies through induction programs, participatory workshops, open discussions, and structured feedback mechanisms (30).

Further research examined public involvement in the National Institute of Health Research's HTA program (28), revealing engagement in topic identification, prioritization, and proposal reviews. However, participation in funding and monitoring was limited. Public contributions improved research relevance and prioritization methods, with the most significant impact occurring in the early stages of HTA (28).

A historical review of the HTA processes of the National Institute for Health and Care Excellence (NICE) (1999–2020) highlighted the progressive expansion of patient participation (25). NICE has included lay members on all HTA committees since 1999, introduced a “lay leader” role in 2008, and developed standardized evidence submission templates and structured feedback mechanisms. Patients began contributing clinical evidence in 2014, and pre-submission meetings with NICE experts were

introduced in 2019. Barriers included challenges in translating personal experiences into formal evidence, committee resistance to qualitative data, and insufficient patient training. However, structured patient involvement significantly influenced guideline formulation, particularly when qualitative evidence was systematically integrated (25).

In Europe, the EUPATI guidelines recommended allocating resources, providing specialized training, and implementing effective communication strategies (26). Key recommendations included early patient involvement, educational support, plain-language summaries, and transparent decision making. However, barriers such as the absence of standardized participation guidelines, the technical complexity of assessments, and financial constraints remained significant challenges (26).

A Finnish study explored patient participation through a seminar with patient organization representatives focused on hypertension (27). Participants agreed that patient perspectives should be collected through organized groups rather than individuals, with surveys emerging as the most effective method. The barriers included difficulty in finding suitable representatives and limited training resources. The study emphasized the importance of multi-channel communication—via the Internet, social media, specialized magazines, and healthcare professionals—and recommended integrating patients into the HTA and Clinical Practice Guideline working groups (27).

Strong interest in HTA participation was reported among patient organizations in Canada (29), with 82 percent engaging in surveys, 80 percent in focus groups, and 71 percent in decision-making

Table 2. Learning strategies practiced by HTA agencies for laypeople

Institution	Strategy	Topic
ICER	Guidance material	Handbook: guide to understanding health technology assessment
ECPC	Guidance material	Handbook: understanding health technology Assessment: a guide for patients
NICE	Online course	Introduction to HTA (https://academy.ehden.eu/)
NICE	Online course	Seminars, lectures and webinars about HTA (https://www.nice.org.uk/about/what-we-do/life-sciences/scientific-advice/education-and-training)
NICE	Guidance material	Guide to the Methods of Technology Appraisal (https://www.nice.org.uk/process/pmg9/resources/guide-to-the-methods-of-technology-appraisal-2013-pdf-2007975843781)
NICE	Guidance material	A guide for patient/carer groups: contributing to a technology appraisal (https://archive.org/details/b32231878)
NICE	Guidance material	Overview of technology appraisals: a factsheet for patient and carer organizations (https://www.nice.org.uk/Media/Default/About/NICE-Communities/Public-involvement/Developing-NICE-guidance/Overview-of-technology-appraisals-patient-carer-groups.pdf)
Ministry of Health (Brazil)/HAOC	Online course	HTA for health professionals and patients https://proadi.eadhaoc.org.br/course/view.php?id=281&section=2#start)
ISPOR	Online course	Introduction to HTA laypeople (https://www.ispor.org/education-training/hta-training-program)
EUnetHTA/INAHTA	Guidance material	Handbook on HTA Capacity Building (https://www.eunetha.eu/wp-content/uploads/2018/01/EUnetHTA-Handbook-on-HTA-Capacity-Building.pdf)
EUPATI	Online course	Patient Expert Training Programme (https://www.learning.eupati.eu)

ICER, Institute for Clinical and Economic Review; NICE, National Institute for Health and Care Excellence; ECPC, European Cancer Patient Coalition; ISPOR, Professional Society for Health Economics and Outcomes Research; EUnetHTA, European Network for Health Technology Assessment; INAHTA, International Network of Agencies for Health Technology Assessment; EUPATI, European Patients Academy on Therapeutic Innovation; HAOC, Hospital Alemão Oswaldo Cruz (German Hospital Oswaldo Cruz).

committees. The study reviewed international public involvement models, such as NICE (UK) and Breast Cancer Network Australia, highlighting strengths and weaknesses. Barriers included training gaps, technical complexity, and resource constraints. The proposed solutions involved HTA training, educational materials, financial support for travel, and a national database for consumer engagement, leading to recommendations for a federally funded independent organization to strengthen consumer involvement in HTA (29).

A study examined patient participation in HTA in Taiwan, emphasizing the impact of COVID-19 and the shift to virtual meetings (24). Patient involvement began in 2013, with an online platform for submitting opinions on health technologies introduced in 2015. Regulations required at least two patient representatives to be present at Joint Committee meetings by 2019. Challenges included limited representation, low visibility of participation processes, and inadequate preparation time. Although mechanisms such as online platforms, committee participation, and patient training have been introduced, the extent to which patient input influences reimbursement decisions remains unclear (24).

A recent review (31) identified global approaches to integrating social participation in HTA, including online dissemination, simplified summaries, rapid reviews, public comments, structured surveys, focus groups, committees, and conferences. Effective implementation required infrastructure (computers, videoconferencing tools, and internet access); balancing rapid and extended consultations; human resources for public engagement; and educational materials. Barriers included the lack of clear guidelines, time constraints, financial limitations, resistance from regulatory agencies, and concerns about neutrality and decision-making timelines. Public distrust and fears regarding technology availability were also noted. Key facilitators included developing methodological guidelines, enhancing transparency, providing training, establishing patient-HTA agency networks, and fostering an organizational culture supportive of public participation. Overall, social involvement in HTA improves decision making, enhances

acceptance among health system users, and promotes equity by incorporating diverse perspectives (31).

Barriers

To summarize, the studies included in the present scoping review identified several barriers that hinder public participation in HTA, including communication challenges, lack of training, resource constraints, and limited influence on decision making. The technical complexity of HTA processes and the use of specialized jargon make it difficult for patients to engage meaningfully. A lack of structured training and guidance prevents effective participation, whereas some committees resist incorporating qualitative patient input. Financial and logistical constraints, such as travel costs, time limitations, and insufficient institutional support, further restrict involvement. Additionally, structural barriers, including the absence of standardized participation guidelines and minimal patient influence in the funding and dissemination phases, limit the impact of public contributions. Addressing these challenges requires improved communication strategies, accessible training programs, adequate resources, and stronger integration of public input into decision making.

Learning strategies

Synthesizing, various methods have been employed to enhance public participation in HTA, including structured consultations, digital platforms, and capacity-building initiatives. Structured consultations involve public comments, focus groups, advisory committees, and stakeholder conferences, facilitating direct engagement in decision making. Digital platforms, such as online opinion submissions, virtual meetings, and interactive websites, improve accessibility and broaden participation. Capacity-building initiatives, including training programs, educational materials, and plain-language summaries, help patients and representatives navigate complex HTA

processes. In addition, standardized evidence submission templates and structured feedback mechanisms ensure that patient input is systematically integrated. Combining these methods enhances transparency, strengthens patient engagement, and promotes more inclusive decision making in HTA.

Impact of laypeople participation in HTA

Finally, public participation in HTA has improved research relevance, decision-making transparency, and stakeholder engagement. Involving patients in topic selection and prioritization has led to more patient-centered research agendas, ensuring that assessments address real-world concerns. Structured participation frameworks have enhanced communication between researchers and the public, making technical information more accessible and fostering mutual understanding. Additionally, integrating patient perspectives into guideline formulation has improved the quality and acceptability of decisions, increasing public trust in HTA outcomes. Despite existing challenges, the structured and early involvement of the public strengthens the legitimacy of HTA processes and promotes more equitable and inclusive decision making.

Limitations

This review identified 15 studies (7 full-text articles and 1 doctoral thesis) on strategies to train or educate lay people in HTA, focusing on improving people's participation in HTA processes in several contexts worldwide. The small number of studies allowed for an overview of the strategies and barriers reported in the literature limited to the contexts represented by the included studies. The small number of full-text studies does not mean that work is not being done, but that little has been published on the subject. It is possible that many of the studies presented at conferences do not evolve into full-text articles. It is worth noting that HTA agencies are not required to conduct research or publish their findings in scientific journals. Their primary purpose is to support decision making, which may limit the results of this review.

Conclusions

This scoping review identified several learning strategies to help laypeople participate in HTA processes. Efforts to enhance public participation in HTA have primarily focused on structured consultations, digital engagement platforms, and capacity-building initiatives, improving accessibility and stakeholder involvement. Learning strategies such as workshops, the production of educational material, courses, online training, and the use of plain language offer various ways of improving laypeople's participation. However, technical complexity, insufficient training, and resource constraints continue to limit effective participation and influence in decision making. Despite these barriers, integrating patient perspectives has enhanced research relevance, strengthened transparency, and improved public trust in HTA processes. Future studies should explore standardized frameworks for public involvement, the long-term impact of lay participation on policy decisions, and innovative strategies to address financial and logistical barriers, ensuring a more equitable and effective HTA process.

Supplementary material. The supplementary material for this article can be found at <http://doi.org/10.1017/S0266462325000200>.

Author contribution. A.I., Q.M., and M.S. contributed to the conceptualization of this article. All authors contributed to the revisions of this analysis and approved the final version. A.I., Q.M., and M.S. were responsible for planning the analysis, protocol redaction, and interpretation of data. A.S. and Q.M. wrote the paper, and M.S. oversaw the subsequent steps of the writing process. The other authors reviewed and provided comments to improve the manuscript.

Funding statement. This study was financed by the National Council for Scientific and Technological Development – CNPq.

Competing interests. The authors declare none.

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