



# Patient and public involvement in health technology assessment: update of a systematic review of international experiences

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## Assessment

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## Abstract

**Objective.** To summarize current evidence on patient and public involvement (PPI) in health technology assessment (HTA) in order to synthesize the barriers and facilitators, and to propose a framework to assess its impact.

**Methods.** We conducted an update of a systematic review published in 2011 considering the recent scientific literature (qualitative, quantitative, and mixed-methods studies). We searched papers published between March 2009 (end of the initial search) and December 2019 in five databases using specific search strategies. We identified other publications through citation tracking and contacting authors of previous related studies. Reviewers independently selected relevant studies based on prespecified inclusion and exclusion criteria. We extracted information using a pre-established grid.

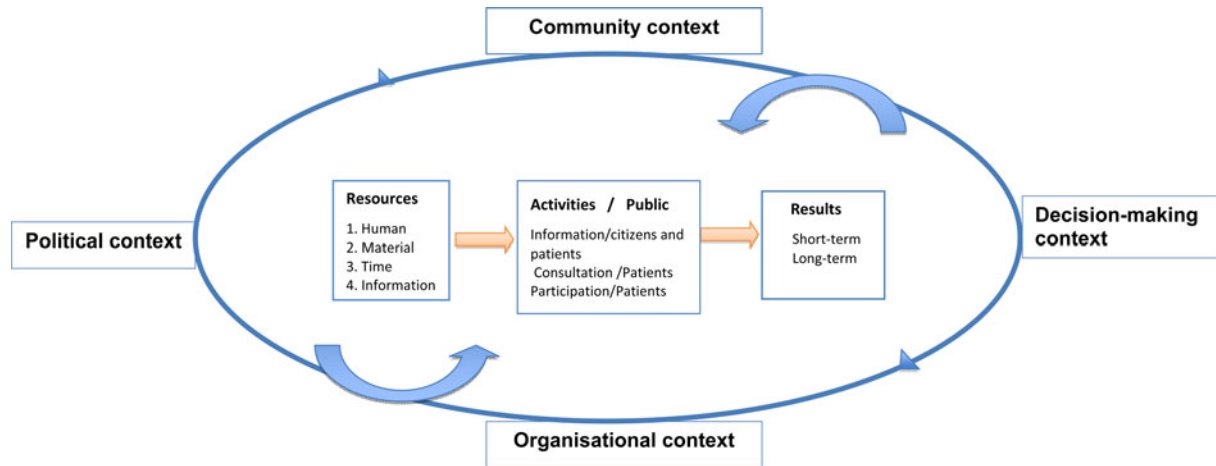
**Results.** We identified a total of 7872 publications from the main search strategy. Ultimately, thirty-one distinct new studies met the inclusion criteria, whereas seventeen studies were included in the previous systematic review. PPI is realized through two main strategies: (i) patients and public members participate directly in decision-making processes (participation) and (ii) patients or public perspectives are solicited to inform decisions (consultation or indirect participation). This review synthesizes the barriers and facilitators to PPI in HTA, and a framework to assess its impact is proposed.

**Conclusion.** The number of studies on patients or public involvement in HTA has dramatically increased in recent years. Findings from this updated systematic review show that PPI is done mostly through consultation and that direct involvement is less frequent. Several barriers to PPI in HTA exist, notably the lack of information to patients and public about HTA and the lack of guidance and policies to support PPI in HTA.

## Introduction

Both patients and members of the public are increasingly involved in many domains of the healthcare system, including health technology assessment (HTA) (1–4). Patient and public involvement (PPI) in HTA has emerged as an imperative for more informed, transparent, accountable, and legitimate decisions about health technologies (5–9). In recent years, several efforts have been initiated around the world to achieve PPI in HTA (1;10–12). The rationale behind patient involvement in HTA is that patients—referring to *individuals with personal experience of a health issue and their informal caregivers, including family and friends* (13)—can give their perspectives on experiences, attitudes, beliefs, values, and expectations about health, illness, its effects, and the use of health technologies (6;14). Thus, patient involvement in HTA should help produce care that is responsive to their needs and values (15;16). Along with providing experiential knowledge, it is believed that involving patients in health decision making will promote a sense of empowerment and contribute to more efficient solutions regarding the distribution of scarce health resources (14–17). Therefore, patient involvement in HTA allows considering their needs and values in decisions regarding health technologies, which could increase their relevance (18).

Abelson and collaborators (12) highlight the principal reasons for involving the public—referring broadly to citizens and patients—in HTA, including: (i) to gain public support for funding the work of HTA agencies (19;20); (ii) to ensure that the assessment adopts a broader health condition perspective, rather than the narrower technology perspective characteristic of more traditional HTAs (20); (iii) to avoid potential conflicts between individual patient



**Figure 1.** Conceptual framework to evaluate patient and public involvement (PPI) in health technology assessment (HTA).

interests with the desire to distribute resources fairly (20); and (iv) to provide context for the research, which improves the usefulness of assessments for decision makers (7).

Despite the general consensus on the need to involve patients and the public in HTA, questions remain about the best strategies for involving them into the structures and activities of HTA agencies and hospital-based HTA units (21;22). In 2011, Gagnon and collaborators (7) published a systematic review aiming to describe international experiences of PPI in HTA. As this field has rapidly evolved in recent years, decision makers and researchers need more recent evidence on the impact of PPI in HTA (23). Hence, this paper aims to synthesize knowledge on how patients and the public have been involved in HTA activities over the last decade and to propose a framework to assess the impact of PPI in HTA.

### Conceptual Framework

We used a framework developed by our team (24) to organize data collection and analysis regarding PPI in HTA (Figure 1). This framework is presented as a logic model, which is a visual illustration of a program's resources, activities, and expected outcomes. The framework has three main components: (i) resources (inputs), activities, and results (outputs); (ii) evaluation criteria of PPI issued from general frameworks for evaluating PPI (25;26) and our initial systematic review of PPI in HTA; and (iii) contextual factors as highlighted by Abelson and colleagues (27). This framework allows looking at the relationship between the process and the outcomes of PPI in HTA and the influence of the context in which this involvement takes place.

We used the PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) (28) guidelines to perform and report this systematic review (See PRISMA checklist in the Supplementary material).

### Methods

#### Search Strategy

We undertook a literature search in the following databases: PubMed, Embase, CINAHL, Web of science, and Business Source Premier, covering 1 March 2009 (the date of the last search in the previous review) to 31 December 2019 using the following concepts: "HTA"; "INAHTA"; "Public involvement"; "Patient Satisfaction/

Education/Preferences"; "Patient-Centered Care/Shared decision making/Professional-Patient Relations" (See Supplementary material for the PubMed full electronic search strategy). Relevant references from studies selected for extraction were followed up and obtained for assessment. We also contacted three authors for which study abstracts were available for potentially eligible published or unpublished studies. Other literature was identified through discussion with experts in the field through contacts of the team members.

#### Study Selection

We used the following inclusion and exclusion criteria, based on those used for the initial systematic review:

*Type of studies:* Only papers describing qualitative, quantitative, or mixed-methods empirical research were included. Editorials, commentaries, as well as opinion articles were excluded.

*Types of participants:* We included patients, consumers, service users, informal caregivers, public, citizens, and all similar terms in order to be as inclusive as possible, given the lack of terminology consensus about these terms. However, we used either patient, informal caregiver, or member of the public when describing the population of interest to avoid confusion.

*Types of interventions:* The study had to describe, in whole or in part, any experience of patient or public involvement practice in the field of HTA. We did not include studies that were related to PPI in general, such as surveys of PPI among HTA agencies. The interventions of interest in this review are PPI activities. Thus, when more than one publication reported a same study involving the same participants and presenting the same PPI activities, we included only the most recent publication. However, if different participants and/or different PPI activities were described in publications related to a same study, we included all relevant publications.

#### Data Collection Process

First, one reviewer (MTD) screened titles. Then, pairs of two reviewers (MPG and MTD; MPG and GM) independently screened abstracts for possible inclusion in the review. After a first selection of potentially relevant articles, full copies of these papers were retrieved and allocated to two reviewers among all authors (MPG, MTD, TGP, JPG, GM, and VB) who screened

them independently, using the set of inclusion criteria. We ensured that papers written by some of the authors (MPG, MTD, and TGP) were reviewed by other authors without conflict of interests or by a research associate not involved in the publication (AL, *see Acknowledgments*).

### Data Extraction

We used the template developed for our initial systematic review to extract information. We extracted information on the type of patient or public involvement in HTA, based on Gauvin's model (29), information about factors facilitating or limiting patient participation, and impact on clinical interventions, costs, and perceptions of other stakeholders. We further enriched this template by adding attributes related to the type of participants, information related to the context of involvement, and short-term results. For each retained study, data extraction was done independently by two reviewers among all authors (MPG, MTD, TGP, JPG, GM, and VB), and any discrepancies were resolved through discussion during a meeting involving all reviewers.

We extracted study characteristics including: country of the study, year and language, main objective, methodological approach, study design, and data collection strategy. Study description included: the type of technology (nature, life cycle), the domain/type and the stage of involvement, the level of involvement, and the use of a theoretical model. The type of participants included: members of the public, patients, and other stakeholders (e.g., decision makers, healthcare providers, HTA staff, etc.). We also extracted the main findings of the studies. The outcomes of interest were the documented impact of PPI on the HTA process and recommendations, as well as the barriers and facilitators to PPI.

### Quality Assessment

We used the Mixed Methods Appraisal Tool (MMAT) to assess the quality of studies for this update (30). We used this tool because, to the best of our knowledge, it is the only one that allows to concomitantly appraise the methodological quality of quantitative, qualitative, and mixed-methods studies, using a valid and usable specific set of criteria.

## Results

### Study Selection

A total of 7872 records were identified by the main search strategy. Of these, thirty-two publications (1;10;12;23;24;31–57), referring to twenty-eight studies, met the inclusion criteria. Discussions with experts in the field and follow-up of relevant references from studies selected allowed us to identify four more publications (58–61). This yielded the inclusion of a total of thirty-one distinct studies, described in thirty-six publications. The study selection process is outlined in Figure 2.

### Characteristics of Included Studies

Study characteristics are presented in Table 1. A large number of included studies (12/32) were conducted in Canada (1;12;23;24;33;38;39;42;43;50;51;60), followed by Australia (4/32) (47;55;56;60), Italy (3/32) (37;40;48), England (3/32) (34;49;53), Germany (2/32) (10;35), and Finland (2/32) (41;46). The

remaining studies were conducted in Austria (36), Ireland (52), Scotland (45), South Korea (57), Spain (44), and one from more than one country (31).

The following results are presented according to the categories of our analytical framework and cover: (i) the types of resources mobilized; (ii) the types of involvement activities; (iii) the types of patient or public involved; (iv) the short-term results of PPI; and (v) the barriers and facilitators to PPI.

### Types of Resources Mobilized for Patient or Public Involvement

Resources mobilized for PPI included information resources in almost all of the included studies (see Table 1). Other studies described time resources (1;34;37;41;40;44;46;48;51;52;59), material resources such as computers, meeting rooms and office supplies (37;46;49;50;56;59), human resources (32–34;37;41;44;46–52;54;55;60;61), and financial resources (34;49;52;61).

Specific human resources were dedicated for PPI in the majority of studies (17/32). Six studies (37;46;49;50;56;59) reported the use of material resources, and only four studies (34;49;52;61) reported the use of financial resources. With respect to informational resources, written information such as evidence brief (12), e-mail invitation (59), and draft of the recommendations (46) were the most used. Staff for the provision of care (49), support person (54), patient recruiter (52), and discussion facilitator (32;41;61) were reported as human resources.

### Types of Patient or Public Involvement Activities

The studies reported two main types of patient or public involvement in HTA activities. In the first type, participants give their view on the topic under study (draft of HTA recommendations, a framework or a test, etc.) (31–34;36;42–44;49;50;55;56;59). In the second type, they are directly involved in different stages of the HTA process, often at the same table with other stakeholders in working groups, and/or participants receive information about the HTA being conducted (1;10;12;23;32;35;37;39–41;46–48;51;53;54;60).

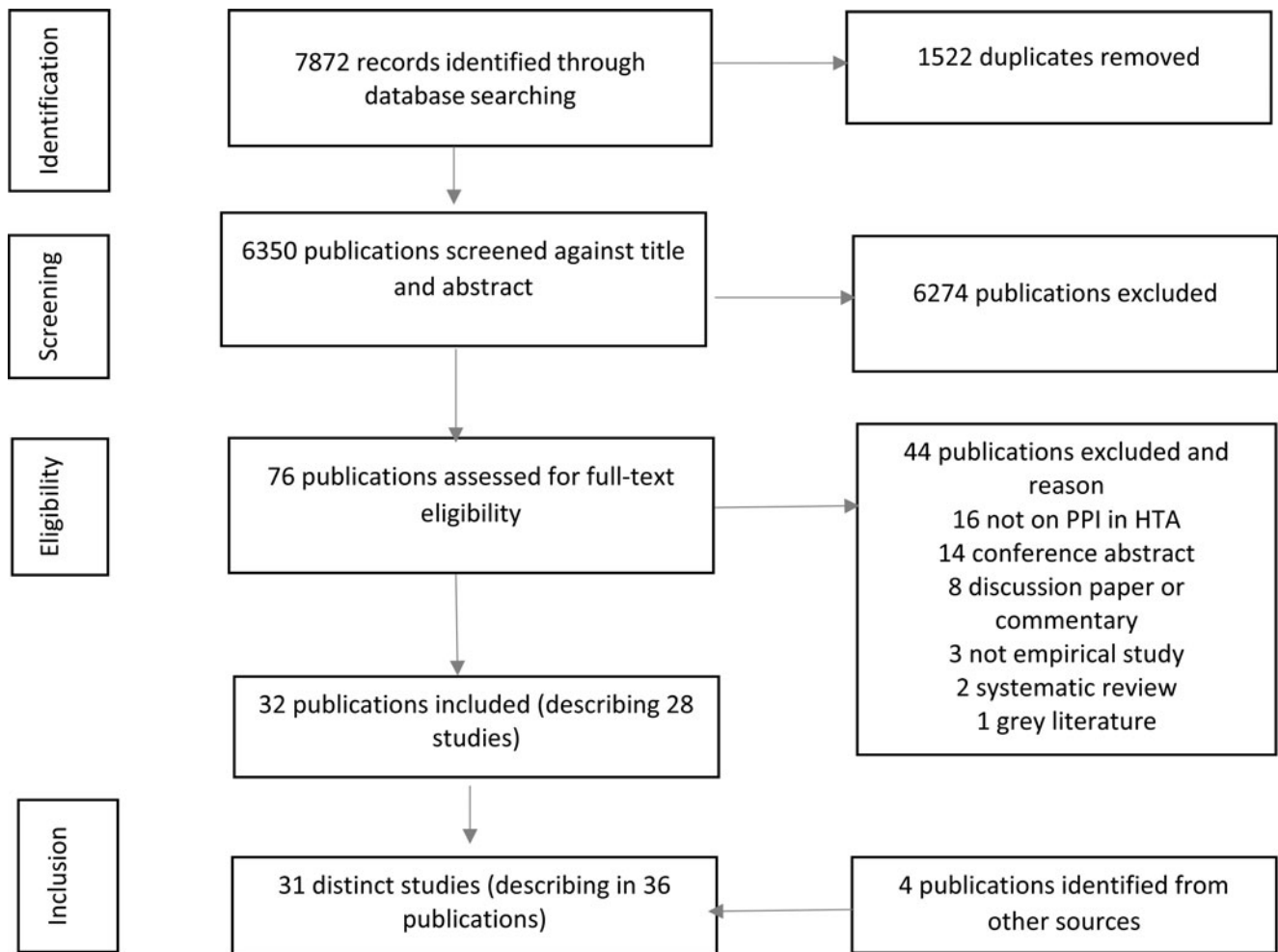
### Type of Patient or Public Involved

All studies reported the total number of participants, but the number per group was not clear in three studies (10;49;52). This number varied from 4 to 949. Five studies included the participation of members of the public only (12;32;34;56;60), fourteen studies included the participation of patients only (23;31;35–37;40;42;43;45;48–51;53), whereas both members of the public and patients were involved in twelve studies (10;33;38;39;41;44;46;47;52;54;57;59).

The involvement of other stakeholder groups such as healthcare professionals and managers was also mentioned in ten studies (23;33;35;39;41;46;47;50–52).

### Short-Term Results of Patient or Public Involvement

In this review, we focused on short-term results that are those obtained within 1–3 years after the intervention. Five studies reported the input of PPI in HTA recommendations (23;32;33;40;48), whereas three studies reported this input in the development of a framework for PPI (10;12;23). Several studies (15/32) reported awareness raising in decision making at different stages of the HTA process following PPI (12;23;31–33;35;36;39;41;45;46;49;50;57;60). Two studies discussed the relevance of PPI



**Figure 2.** PRISMA flow diagram. PPI, patient and public involvement; HTA, health technology assessment.

activities (24;47), and five studies analyzed the perceptions of stakeholders regarding patient involvement (23;33;37;38;59). Among other impacts, five studies reported the influence of patients at different stages of the HTA process (39;52;55;56;59), one study reported the development of a software program (44), another study led to the development and validation of a tablemat sticker (50), and one study identified possible collaborations (53). These results are detailed in Table 2.

### Barriers and Facilitators to PPI in HTA

Among the thirty-two included studies, twenty-six reported data on barriers and facilitators. Table 2 presents the examples of the barriers and facilitators that were reported, according to the context in which they were identified (organizational, decision making, political, and community).

The two barriers most often cited were related to the organizational context (1;38;39;41;46;47). For example, three studies reported the difficulty to find and recruit the right patient interested by the topic and available (38;39;46), and three others argued that the time and efforts needed could represent a barrier for PPI activities (1;41;47). Other barriers were related to the political and community contexts, such as the fear that patient groups could act as lobbyists for the industry (33;38;39), and

the lack of preparedness for healthcare professionals and managers for including the patient perspective (38;39).

We also identified four main facilitators of PPI reported in the studies. Half of them were related to the organizational context (1;10;23;31;33;34;35;38;39;41;44;46;53;54). For instance, ten studies reported varied sources of recruitment (user committees or patient associations, service delivery points, managers, healthcare providers, research networks) to facilitate participant enrolment in the HTA process (1;10;23;34;37;38;39;44;46;51). The two other facilitators were related to the decision-making context (37;38;47;50;51;52;56;60). Regarding the political context, better information targeting patients and the public about HTA from governmental institutions appears as a facilitator for PPI in four studies (33;38;47;56). Finally, four studies identified facilitators in the community context (34;39;46;52), such as the collaboration of patient associations and community groups in the recruitment, and the use of social media.

### Discussion

Involving patients and the public in HTA is now recognized as a way to ensure that the evaluation is made on issues of importance to patients, thus improving the relevance and the quality of decisions (62). We found several experiences of PPI in HTA documented in the literature over the last decade (7).

**Table 1.** Characteristics of included studies

Study reference	Country/setting	Study objective	Resources for PPI	Type of PPI/activities	Target group/type of patient or public (number)	Short-/long-term results
Abelson 2013 (1) + Bombard 2011 (32)	Canada/Regional	To assess the impacts of a Citizens' Reference Panel on the deliberations of a provincial health technology advisory committee and its secretariat. To elicit ethical and social values in HTA recommendations.	<i>Information resources:</i> evidence summaries and draft recommendations; relevant review articles and newspapers clipping, workbook <i>Time resources:</i> five meetings over 18 months, through 1-day structured deliberated sessions <i>Human resources:</i> external group discussion facilitator; self-facilitated group discussion	Consultation/ Comment Participation/ Collaborate	Members of the public (14)	Awareness raised about social values and ethics in HTA; Direct uptake of the panel's input in some HTA recommendations. Identification of a set of core values to consider in the evaluation of health technologies and recommendations; Definition of six types of information required for enabling informed choice.
Abelson 2016 (12)	Canada/Regional	To describe the development and outputs of a comprehensive framework for involving the public and patients in a government agency's HTA process.	<i>Information resources:</i> evidence brief	Consultation/Provide data	Members of the public (4)	Dialog summary provided new information and critical input; Informed the development of a framework for PPI in HTA; The board of Health Quality Ontario moved toward implementing several of the recommendations.
Bae 2016 (57)	South Korea/ National	To describes the process and results of drug reimbursement decision making in South Korea and evaluates its performance from the perspectives of the various stakeholders involved.	<i>Information resources:</i> invitation of some interviewees; e-mail of questionnaires	Consultation/Provide data	<i>For questionnaires:</i> Members of the public (104); <i>For interviews:</i> Members of the public, patients (19)	Agreement among stakeholders that the consistency of reimbursement decision making has improved since 2007, while accessibility to new drugs has decreased; Preference of respondents toward improved public access to decision-making information.
Bastian 2011 (10)	Germany/ National	To develop a priority-setting framework based on the interests of patients and the general public.	<i>Information resources:</i> summaries of 124 Cochrane systematic reviews	Consultation/ Comment	Members of the public, patients (194)	Inclusion of patients'/ consumers' interests in the three major dimensions of the framework.
Brereton 2017 (31) + Brereton 2017 (58)	England, Italy, Germany, The Netherlands, Norway, Lithuania, and Poland/ International	To report on the extensive stakeholder involvement that occurred throughout a case study on HTA in palliative care, and reflect on the successes, challenges, and lessons learned from stakeholders' involvement at each stage of the HTA.	<i>Information resources:</i> individual face-to-face or telephone interviews, consultation meetings, or focus group	Consultation/Provide data, Comment Participation/ Collaborate	Stakeholders (132)	Stakeholders highlighted several important issues related to the benefit of reinforced home-based models of palliative care and the relevant evidence in the case study. The framework for considering consumer-oriented priorities was adapted by including three major dimensions: healthcare evidence, ethical considerations, and patients'/ consumers' interests.

(Continued)

Table 1. (Continued.)

Study reference	Country/setting	Study objective	Resources for PPI	Type of PPI/activities	Target group/type of patient or public (number)	Short-/long-term results
Boothe 2019 (33)	Canada/National	To explore how 10 years of experience with public and patient involvement in Canadian drug assessment has affected participants' ideas about how it works.	<i>Information resources:</i> published reports on public and patient involvement; interviews <i>Human resources:</i> interviewer	Consultation/Submit assessment requests, Provide data Participation/ Collaborate	Patients (3) Members of the public (3) Other stakeholders, that is agency officials and technical staff (9)	Public and patient involvement had some influence on deliberations and/or recommendations, although their interpretation varied. The contribution of PPI allowed considering social values and getting patient input on unmet needs.
Cockcroft 2019 (34)	England/National	To understand what knowledge and experience is shared during patient committee meetings, and how this knowledge is shared with researchers.	<i>Information resources:</i> Introductory session to explain what is HTA, including a video explanation <i>Time resources:</i> Three separate 2-hour meetings <i>Human resources:</i> two facilitators <i>Financial resources:</i> financial compensation	Consultation/Provide data, Elaborate the protocol	Members of the public (17)	Members of the public brought three different "sources" of knowledge and experience to meetings: direct lived personal experience; learnt knowledge; and experience and values of others. The data suggest that group settings allow for dynamic discussions and sharing of different types of knowledge.
Danner 2011 (35)	Germany/National	To introduce the analytic hierarchy process (AHP) as a preference elicitation method in HTA to ascertain patients' preferences for treatment end points.	<i>Information resources:</i> patient group Web sites; Internet search engines; patient interest groups; self-help groups; written information on treatment end points	Consultation/Provide data	Patients (12); Other stakeholders, that is, healthcare professionals (7)	Rating of some of the included end points of antidepressant treatment was different; The same six of the eleven end points were rated for more than 85 percent of the total weight.
Ettinger 2017 (36)	Austria/National	To summarize the evidence on clinical effectiveness and safety of wearable cardioverter defibrillator (WCD) therapy for primary and secondary prevention of sudden cardiac arrest in patients at risk.	<i>Information resources:</i> focus groups, semi-structured interviews, systematic review	Consultation/Provide data Participation/ Collaborate	Patients (10)	Collection of the perceptions of patients about the use of the technology under evaluation.
Fratte 2015 (37)	Italy/Regional	To explore patients' perspective regarding cervical cancer screening with Human Papillomavirus (HPV) co-testing	<i>Information resources:</i> interview guide; information guide; questionnaire to match all selection criteria <i>Time resources:</i> user information tool sent to participants at least 10 days before each session; a 1-hour session with an expert immediately before the focus group <i>Human resources:</i> focus group facilitator <i>Material resources:</i> phone calls to invite participants	Consultation/Provide data	Patients (14)	Enable healthcare decision makers to consider specific implications of the introduction of the HPV co-testing screening.

Gagnon 2014 (38)	Canada/Regional	To explore the practices, perceptions, and views of the various HTA stakeholders concerning patient involvement in HTA at the local level.	<i>Information resources:</i> contacts with user committees; semi-structured interviews based on a framework	Consultation/Provide data	Patients (13); Members of the public (11)	Agreement of all stakeholder groups on the need to select patient participants in HTA based on specific criteria.
Gagnon 2015 (39)	Canada/Regional	To explore stakeholders' points of views regarding the applicability and relevance of a framework for user involvement in HTA at the local level.	<i>Information resources:</i> framework and interview guide sent to participants few days before the interview; support of community groups that collaborated in other components of the project	Consultation/Provide data, Comment	Members of the public (15); Patients (5)	Direct participation of users seen as a way to involve them in the decision-making process; Suggestion from some user representatives to integrate user consultation in a more holistic and participatory way.
Gagnon 2016 (59)	Canada/Regional	To describe the process of engaging patient representatives and its results on the identification and prioritization of HTA topics in the field of cancer.	<i>Information resources:</i> e-mail invitation to potential participants with information on the project; Web site of community resources in oncology; form to suggest topics; preparatory documents sent 14 days before the meeting; pre-meeting prioritization questionnaire sent to participants; PowerPoint presentation <i>Material resources:</i> telephone, videoconferencing <i>Time resources:</i> topic filtration and refinement, preparation of vignettes, 1-day prioritization meeting	Consultation/Provide data	<i>For the consensus meeting:</i> Members of the public (6); Patients (5) <i>For topic suggestions:</i> Members of the public, patients (20)	Good acceptance of patient representatives' participation; Influence of patient representatives in the selection of priority HTA topics.
Gillespie 2015 (40)	Italy/National	To develop an HTA report able to compare efficacy, safety, cost-efficacy of the different modalities of conducting dialysis in Norway and adapt it to the Italian context, by including patients' preferences as decisional factor.	<i>Information resources:</i> literature review, surveys <i>Time resources:</i> meetings with patient associations	Consultation/Provide data Participation/ Collaborate	Patients (27); Patient associations (4)	Patients agreed that the technology under evaluation would provide easier life management, is easy to implement, but highlighted difficulties associated with support. Patient associations noticed differences in the access to the technologies across regions.
Hameen-Anttila 2016 (41)	Finland/National	To (i) discover ways to involve patients in HTA and CPG processes, (ii) describe challenges, and (iii) find ways of informing patients about HTAs and CPGs in Finland.	<i>Information resources:</i> seminar invitation; mini lectures <i>Human resources:</i> two facilitators per focus groups <i>Time resources:</i> 1-day seminar	Consultation/Provide data	<i>Participants in a 1-day seminar:</i> Patients (22); Members of the public (7) <i>Participants in focus groups:</i> Patients (14); Members of the public (6)	Importance of gathering patient views from a group of patients rather than individuals; Surveys through patient organizations is the most frequent means of gathering patients' views; Finding appropriate representatives of the target group, and conveying information about HTA and CPG to patients are the most often mentioned challenges.

(Continued)

Table 1. (Continued.)

Study reference	Country/setting	Study objective	Resources for PPI	Type of PPI/activities	Target group/type of patient or public (number)	Short-/long-term results
Health Quality Ontario 2018 (42)	Canada/Regional	To assess values, needs, and preferences surrounding Cognitive Behavioral Therapy (CBT) and other treatments for people affected by schizophrenia	<i>Information resources:</i> interviews	Consultation/Provide data	Patients (7) and family members (6)	Patient and family members insisted that CBT could only be effective in combination with medication. Neither treatment alone could be as effective as the two together. Access to CBT was challenging, with long wait times and large costs associated with faster access.
Health Quality Ontario 2018 (43)	Canada/Regional	To understand patient experiences with remote monitoring of implantable cardiac devices	<i>Information resources:</i> interviews	Consultation/Provide data	Patients (13) and family members (3)	Patients and family members reported positive experiences with remote cardiac monitoring: increased freedom and reduced anxiety. People living in rural areas are particularly enthusiastic about remote monitoring. A minority of patients and families expressed concerns about using remote cardiac monitoring.
Izquierdo 2011 (44)	Spain/National	To develop a breast cancer Patient Decision Aid (PDA), using the HTA process, to assist patients in their choice of therapeutic options, and to facilitate shared patient/physician decision making	<i>Information resources:</i> written script to elicit responses to relevant topics; personal and social networks of the researchers not involved in the project, including patient organizations <i>Human resources:</i> a moderator and an observer <i>Time resources:</i> focus group and discussion sessions synchronized in time with the interviews	Consultation/Provide data	Members of the public (7); Patients (10)	Agreement from both breast cancer patients and healthcare professionals that surgery, adjuvant treatments, and breast reconstruction represent the most important decisions to be made; This HTA used as the basis for developing a PDA software program.
Kelly 2016 (45)	Scotland/National	To explore what patients want from antimicrobial wound dressings and their experiences of them.	<i>Information resources:</i> focus group and telephone interviews	Collaborate/Provide data	Patients (14)	Increased awareness of the impact of living with a chronic wound. Topics included dealing with the inconvenience and physical aspects (such as pain and limited mobility), and struggling emotionally.



Kleme 2014 (46)	Finland/National	To describe the development of the recommendation for integrating the patient perspective into the HTA process of pharmaceuticals in Finland.	<i>Information resources:</i> draft of recommendations, letter, diabetes-specific forum on the internet <i>Human resources:</i> patient organizations, diabetes specialist nurses, researchers <i>Time resources:</i> drafting of the recommendations, pilot testing of recommendations, public consultation <i>Material resources:</i> premises most suitable and convenient for the participants	Consultation/ Comment	Patients (12); Member of the public (1)	Involvement of patients at many stages of the HTA process preconized; Qualitative interviews seen as the main focus to gain information on patient preferences and values.
Lopes 2016 (47)	Australia/National	To (i) understand the perspectives of selected stakeholders with regard to involvement processes used by Australian Advisory Committees to engage the public and patients; (ii) identify barriers and facilitators to participation.	<i>Human resources:</i> participants with different roles in the processes <i>Material resources:</i> organizations with different characteristics mobilized for recruitment, telephone and/or e-mail for patient recruitment and interview	Consultation/ Comment Participation/ Collaborate	Patients (9); Members of the public (4)	Difference of opinions about the relevance of the information provided by patient organizations across Advisory Committee members; The small number of consumer representatives on the Advisory Committee board was seen as problematic.
Lo Scalzo 2018 (48)	Italy/National	To present a description of the technology and its regulatory status as well as a comparative analysis of its diffusion in the Italian Regions, by including actions and reactions of patients.	<i>Information resources:</i> online survey, public call	Participation/ Collaborate	Patients (3)	Identification of the pros and the cons of the technology and its comparators.
Moreira 2015 (49)	United Kingdom/ National	To propose a conceptually robust typological model of the knowledge and expertise held by patient organizations.	<i>Material resources:</i> volunteer membership; public helpline, campaign, and lobbying actions <i>Human resources:</i> staff in the provision of care services <i>Financial resources:</i> grant from the Department of Health and Social Services	Consultation/Provide data	Patients (8)	Three phases shaped the dynamic relationship between the forms of knowledge assembled and deployed by the Alzheimer' Society (AS). In the third phase (2005–12), the AS deepened and expanded its network of associations to secure its role in the production of evidence to inform health policy making.
Poder 2018 (50)	Canada/Local	To assess the validity of the content of the tablemat sticker as an information tool for hospitalized patients.	<i>Information resources:</i> scoping review about the use of patient communication tools, interviews, focus groups, questionnaire <i>Material resources:</i> tablemat sticker printed on self-adhesive laminated paper <i>Human resources:</i> Contribution from the communication department, staff of the HTA unit, external interviewer	Consultation/ Comment, Provide data	Patients (99); Other stakeholders (4)	Patients showed a good understanding of the message and objective of the tablemat sticker despite some difficulty with the pictograms. This study by the HTA unit allowed informing decision regarding the design of the communication tool and its implementation.

(Continued)

Table 1. (Continued.)

Study reference	Country/setting	Study objective	Resources for PPI	Type of PPI/activities	Target group/type of patient or public (number)	Short-/long-term results
Poder 2019 (51)	Canada/Local	To describe the process of identification, refinement, and selection of attributes and levels for a discrete choice experiment (DCE) in the context of a hospital-based HTA unit project on low back pain (LBP) treatments.	<i>Information resources:</i> synthesis factsheet on the aim of the study and the necessity for conducting the DCE, focus group, one-on-one interactions and discussions, preference exercises completed at home <i>Human resources:</i> An HTA consultative committee was set up <i>Time resources:</i> Focus group and discussions lasted 2 hours each	Consultation/ Comment, Provide data	Patients (8); Other stakeholders (12)	Seven attributes were identified: treatment modality, pain reduction, onset of treatment efficacy, duration of efficacy, difficulty in daily living activities, sleep problem, and knowledge about their body and pain. Patient participation allowed to select the most important attributes and to revise the questionnaire for the DCE.
Pomey 2019 (23)	Canada/Regional	To describe the process of co-construction of recommendations and to propose methods of building best practices for patient involvement in HTA.	<i>Information resources:</i> summary of the patient literature and a list of questions sent to expert patient committee before meetings, questionnaires, feedback forms, logbook of observations, interviews, 2-round modified Delphi <i>Human resources:</i> patients recruited by a duo made up of a patient recruiter and researcher, two researchers conducted the interviews <i>Financial resources:</i> financial compensation for patients	Consultation/ Comment, Provide data Participation/Member of expert committee, Review recommendations	Patients (12); Healthcare professionals (2); HTA agency staff (9)	The concerns raised by the patients were incorporated into seven of the relevant recommendations. Patient involvement allowed other experts to be comfortable with recommendations related to the patient experience. Healthcare professionals appreciated the transparency of the process and reduced their uncertainty about having patients as partners in HTA.
Ryan et al. 2017 (52)	Ireland/National	To illustrate the contribution of stakeholder engagement to the impact of HTA using an Irish HTA of a national public access defibrillation (PAD) program.	<i>Human resources:</i> individual members of the Expert Advisory Group provided access to data and expert opinion to guide interpretation of data and assumptions in the economic model	Information/Receive or seek information Consultation/ Comment, Provide data Participation/ Collaborate	Twenty individuals and organizations provided comments (n/a)	A decision was made not to progress with the Bill. Decision makers highlighted the importance of the HTA in informing the decision. This HTA was specifically requested by the decision maker to inform an imminent decision on a proposed legislation, thereby increasing the likelihood that its findings would be considered in the policy-making process.
Simpson 2018 (53)	United Kingdom/ National	To report on the experiences, benefits, and challenges of patient and public involvement and engagement from a publicly funded early awareness and alert (EAA) system in the United Kingdom.	<i>Information resources:</i> non-confidential versions of all output documents were disseminated on the Web site	Information/Receive or seek information Consultation/Provide data, Comment Participation/ Collaborate	Patients (14); Others (n/a)	Assistance in the Prioritization of a Medical Device. Patient input was sought on the potential for impact of a wearable technology designed to reduce acid reflux into the throat and lungs and the associated symptoms of laryngopharyngeal reflux disease.

Street 2015 (60)	Australia/Local	To describe the use of a deliberative forum to explore community perspectives on a complex health problem—disinvestment. The forum was informed by a systematic review of B12/folate pathology test effectiveness and expert testimony	<i>Information resources:</i> draft of the recommendations; letter; diabetes-specific forum in the internet <i>Human resources:</i> medical practitioner, epidemiologist, health economist, pathologist; a facilitator; a court reporter <i>Time resources:</i> the forum was held over a week end	Information/Receive or seek information Consultation/ Comment	Members of the public (11 first day and 10 second day)	Agreement among participants that the cost of the test was a central point to consider for potential disinvestment; Participants questioned the “authority” of policy makers to make decisions regarding disinvestment; No consideration of equity issues by citizens and experts neglected the “cost” of social and emotional impact of disinvestment on users and the society.
Tantchou Dipankui 2014 (55) + Tantchou Dipankui 2015 (24)	Canada/Regional	To explore the perceptions of members of a working group of care providers, HTA producers, healthcare facilities managers, and patient representatives regarding the participation of the latter in the assessment of alternatives to restraint and seclusion among adults in short-term psychiatric wards and in long-term care facilities for the elderly.	<i>Information resources:</i> agenda of the day and PowerPoint presentation, training of patient representatives <i>Human resources:</i> reference person	Information/Receive or seek information; Consultation/ Comment Participation/ Collaborate	Members of the public (10); Patients (4)	Patient representative involvement allowed refocus of discussions on patient issues rather than economic, administrative, or management issues; Examples brought by patient representatives allowed nuances and improvement of comprehension of observations and research evidence.
Whitty 2014 (55)	Australia/Regional	To assess public preferences for funding new health technologies and to compare a profile case best-worst scaling (BWS) and a traditional discrete choice experiment (DCE) method.	<i>Information resources:</i> DCE and BWS tasks; attributes for the profiles for DCE and BWS; large online panel <i>Human resources:</i> a third-party provider <i>Material resources:</i> cards—for card sorting, web-based administration	Consultation/Provide data	Members of the public (949)	Exhibition of stronger preferences for technologies offering prevention over other benefit types (e.g., improving survival or quality of life), from both the BWS and DCE; Prioritization of technologies that: (i) benefit younger people, larger numbers of people, those in rural areas, or indigenous Australians; (ii) provide value for money; (iii) have no available alternative; or (iv) upgrade an existing technology.
Wortley 2016 (56) + Wortley 2016 (61)	Australia/Local	To describe community views and perspectives on public engagement processes in Australian health technology assessment (HTA) decision making.	<i>Information resources:</i> brief introduction to HTA and current public engagement approaches in HTA <i>Human resources:</i> a facilitator; a market research company; an observer <i>Financial resources:</i> financial compensation	Consultation/Provide data	Members of the public (58)	People would only be aware of the process if it was going to impact them directly and/or they had a financial interest; Public input at an early stage helped shape the assessment and inform (influence) what was important to those affected by the decision-making process.

**Table 2.** Examples of short-term results, barriers and facilitators related to PPI in HTA

Short-term results	Facilitators	Barriers
<p><i>Patient and public input in recommendations</i></p> <ul style="list-style-type: none"> <li>• Direct uptake of patient input in some HTA recommendations (1)</li> <li>• Identification of a set of core values to consider in the evaluation of health technologies and ensuing recommendations (32)</li> <li>• Identification of the impact on patients, their everyday life, social and family relations, and of the information needs associated with the use of the technology (40)</li> <li>• Identification of patient and family member experience with remote monitoring for implemented cardiac devices (43)</li> <li>• Identification of patients' reactions (48)</li> <li>• Patient input was incorporated into seven of the eleven recommendations (23)</li> </ul>	<p><i>Organizational context</i></p> <ul style="list-style-type: none"> <li>• Having a support person for patient participants (50)</li> <li>• Providing documents and training for patients in advance (23;36;38)</li> <li>• Having support from patient groups and peer-support (35;39;50;56)</li> <li>• Discussing questions in advance to clarify their meaning (57)</li> <li>• Providing adequate materials (32)</li> <li>• Involving patients in organizing the consultation (39)</li> <li>• Having a patient as facilitator (39)</li> <li>• Using various sources for recruitment (user committees, service delivery points, managers, healthcare providers, patient associations) (1;10;35;37–39;44;46)</li> <li>• Recruiting through an online panel (55;56;60)</li> <li>• Recruiting at least two patients (39)</li> <li>• Favoring small working groups (39)</li> <li>• Valuing the patients' perspectives and their participation (38;51)</li> <li>• Looking for a diversity of views (38)</li> <li>• Defining patients' role and what is expected from them (38)</li> <li>• Selecting patients based on well-established criteria (38;39;52;57)</li> <li>• Organizational culture demonstrating openness toward patients' perspectives (39)</li> <li>• Financial compensation (56)</li> <li>• Facilitating role played by researchers (41)</li> <li>• Previous collaboration (53)</li> </ul>	<p><i>Organizational context</i></p> <ul style="list-style-type: none"> <li>• Patients and citizen may feel ill equipped with the task (32;38)</li> <li>• Insufficient training and resources for patients to prepare submissions (33)</li> <li>• Small number of patients on the committee limits their influence (38;47)</li> <li>• Time and effort needed (unworkable deadlines) (1;41;47)</li> <li>• Difficult to find and recruit the right patients (38;46)</li> <li>• Lack of interest in involving family in assessment of certain topics (39)</li> <li>• Lack of knowledge of the patients' reality (39)</li> <li>• Time constraints, complexity, and heaviness of the consultation approach in the HTA context (38;39)</li> <li>• Lack of financial and human resources in HTA units with limited budget (38)</li> <li>• Limited time and resources for patient recruitment (44)</li> <li>• Challenges regarding the quality of patient submissions (33)</li> <li>• Lack of previous experience of patient involvement (23)</li> </ul>
<p><i>Influence on the development of a framework for PPI</i></p> <ul style="list-style-type: none"> <li>• Patient input informed the development of a framework for PPI in HTA (12;23)</li> <li>• Inclusion of patients' interests in the three major dimensions of the framework (10)</li> </ul>	<p><i>Decision-making context</i></p> <ul style="list-style-type: none"> <li>• Information in an accessible language (54)</li> <li>• Receptivity of other stakeholders (54)</li> <li>• Focus on specific questions for consultation (38)</li> <li>• Facilitation of the meetings by an independent facilitator trained in public participation (37;38;50;59)</li> <li>• Ensuring that all participants express themselves (38)</li> <li>• Provide lay language summaries of scientific results and avoid or explain abbreviations and jargon (38;57)</li> <li>• Providing feedback about their participation (38)</li> </ul>	<p><i>Decision-making context</i></p> <ul style="list-style-type: none"> <li>• Online consultation not appropriate for all patients (47)</li> <li>• Patients not involved in defining the issues of interest and objectives (39;52)</li> <li>• Uneven understanding of patients' role (52)</li> <li>• Risk of symbolic participation (54)</li> <li>• Fear of slowing down the HTA process (38)</li> <li>• Fear of diverting the focus of the evaluation toward less essential aspects (38)</li> <li>• HTA producers felt unprepared, lack of instruments or tools (38)</li> <li>• Unsuitable health condition of the targeted patients (39)</li> <li>• Sensitive or difficult topic for patients (39)</li> <li>• Different levels of productivity and motivation (39)</li> <li>• Perceptions that patients lack knowledge and overall perspective in making decisions (39)</li> <li>• Patients intimidated by HTA experts and healthcare professionals (38;41)</li> <li>• Lack of familiarity with the scientific language and lack of knowledge in HTA (38)</li> </ul>
<p><i>Awareness raising</i></p> <ul style="list-style-type: none"> <li>• Dialog summary provided new information and critical input (12)</li> <li>• Awareness raised about social values and ethics in HTA (1)</li> <li>• Definition of six types of information required for enabling informed choice (32)</li> </ul>	<p><i>Political context</i></p> <ul style="list-style-type: none"> <li>• Better information from government institutions to patients and public about HTA (38;47;56)</li> <li>• Funding granted to support patient and public involvement (53)</li> <li>• Presence of strong user committees in hospitals (39)</li> </ul>	<p><i>Political context</i></p> <ul style="list-style-type: none"> <li>• Top-down system and biomedical world not used to taking the user's perspective into account (39)</li> <li>• Hospital managers and HTA producers feel unprepared for the integration of patient viewpoint (38)</li> </ul>

<ul style="list-style-type: none"> <li>• PPI allowed considering social values and getting patient input on unmet needs (33)</li> <li>• Rating of some of the included end points of antidepressant treatment differently (35)</li> <li>• Direct patient participation allowed to involve them in the decision-making process (39)</li> <li>• Agreement from both breast cancer patients and healthcare professionals about the most important decisions to be made (44)</li> <li>• Qualitative interviews seen as the best way to gain information on patient preferences and values (46)</li> <li>• Patient participation allowed to select the most important attributes and to revise the questionnaire (50)</li> <li>• No consideration of equity issues by citizens and experts neglected the “cost” of social and emotional impact of disinvestment (60)</li> <li>• Preference of respondents toward improved public access to decision-making information (57)</li> <li>• Identification of the patients’ perspectives about key issues and topics of importance for palliative care (31)</li> <li>• Evaluation of ethical, organizational, patient, social, and legal aspects of the wearable cardioverter defibrillator use (36)</li> <li>• Identification of patients’ understanding of the technology, their experiences, perceptions, and expectations (45)</li> </ul>	<ul style="list-style-type: none"> <li>• Increased recognition of the importance of patient involvement in decisions regarding care and services (39)</li> </ul>	<ul style="list-style-type: none"> <li>• Patients have suspicions about the technology under evaluation becoming unavailable (45)</li> </ul>
<p><i>Relevance of PPI</i></p> <ul style="list-style-type: none"> <li>• Difference of opinions about the relevance of the information provided by the small number of patients in the advisory committee (47)</li> <li>• Patient involvement allowed refocus of discussions on patient issues rather than economic, administrative, or management issues (54)</li> <li>• Better fit with patient preferences by considering their voice. Providing experiential knowledge promotes a sense of empowerment and contributes to more efficient distribution of scarce health resources (24)</li> </ul>	<p><i>Community context</i></p> <ul style="list-style-type: none"> <li>• Collaboration with patient groups in the recruitment (46)</li> <li>• Presence of community groups in the field of assessment (39)</li> <li>• Promotion of the consultation on social media (52)</li> <li>• Media campaign to raise awareness of the findings and public consultation (52)</li> </ul>	<p><i>Community context</i></p> <ul style="list-style-type: none"> <li>• Bias and industry lobbies associated with some patient groups (33;38)</li> <li>• Use of working groups as a lobbying platform for activist organizations (39)</li> <li>• Complexity of the exercise in multicultural contexts (38)</li> </ul>
<p><i>Perceptions of other stakeholders</i></p> <ul style="list-style-type: none"> <li>• Enabled decision makers to consider specific implications of the introduction of the technology (37)</li> <li>• Agreement of all stakeholders on the need to select patients based on specific criteria (38)</li> <li>• Good reception of patient participation (59)</li> <li>• Experts were more comfortable with recommendations related to patient experience (23)</li> </ul>		
<p><i>Topic prioritization</i></p> <ul style="list-style-type: none"> <li>• Influence of patients in the selection of priority HTA topics (59)</li> <li>• Suggestion from some patients to integrate consultation into a more holistic and participatory perspective (39)</li> <li>• Exhibition of stronger preferences for technologies offering prevention over other benefits (e.g., improving survival or quality of life) (55)</li> <li>• Public input at an early stage helped shape the assessment and informed what was important to those affected by the decision-making process (56)</li> <li>• Information and guide of the HTA process (52)</li> </ul>		

(Continued)

**Table 2.** (Continued.)

Short-term results	Facilitators	Barriers
<p><i>Development of patient material</i></p> <ul style="list-style-type: none"> <li>• HTA used as the basis for developing a Patient Decision Aid software program (44)</li> <li>• Development and validation of a tablemat sticker as an information tool for hospitalized patients (50)</li> </ul>		
<p><i>Identification of collaborations</i></p> <ul style="list-style-type: none"> <li>• Identification of the areas of work where horizon scanning could build and strengthen mutually beneficial relationships with patients and the public (54)</li> </ul>		

The majority of studies found in this update are from Canada, Australia, and Italy. In the previous review, the UK and the U.S. were the most represented countries (7). Additionally, this review found an example of PPI in HTA from an emerging country (South Korea) (57).

Consistent with the previous review, the two main forms of PPI in HTA are when patients and the public are consulted to collect their perspectives to inform HTA or when they directly participate in the HTA process (7). As we found previously, patients and the public are still mostly consulted than directly involved in the HTA process. As underlined in our previous work, this may be due to a lack of guidance for HTA producers to integrate patients and members of the public into their work processes (38;62). Additionally, the commitment of different stakeholders, among which governments and community organizations, is needed in order to facilitate PPI in HTA. This review highlighted some facilitators and barriers to PPI related to the wider political and community context. For instance, the need to inform the general public about HTA is recognized by several authors as a potential lever to facilitate PPI in HTA (38;47;56). Providing clear guidance and policies to support PPI in HTA, including a recognition of the investments it needs in terms of time, human, and material resources, will also facilitate its integration into practices.

This review is in line with previous studies, suggesting that there is evidence that PPI impacts the HTA process in several ways, but structured methods to perform PPI evaluation are lacking (7). Evaluating the impact of PPI in HTA remains a major methodological challenge because of the various dimensions that should be considered (2;23).

In this review, we applied an evaluation framework (24) in order to map the context of involvement when considering different components that affect PPI in an integrated way. Using this framework made it possible to better organize the types of impacts that could be related to PPI in HTA. Thus, our results support the applicability of this framework to evaluate PPI in HTA. We were rather able to highlight the short-term results of PPI that are described in most of the studies, but also some long-term results such as those reported in the study by Moreira on the history of patient involvement in the Alzheimer Society in the UK, which allowed an assessment of the impact of involvement over time (49). The fact that most studies discussed short-term results of PPI in HTA can be explained by the relative novelty of this practice. With the practice of PPI in HTA becoming mainstream, it will be possible to better measure the medium- and long-term impacts of involvement on several dimensions and, ultimately, to gather stronger evidence on its benefits. To do so, we recommend that HTA bodies that are implementing PPI make sure that they document their process based on an evaluation framework and make their results available to others. The use of the GRIPP checklist (63) should be encouraged for reporting PPI in HTA but also when designing these activities.

The main contribution of this systematic review is twofold. First, this update shows that PPI is growing in the field of HTA and expanding to several countries. However, strong evidence on the impact of PPI, especially on the long term, is lacking. It is important that studies evaluate the impact of PPI in HTA in a robust manner, using appropriate frameworks, and disseminate their findings. Second, this review confirms the applicability of our evaluation framework to map the different components affecting PPI in an integrated way. Using this framework, it was possible to highlight the short-term results of PPI reported in

the included studies, but also to foresee impacts that may happen over a longer period of time, when PPI practice in HTA is more common and institutionalized. We, thus, recommend further validation of the proposed framework by using it to guide the evaluation of PPI in HTA.

### Study Limitations

This updated systematic review has some limitations. First, we made the choice to report only the findings from the most recent studies (published since 2009) in this review. As the field of PPI in HTA evolves rapidly, earlier experiences of PPI could be less informative in the actual context. Second, we did not specifically search for studies published in the grey literature, apart from those referenced in included studies. Thus, it is likely that many PPI experiences reported in HTA reports have not been captured. However, considering the large body of HTA reports published around the world in several languages would be very demanding. Additionally, we did not formally consult international experts in the field, but this was done informally through our contact network and at HTA meetings. Consequently, some valuable international studies may have been overlooked. Third, despite the fact that we assessed study quality based on the MMAT tool (30), it has not been considered when interpreting the results. As the aim of this review was to get a broad overview of PPI in HTA, we decided to keep all studies in the analysis. This limitation opens avenues for further research that could consider the quality of evidence in the interpretation of the results.

Fourth, although we included qualitative, quantitative, and mixed-methods studies, we did not explore the quantitative impact of PPI in this review. The use of experimental designs to assess the effectiveness of PPI is still very limited; thus, it is not possible to provide quantitative estimations such as effect size. Given the limited quantitative data available, a narrative synthesis was deemed more appropriate to answer the review question. However, further research could use relevant metrics to provide quantitative evidence in this field.

Finally, we did not directly seek the input of patients or members of the public in this review. This is an important limitation because we lack their perspective regarding what are the important outcomes of PPI in HTA. Future primary studies and reviews about the impact of PPI in HTA should involve patients and the public in their design to ensure that all important outcomes are captured.

### Conclusions

The number of published studies on PPI in HTA has increased over the last years, but few of these experiences reported their impacts. It is essential to pursue the development of best practices and guidelines for PPI in HTA, to report PPI experiences using the GRIPP checklist, and to ensure rigorous evaluation in order to highlight its impact on the HTA process, recommendations, and outcomes.

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