

Introducing patients' and the public's perspectives to health technology assessment: A systematic review of international experiences

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Objectives: The aim of this study was to review international experiences of patient or public involvement in the field of health technology assessment (HTA).

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Methods: A systematic review of the scientific literature was conducted. A literature search was performed across nine databases. Other literature was identified through citation tracking, government websites (HTA agencies), and Internet search engines. Characteristics of the studies, description of the activities related to patient or public involvement, impact of these activities on the HTA process, and factors facilitating or limiting involvement were abstracted independently by two reviewers.

Results: A total of 1,441 potentially relevant papers were identified by the main search strategy. Among these, seventeen papers met the inclusion criteria; other search strategies identified seven additional documents. The findings reveal that patient or public involvement in HTA activities was reported in two domains, research and HTA process. In the research domain, patients are consulted to gather evidence about their perspectives, experiences, or preferences about a health technology. These perspectives could add key dimensions to the evaluation of health technologies that might otherwise be overlooked. In the domain of the HTA process, patients or public representatives participate in different stages of this process: prioritization, evidence assessment, or dissemination of findings.

Conclusions: There are few published examples of experiences involving patients and the public in HTA. These examples show that patients' or the public's perspectives could add important dimensions to the evaluation of health technologies. However, there is a need to develop more systematic approaches to considering patients' and the public's perspectives in HTA.

Keywords: Health technology assessment, Patients' perspectives, Patients' participation, Public participation, Systematic review

Health technology assessment (HTA) is considered as a multidisciplinary process that "summarizes information about the medical, social, economic and ethical issues related to the use of a health technology in a systematic, transparent, unbiased, robust manner" (15). However, the majority of HTA activities currently perform quantitative assessment of clinical effectiveness and sometimes cost-effectiveness of health technologies, often neglecting social, ethical, and political aspects of these technologies (11;22;24).

Many authors have argued for the importance of considering the patients' perspectives in HTA (3;4;6;16;22;35). Patients may be the direct beneficiaries of health technologies and could provide "experiential" evidence to the HTA process. They have the knowledge of living with a clinical condition and/or using health services and can provide valuable information about specific diseases and the impact of healthcare technologies, such as benefits and unwanted effects (15). Introducing patients' perspectives to HTA could allow a more accurate assessment of the value of health technologies.

There is a general consensus on the need for more patient-centered HTA methods and several HTA agencies and academics associated with HTA are now considering ways to incorporate the patients' or, more generally, the public's perspectives in their methods (1;4). However, questions about the ways in which these perspectives could be translated into evidence used by HTA organizations and how they could be incorporated into the structures and activities of HTA (particularly at the local level) remain unanswered.

Within the context of a larger project involving decision makers in hospital-based HTA units (12), we aimed to re-

view international experiences that introduced patients' or the public's perspectives in HTA.

Conceptual Framework

Several authors have proposed models for involving patients or the public in HTA or in healthcare decision making (1;5;10;34;36;39). The model developed by Gauvin et al. (10), which was based on other frameworks of patient and public involvement (32;36;39), was used in this review for mapping the concepts related to patient and public involvement in HTA. From this conceptual model, three main features arise: the domains of consumer involvement (the policy-making domain, the organizational domain, and the commissioning of research); the type of public (a societal or lay perspective: citizens and representatives of citizens; and the perspectives of those directly affected by a given health condition: patients, caregivers, and representatives); and the level of involvement (information, consultation, and participation). These three levels of involvement are defined as follows: *Information* is related to dissemination and communication of information to the public; *consultation* includes different ways of asking consumers about their values, perspectives, needs, or preferences to feed different phases of the HTA process (consumers are involved as human subjects or informants); and *participation* comprises collaboration of patients or the public in the HTA process, their engagement as partners in the HTA process, and at a higher level, their control over the HTA process.

Other dimensions were also explored: the purpose and context of involvement, the type of health technology evaluated, and the methods used to capture patients' or the public's perspectives. Information about factors that facilitated or

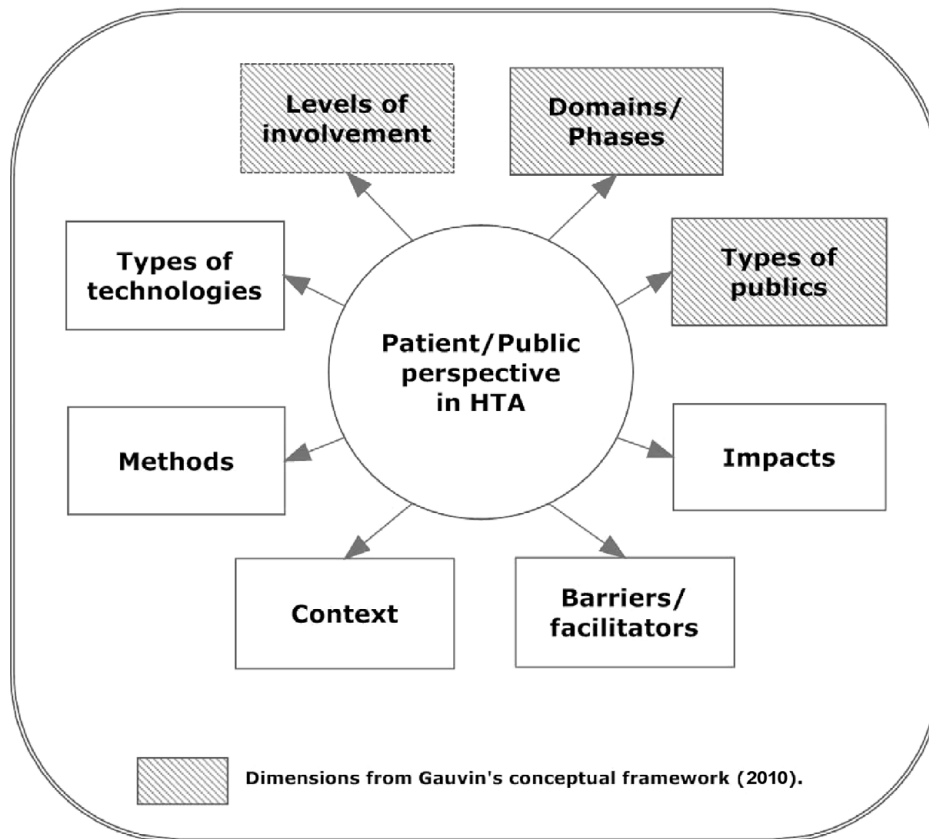


Figure 1. Dimensions of patient and public involvement in health technology assessment (HTA) from the analysis framework.

limited patient or public involvement in HTA, as well as the impact of this involvement on clinical interventions, costs, and perceptions of other stakeholders were also considered. Our analytic framework is presented in Figure 1.

METHODS

Data Sources

An information specialist undertook a literature search in the following databases: PubMed, Embase, CINAHL, PsycINFO, Cochrane Library, Science Citation Abstract, Social Science Citation Abstract, Business Source Premier, ABI/Inform, and Dissertation Abstract. Relevant references from studies selected from the above sources were assessed. Other literature was identified through Internet search engines (Google and Google Scholar). ISI Citation Index was used to track the publications in which the selected articles were cited as well as the papers published by authors of the selected articles. Finally, member agencies of the International Network of Agencies for Health Technology Assessment (INAHTA) and members of the HTAi Interest Group on Patient/Citizen Involvement in HTA were contacted (by e-mail) for potentially eligible published or unpublished studies. The search strategy is avail-

able online as Supplementary Table 1, which is available at www.journals.cambridge.org/thc2011004.

Study Selection Criteria

To be included in this study, experiences of patient and public involvement in HTA were identified based on the following criteria:

Type of publication: Only papers describing empirical research were included. Editorials, commentary pieces, and opinion articles were excluded.

Types of participants: We included patients and caregivers, consumers, members of the public (i.e., citizens) in our literature review to be as inclusive as possible given the lack of terminological consensus about these terms.

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 included only studies that had been explicitly conducted in the field of HTA.

Two reviewers independently screened titles and abstracts for possible inclusion in the review. After a first selection of potentially relevant articles, full copies of these papers were retrieved and screened independently by two reviewers using the set of inclusion criteria. Any discrepancies

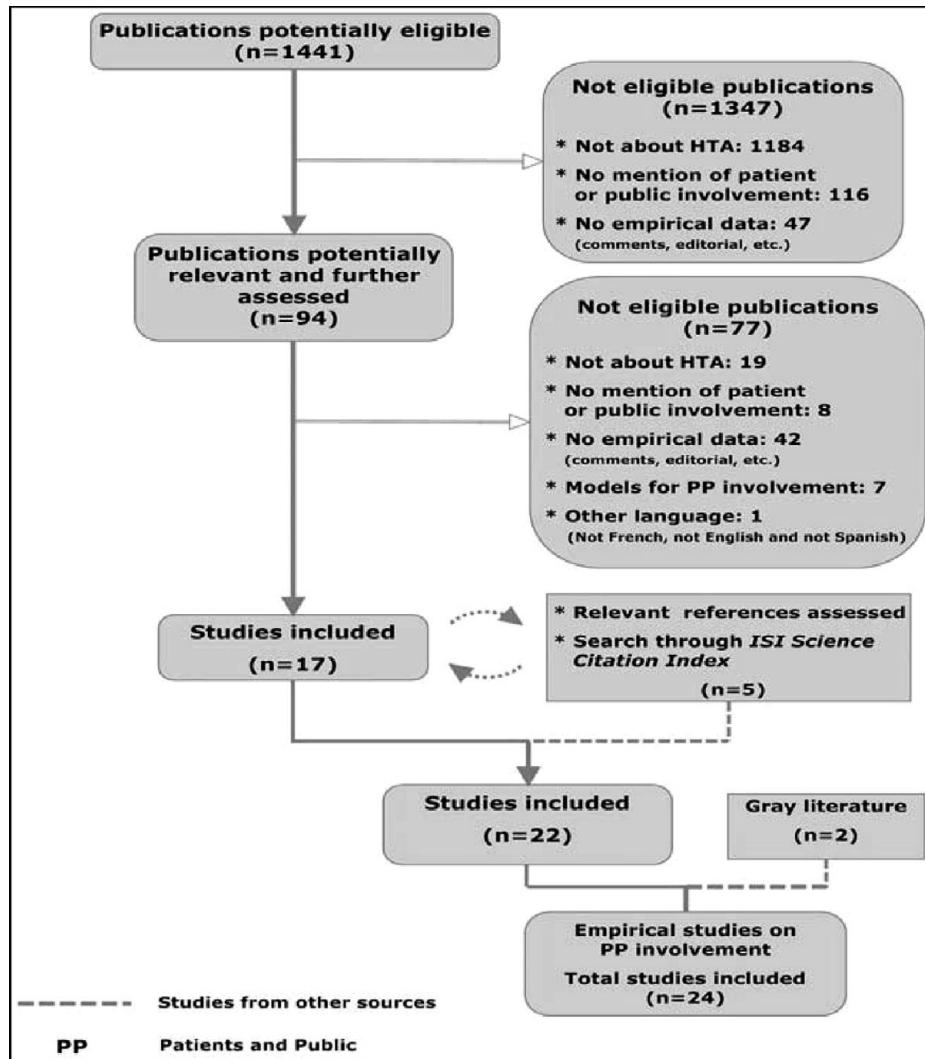


Figure 2. Flow diagram of study selection.

were resolved by discussion including a third reviewer when necessary.

Data Extraction

A specifically designed template was used to extract the information about patient/public involvement. The conceptual model developed by Gauvin et al. (10) (see Figure 1) was used to categorize the type of patient or public involvement in HTA. However, as this review focuses on patients' or the public's input in HTA, we did not include studies in which their participation was limited to the level of information. Two reviewers independently extracted these data, and discrepancies were resolved through discussions.

RESULTS

A total of 1,441 titles were identified by the main search strategy, and of these, 17 studies met the inclusion criteria. Other

search strategies (see Figure 2) allowed seven other studies to be identified. A total of twenty-four studies (2;7;8;11;14;17–21;26–31;33;37;38;40–42;44;45) were thus included in the systematic review. The study selection process is outlined in Figure 2.

Overview of identified studies

Supplementary Table 1 reporting the characteristics of included studies is available online. The majority of included studies are from the United Kingdom (thirteen studies), three studies are from the United States, and three studies from the Netherlands. The following countries were also represented by one study: Canada, Denmark, Germany, New Zealand, and Austria. The majority of the studies were published since 2005 (14/24), and only four studies before 2000. Method research designs were mainly mixed (thirteen

Table 1. Studies Reporting Consultation of Patients and Public in the Research Domain

Study	Setting	Type of technology or issues	Type of patient or public (no. of participants)	Level of involvement	Methods for capturing users' perspectives
Appel 1990 USA	Hospital	Diagnostic	Patients (95)	Consultation/ provide data	Questionnaire assessing willingness to pay
Goven 2008 New-Zealand	Occupational health context	Diagnostic	People from support groups (10)	Consultation/ provide data	Interviews
Happ 1994 USA	Hospitals	Organizational	Patients (90)	Consultation/ provide data	Questionnaires, open-ended interviews
Hutchinson 2003 USA	Hospital	Diagnostic	Patients (47)	Consultation/ provide data	Focus groups
Jolly 2007 UK	Hospitals	Means of dispensing or organizing services	Patients (75)	Consultation/ provide data	Individual interviews and focus group
Kinter 2009 Germany	5 major cities	Therapeutic	Patients: 30 (focus group) + 25 (interviews)	Consultation/ provide data	1) Focus group 2) Interviews including card ranking exercise
Lassen 2006 Denmark	Hospitals	Supportive technology	Patients (75)	Consultation/ provide data	Structured interviews
Mihaylov 2008 UK	General practices	Therapeutic	Patients (24)	Consultation/ provide data	In-depth interviews
Nixon 2006 UK	Hospital-based research centers	Supportive technology	Patients (23)	Consultation/ provide data	Quality of life (QoL) substudy: interviews
Ratcliffe 1999 UK	Hospital	Intervention modes	Patients: interviews (12) / questionnaire (189)	Consultation/ provide data	Conjoint analysis (CA) exercise: interviews and CA questionnaires
Ratcliffe 2002 UK	Hospitals	Intervention modes	Patients (257)	Consultation/ provide data	1) focus groups 2) discrete choice questionnaire
Stolk 2000 Netherlands	University and Institute for HTA	Therapeutic	General public (150)	Consultation/ provide data	Health state valuation: with trade-off method
Street 2008 Australia	NS	Diagnostic	Patients (102 blogs)	Consultation/ provide data	Informal Web pages, personal blogs
Thomas 2006 UK	NHS HTA	Therapeutic	Patients (14)	Consultation/ provide data	Focus groups

studies) and qualitative (nine studies). However, among the mixed methods studies, the methodological approach used for considering patients' or public perspectives was primarily qualitative.

Characteristics of Patient or Public Involvement in HTA

The studies reported two main types of patient or public involvement in HTA activities: consultation and participation. In the first type (see Table 1), patients (rarely representatives of the public) are consulted to gather evidence about their

perspectives, experiences, or preferences about technologies, clinical procedures, or healthcare services. In the second type (see Table 2), public or patient representatives participate in different stages of the HTA process: prioritization, scoping, evidence assessment, and dissemination of HTA findings.

In the latter category, patient or public participation in the HTA process is direct, while in the former it is indirect, that is, patients do not make decisions but are consulted about their perspectives, values, etc., to inform decision making. These two categories are associated with different issues, purposes, and methods of involvement. Key details about patient or

Table 2. Studies Reporting Participation of Patient and Public in the HTA Process

Study	Setting	Type of technology or issues	Type of patient or public (no. of participants)	Domain of involvement/ phases	Level of involvement	Methods or data collection
Davies 2005 UK	National	The Citizens Council of NICE	Citizens (30)	Organizational/Not applicable	Participation/engagement	Observations of the Citizens Council session, interviews, and document analysis
Entwistle 1999 UK	Local (3 projects); national (1)	Diagnostic, therapeutic, medical and surgical procedures, intervention modes	Patients and parents; middle-aged men and partners	Research/ collecting evidence; Organizational/ publishing final reports (develop information materials available to patients)	Consultation/ provide data and comment Participation/collaboration	Focus groups, structured interviews, and questionnaires
Johanson 2002 UK	National	Intervention modes	Citizens (11)	Organizational/ prioritizing requests	Participation/ collaboration	Counting the number of votes and comparison between health professionals and citizens votes
Menon 2008 Canada	Regional	Therapeutic	Citizens (16)	Organizational/ prioritizing requests	Participation/engagement	Analysis of a jury session and questionnaires at the end of the session
Milewa 2008 UK	National	Therapeutic technologies (3); surgical procedure (1)	Citizens and consultees associated with patient advocacy bodies (33)	Organizational/ appraisal process administered by NICE	Participation/ engagement	Case study: interviews and observation of 4 meetings
Moret-Hartman 2007 Netherlands	National	Therapeutic	Patients	Political/ making coverage policies	Participation/ collaboration and engagement	2 workshops and interviews
Oliver 2001 UK	National NCCHTA	Diagnostic (2); Therapeutic (4); Intervention modes (2); Surgical procedures (1)	Consumers (17)	Organizational/ 1) submitting requests; 2) prioritizing topics; 3) commissioning research Research/ 4) synthesizing evidence; 5) writing report Organizational/ 6) publishing final reports	Information Consultation/ provide data; comment Participation/engagement	Interviews, focus groups, observation, document analysis, questionnaire

public involvement in the included studies are presented in Tables 1 and 2.

Oliver 2006 UK	National NCCHTA	Not applicable	Representatives of citizens and of patient groups (not provided)	Organizational/ 1) submitting assessment requests; 2) prioritizing research topics; 3) commissioning research	Consultation/ provide data, comment, appeal Participation/ collaboration, engagement	Action research approach and economic analysis: Semi-structured interviews, document analysis Interviews, questionnaires, and document analysis
Royle 2004 UK	National NCCHTA	Implication in HTA program	Representatives of citizens and of patients groups (86 to 100)	Organizational/ 1) prioritizing requests; 2) commissioning research; Research/ peer reviewers	Participation/engagement	Interviews, questionnaires, and document analysis
Van Kammen 2006 Netherlands	National	Therapeutic technology	Representatives of patient groups (not provided)	Research/ collecting evidence Organizational/ making recommendations	Consultation/ provide data Participation/ engagement	Semi-structured interviews with participants

Consultation of Patients/Public in Research

In the majority of included studies (14/24), the role of patients or the public is essentially to provide data for the domain of research (2;11;14;17;19–21;27;30;37;38;41;42;44). Representatives of patients were consulted on a variety of issues that included diagnostic, therapeutic, organizational and supportive technologies, medical or surgical procedures, or different means of dispensing and organizing a given type of service (see Table 1).

The purpose of these studies is mainly to explore perceptions, experiences, or valuations of alternative technologies or substitute means of dispensing and organizing a type of service (2;17;19;27;30;37;38;41;44). Other objectives of such consultations could be to elicit patients' perceptions, attitudes, and experiences related to a particular technology (11;14;20;21;42).

Qualitative methods are mainly used to consider patients' perspectives in HTA. Interviews with patients (14;19;21;27;30) or with people from support groups (11) were the strategies of choice, followed by focus groups (17;20;44). In one study, personal weblogs were used to gauge community perspectives on a specific health technology (42). Four studies used a questionnaire to measure patients' or the public's preferences (2;37;38;41). However, two of these studies first used interviews with patients to identify attributes (or key factors) to be included in a subsequent quantitative study (37;38). In only one of these studies (41) did participants come from the general population instead of patients or people from support groups. In this study, a sample of the population compared the cost effectiveness of two treatments for treating erectile dysfunction by means of a session on health state valuation using the trade-off method.

The study by Entwistle et al. (8) presents two categories of involvement: representatives of patients were involved to provide input on their information needs, and to improve communication and implementation of findings (8). In this study, focus groups were first organized with patient groups to explore their information needs with the purpose of developing patient leaflets on different topics. Then, other focus groups allowed patient representatives to comment on drafts of the leaflets targeted for patients.

Participation of Patient/Public Representatives in the HTA Process

The HTA process comprises three domains of activities in which patients or the public could be involved: (i) selecting technologies to be assessed (setting priorities for HTA); (ii) assessing the selected technology (research activities); and

(iii) activities focusing on communication and implementation of the findings (dissemination activities).

Two studies targeted public participation in the prioritization of issues (see Table 2). In the first study, UK citizens participated in a national prioritization of issues related to aspects of care during pregnancy and childbirth (18). In the other study, citizens from Alberta (Canada) were invited to participate in a citizens' jury to develop a set of criteria to guide priority setting for HTA (26).

Five studies (7;28;31;33;40) reported and evaluated experiences of direct participation of public representatives (including patients) initiated by organizations such as the National Institute for Health and Clinical Excellence (NICE) and the National Coordinating Centre for HTA (NCCHTA) in the United Kingdom. Two of these studies also described patient or citizen consultation concerning the research domain (33;40). Two studies from the Netherlands reported experiences of invitational meetings or workshops with various participants (including patient representatives) with the goal of developing recommendations for treatment, use, and reimbursement of assisted reproduction (45) or a new drug (29).

Finally, as seen in the previous section, the study by Entwistle et al. (8) described the involvement of patient and public representatives in the dissemination activities of HTA. This experience showed that patient and public representatives could be consulted to comment on draft versions of HTA reports to ensure their clarity.

Impact of Patient or Public Involvement

Inclusion of patients' perspectives in primary studies. A study by Kinter et al. (20) showed that inclusion of patient-relevant endpoints in the evaluation of a treatment for schizophrenia added crucial dimensions not covered by the traditional clinical measures of treatment endpoints. Street et al. (42) explored how community perspectives gathered from published studies, grey literature, and informal Internet Web pages (blogs and discussion forums) could inform HTA producers. They found that blogs provided a richer explanation of the issues, providing insights not available in the published literature. Another study explored the experiences of patients who developed pressure ulcers (30). These experiences were important to consider because the development of a pressure ulcer could prevent patients from making a full recovery and impact their quality of life.

A study by Goven (11) supports the view that technologies cannot be adequately assessed when isolated from the sociopolitical context in which they will be used. In this study, lay experts highlighted significant deficiencies in the way that confidential information is managed in workplace-related genetic testing. Similarly, patients' involvement in Hutchinson's study (17) helped identify important factors that should be considered in implementing prevention programs. In this case, fear and concern about anonymity were

identified by patients as the most common reasons for refusing testing. The study highlighted the misinformation about the testing process and the lack of trust in HIV/AIDS information.

Jolly et al. (19) explored reasons provided by patients for their nonadherence to cardiac rehabilitation programs. This study showed that many patients, who have been identified by healthcare professionals as nonadherers or nonparticipants in their cardiac rehabilitation because of their behavior in the formal program, had constructed their own informal rehabilitation processes. Because patients are often reluctant to discuss their self-care strategies with healthcare professionals, exploring informal health behaviors may be very important.

In another study, Thomas et al. (44) used issues that arose from focus groups with patients and observation of practice to assist in the design of a questionnaire (a postal survey) and in the development of an economic decision model. Patients' participation provided a wider picture of the factors involved in the choice of ward treatments in a primary care setting.

Two studies used quantitative methods (sometimes in combination with qualitative methods) to measure patients' preferences, and reported reasonably consistent responses (2;37). A study by Appel et al. (2) used willingness to pay to measure patients' preferences between two technologies, while a study by Ratcliffe and Buxton (37) used a discrete choice questionnaire to assess the relative value assigned by patients to the process of treatment vis-à-vis health outcomes in the provision of liver transplantation services. Another study by Ratcliffe and Longworth (38) obtained more mixed results about the structural reliability of the discrete choice questionnaire in determining patients' preferences about alternative modes of clinical intervention.

Impact of the Participation of Patient/Public Representatives in HTA Process. An experience reported by Menon and Stafinski (26) showed a successful example of using a citizens' jury to develop criteria guiding priority-setting. Another experience of public involvement in priority-setting has been described in a study by Johanson et al. (18). An overall agreement in terms of priorities between consumer groups and professionals was reported in this study. However, the authors noticed that only a small number of consumers participated in the process, despite a partnership with a consumer organization.

In a study about consumers' involvement in a needs-led program of NCCHTA, Oliver reported that face-to-face discussion with consumer groups was productive in seeking research topics (33). According to this study, consumers were willing and able to play active roles as panel members in refining and prioritizing topics, and in commenting on research plans and reports (33). In a more recent study, Oliver et al. (31) assessed whether public involvement has influenced research commissioned by the National Health Services (NHS) HTA program. Their evaluation showed that public perspectives could be provided by lay people at all

stages of the HTA program, but that this public input and influence was limited by organizational boundaries (of the HTA program and of the voluntary sector) and by procedural boundaries within the HTA program. The study by Davies et al. (7) relating to the Citizens Council of the NICE reported support and enthusiasm from citizens; however, the host organization faced many challenges in successfully establishing the Citizens Council, sustaining it over time, and engaging with the results produced.

Van Kammen (45) reported an experience of an invitational meeting which included representatives of patient groups with the goal of patients' involvement in making recommendations about subfertility care in the Netherlands. Participants at this meeting developed fifteen recommendations and one of them was acted upon immediately. The use of new scientific insight among patient organizations was another observed impact.

A study by Entwistle et al. (8) described local initiatives that include involvement of patient or consumer groups in the development of research-based information material. The purpose of this initiative was to foster a wider use of such material and the inclusion of more locally accurate information. However, an inconvenient aspect of such local initiatives is their potential vulnerability to external pressures that could compromise research evidence and create bias (8).

Barriers and Facilitators to Participation of Patient/Public in HTA

Six studies (8;18;29;31;33;40) reported on barriers and facilitators to direct participation of patients or the public in HTA activities. Among the identified barriers, the recruitment of participants is a sensitive and time-consuming issue. Many reasons were given to explain this finding, most notably the challenge of identifying appropriate consumers (33;40). Collaboration with consumer organizations may also be difficult, because groups who have very strongly held beliefs could be less willing to be constrained by research evidence (8).

Understanding the role they will have to play, along with the issues addressed, is not always easy for lay people. Additional difficulties related to the speed at which discussions take place, unfamiliarity with the HTA process and the use of technical language and acronyms were also reported (33;40). Some tasks may be too technically demanding for consumers (33;40). Participation in evaluation activities requires some specific abilities or skills, such as the ability to work in a multidisciplinary team. The unfamiliarity of lay people with research needs and reciprocally, researchers' unfamiliarity with consumer organizations, and their ways of working is another possible barrier (40). Time and additional resources required for involving representatives of the general public are also reported as barriers by some studies (8;18;33;40).

Among the factors facilitating patients' or the public's participation in HTA, using focused invitations (i.e., inviting people who have experience related to the topic) is reported

as successful (18). Mentoring, training, support, and the presence of an induction day have been reported as supporting patients' or the public's participation (18). A well-defined outcome-focused presentation, and appropriate setting and timing of consultation activities (easy walking distance and convenient day of the week) have also been identified as facilitators (18). Finally, an open working style and innovative culture in HTA organizations are other important factors that could facilitate public involvement (33).

DISCUSSION

Although patients' and the public's perspectives are increasingly valued in healthcare decisions, few HTA organizations seem to have published structured methods for involving patients or the public in the HTA process. However, a majority of the studies included in this review (14/24) have been published since 2005, which may indicate a relatively recent and increasing interest for this topic. This is concordant with the findings of a survey of the International Network of Agencies for HTA that showed that while agencies may want to involve patients in the processes of HTA, such involvement is not yet widespread (13). As Bridges and Jones (4) argued, a patient-centered approach is yet to be widely adopted in HTA.

Our results underline the two substantive roles generally considered for patient and public participation in HTA. The first role consists of eliciting patients' or the public's perspectives to inform HTA, and the second role refers to direct participation of patient or public representatives in the HTA process. Regarding the first role, a literature review by Lehoux and Williams-Jones (23) has distinguished three broad methodological approaches for introducing ethical and social issues into HTA reports: seeking expert advice from bioethicists and social scientists, conducting qualitative and quantitative primary research, and performing secondary research that includes published literature on social and ethical issues (23). This review documents the second approach, and the examples reported here show that patients' perspectives could add important dimensions to the evaluation of technologies and clinical interventions. Including user-defined viewpoints may channel the focus on issues that are important for patients.

Evidence on patients' perspectives can be derived from quantitative and qualitative primary research, but this review found that qualitative methods are most commonly used. This is congruent with some authors' arguments (15;22;24;25) about the necessity of developing qualitative approaches to collect knowledge about the value and impact of a specific technology on patients' lives (24). In order for this information to be considered as valuable for HTA recommendations, there is a need to develop more systematic approaches to generating patients' perspectives and assessing the quality and validity of these methods, as noted by Facey et al. (9).

Limitations of the Study

Given that only studies published in English, French, or Spanish have been included, some valuable international studies in other languages may have been overlooked. Another possible limitation is linked to the criteria used for identifying studies in the field of HTA. As this field is broad and could include different issues depending on the country involved, only studies that referred specifically to HTA have been kept, potentially leading to the exclusion of some valuable studies. In addition, as this review only includes experiences with empirical data, experiences reported in a descriptive manner and literature reviews have been excluded. For instance, no reports from organizations such as the Danish Agency for Health Technology Assessment (DACEHTA) or the Swiss Technology Assessment Agency (TA-SWISS) were selected, although these organizations have experience with public and patient participation. The TA-SWISS for example, has organized several consultative citizen panel mechanisms, called Publiforums, to explore and debate broader social and ethical issues arising from new technologies (43).

CONCLUSION

Although many examples retrieved in this review showed that patients' or the public's perspectives could add important dimensions to the evaluation of health technologies and clinical interventions, the need remains for systematic and rigorous empirical studies of patient and public involvement in HTA. More research is thus needed to explore the necessary conditions to move toward greater patient and public involvement in HTA. Given the focus of our research project on local HTA initiatives, it would be important to explore local HTA stakeholders' perspectives of patient and public involvement and the feasibility of introducing patients' perspectives in HTA at the local level. Furthermore, given the limited evidence regarding the impact of experiences of patient and public involvement in HTA, more rigorous evaluations of these experiences are needed.

POLICY IMPLICATIONS

Considering patients' and the public's perspectives is increasingly essential as healthcare systems move toward more patient-centered approaches. Several HTA agencies now involve patients and the public in their activities, but these experiences are seldom evaluated. HTA agencies that are developing methods to incorporate patients' and the public's perspectives should make them more explicit by publishing them and ensuring that these experiences are evaluated.

SUPPLEMENTARY MATERIAL

Supplementary Table 1
www.journals.cambridge.org/thc2011004

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CONFLICT OF INTEREST

MP Gagnon, F Légaré, D Lepage-Savary, J Gagnon, M St-Pierre, and R Lemieux report that they have received a grant from the Canadian Institutes of Health Research (CIHR) for conducting this study.

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