

# Public Engagement for Health Technology Assessment at Health Quality Ontario—Final Report From the Ontario Health Technology Advisory Committee Public Engagement Subcommittee

OHTAC PUBLIC ENGAGEMENT SUBCOMMITTEE

APRIL 2015

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## About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care in Ontario, evaluating the effectiveness of health care technologies and services, providing evidence-based recommendations, reporting to the public on the quality of the health system, and supporting the spread of quality improvement throughout the system.

Health Quality Ontario’s research is published as part of the *Ontario Health Technology Assessment Series*, which is indexed in MEDLINE/PubMed, Excerpta Medica/Embase, and the Centre for Reviews and Dissemination database. Corresponding Ontario Health Technology Advisory Committee recommendations and other associated reports are also published on the Health Quality Ontario website. Visit <http://www.hqontario.ca> for more information.

## EXECUTIVE SUMMARY

Health Quality Ontario (HQO) and its Ontario Health Technology Advisory Committee (OHTAC) have made a commitment to strengthening their public and patient engagement (PPE) efforts. In 2007, OHTAC established a Public Engagement (PE) Subcommittee to help HQO involve the public in its evidence review process. Since then, HQO has put in place several of these recommendations and experimented with a variety of PPE approaches. In 2012, the OHTAC PE Subcommittee was re-established to advise HQO on how its current approaches to PPE could be strengthened to “foster transparency, awareness, legitimacy, acceptability and trust in OHTAC recommendations.” The main objective of the renewed PE Subcommittee was to “expand on the public engagement framework established by the previous OHTAC Public Engagement Subcommittee in developing a comprehensive public engagement strategy for HQO.”

Several parallel and complementary initiatives informed the PE Subcommittee’s work. Among these initiatives were:

- The development of HQO’s corporate PPE strategy
- The development of a revised Decision Determinants framework for OHTAC
- A Canadian Institutes of Health Research (CIHR) grant-funded research project that was led by Dr. Julia Abelson from McMaster University. This included a stakeholder dialogue organized by the McMaster Health Forum and titled Strengthening Public and Patient Engagement in Health Technology Assessment in Ontario

In addition to these specific activities, the PE Subcommittee invited external groups, such as the Ontario Drug Policy Research Network and the Ontario Citizens’ Council, to present at its meetings. The information learned from these presentations informed discussions by the PE Subcommittee.

This report outlines these initiatives as well as HQO’s previous experience and current practice. It also explores the evidence and international experiences related to PPE in the context of health technology assessment (HTA). Considering these initiatives, experiences, expert opinion, and evidence, the PE Subcommittee made a series of recommendations to OHTAC (listed below), and provided specific advice on how to put them into practice:

- **Recommendation 1**—HQO should increase the transparency of the evidence review process to facilitate a fuller understanding among interested patients, broader publics, and stakeholder groups of how topics are selected and referred to OHTAC
- **Recommendation 2**—HQO, with the assistance of OHTAC, should increase the relevance and responsiveness of its work by undertaking a range of horizon-scanning and consultation activities to prospectively identify potential review topics and emerging issues of concern to patients and priority populations
- **Recommendation 3**—Public and patient engagement should be embedded in the scoping of all review topics. One or both of the following criteria should be used to justify PPE not being triggered:
  - The topic under review concerns technologies with no direct patient interface
  - The focus of the review is exclusively on the technical aspects of the technology
- **Recommendation 4**—On the advice of HQO’s expert panels, HQO should draw on a range of sources for incorporating societal and patient values into the evidence-based analysis stage. This could include input from patient members of expert panels, consultations with individual patients and/or patient groups, and the synthesis of primary qualitative research studies

- **Recommendation 5**—OHTAC should identify dedicated agenda time at its monthly meetings for the explicit consideration of societal and patient values relevant to all evidence reviews that are being presented for OHTAC recommendations
- **Recommendation 6**—HQO, with OHTAC’s assistance, should enhance its public and patient consultation process at the post-appraisal stage to develop increased awareness of its work and to encourage broader input on its draft recommendations

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## LIST OF ABBREVIATIONS

<b>CIHR</b>	Canadian Institutes of Health Research
<b>HQO</b>	Health Quality Ontario
<b>HTA</b>	Health technology assessment
<b>MAS</b>	Medical Advisory Secretariat
<b>NICE</b>	National Institute for Health and Care Excellence
<b>OHTAC</b>	Ontario Health Technology Advisory Committee
<b>PE</b>	Public Engagement (as in PE Subcommittee)
<b>PPE</b>	Public and patient engagement

## BACKGROUND

In 2007, the inaugural Public Engagement (PE) Subcommittee, formed at the recommendation of an international review panel, (1) provided the Ontario Health Technology Advisory Committee (OHTAC) with its first guidance document for engaging the public in its evidence review process. (2) The report included 11 recommendations (Appendix 1).

The implementation of several of these recommendations is evident in the current Health Quality Ontario (HQO) evidence review process, which identifies opportunities for public and patient engagement (PPE). These include, most notably, its 21-day public consultation process on draft OHTAC recommendations, and the establishment of communication mechanisms such as a Get Involved web page on the HQO website and the posting of draft and final recommendations.

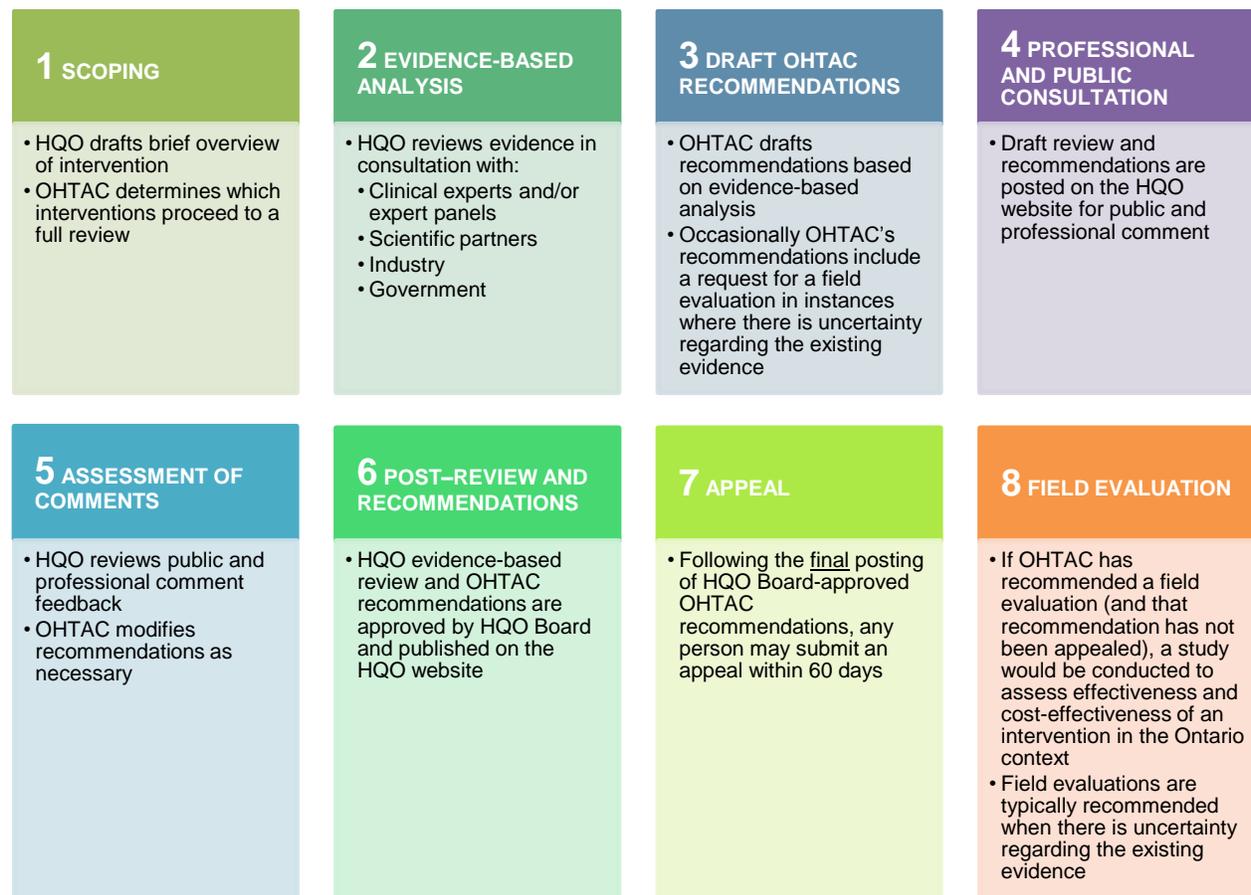
In 2012, OHTAC re-established the PE Subcommittee to “expand on the public engagement framework established by the previous OHTAC Public Engagement Subcommittee” and “to advise HQO on approaches to patient and public engagement in order to foster transparency, awareness, legitimacy, acceptability and trust in OHTAC recommendations” (3) (Appendix 2).

The committee was particularly motivated to address the following question, which is fundamental to any efforts to engage the public and patients in health system decision-making: *when, why, and how might PPE most enrich the HQO-OHTAC health technology review process?*

The re-establishment of the PE Subcommittee was situated in a policy and organizational context related to broader international trends emphasizing more active roles for patients and the broader public in health system design and policy. The *Excellent Care for All Act*, which established HQO in 2010, specifies that HQO should “seek the advice of the public” in making recommendations concerning the provision of funding for health care services and medical devices. (4) More recently, HQO has made efforts toward a PPE strategy for many of HQO’s activities, to ensure that the public, patients, and families “have a strong voice in shaping our health care system and in setting the quality agenda in the province of Ontario.” (5) Care was taken to ensure that the recommendations in this report align with these trends and related HQO activities, in particular HQO’s broader PPE strategy and the work of OHTAC’s Decision Determinants Subcommittee.

## OHTAC'S CURRENT COMMUNICATION AND CONSULTATION PROCESSES

The current HQO-OHTAC process identifies several formal opportunities for PPE (steps 4 to 6 in Figure 1).



**Figure 1: Health Quality Ontario's Evidence Review Process**

Source: Reproduced from Health Quality Ontario. (6)

Once OHTAC has reviewed and approved an evidence review and associated OHTAC recommendations, a 21-day public and professional consultation period is initiated by HQO (step 4). The reports and recommendations, along with a plain language summary, are posted on HQO's website under the Evidence tab and the Get Involved subsection. Along with the posting, the Communications team at HQO sends out a stakeholder advisory, notifying any potentially interested parties that the materials have been posted. This usually includes HQO's strategic partners (e.g., the Ontario Medical Association) and related advocacy groups (e.g., the Ontario Association of Medical Laboratories may receive notice of public commenting for an OHTAC recommendation regarding chronic obstructive pulmonary disease).

Any comments received in the [OHTAC\\_comments@hqontario.ca](mailto:OHTAC_comments@hqontario.ca) inbox are forwarded to the appropriate and responsible individuals for review. These usually include the report authors and the vice-president of Evidence Development and Standards. If necessary, and on rare occasions, the public/professional commenter is invited to provide additional feedback.

Once the 21-day period has concluded, the results of the public and professional consultation are presented to OHTAC for feedback. At this time, OHTAC may request changes to either the

report or the recommendation. After this presentation, the recommendation and any associated reports, with revisions made as appropriate, are posted as final to the HQO website.

### **Experience with Public and Patient Engagement in the HQO-OHTAC Process**

Public and patient engagement in the current HQO-OHTAC process could be strengthened, since most of the emphasis is currently placed on the late stages of the evidence review process. The bulk of comments HQO currently receives originate from stakeholder groups, individual health care providers, and academics (Appendix 3).

Between 2008 and 2010, HQO and OHTAC experimented with several PPE initiatives. These included consultation mechanisms such as focus groups, surveys, polling, (7) and a citizens' reference panel that provided input to OHTAC on a generic set of social values that should guide OHTAC decision-making, as well as input to inform the appraisal of five technologies at various stages of review (i.e., the scoping and draft recommendation stages). (8, 9)

More recently, HQO has drawn on the expertise of McMaster researchers, led by Dr. Mita Giacomini, to undertake several qualitative meta-synthesis research projects. In these projects, patient perspectives, values, and experiences with various health conditions and interventions reported in primary qualitative research studies were synthesized to inform several multi-technology appraisals centred on a specific health state (i.e., "mega-analyses"). (10-14)

Anecdotal evidence from HQO staff and OHTAC members suggests that the input obtained from these innovative activities has influenced OHTAC's work; however, few of these initiatives have been systematically reviewed to assess their value, impact, or prospects for being more formally institutionalized into the HQO-OHTAC process.

## CONCEPTUAL FOUNDATION FOR THE REPORT

This report draws on a number of key concepts from a large and well-established public participation literature and from more recent but growing literature on PPE in health research, health system and policy decision-making, and health technology assessment (HTA). Key terms and concepts discussed below include the *who*, *what*, and *why* of PPE.

### Patients, the Public, and Stakeholders

As HTA organizations around the world seek to incorporate a broader range of perspectives into their evidence review and appraisal processes, clarifying *whose* perspectives will be considered is of central concern. A lack of agreed-upon terminology has plagued the public participation field broadly and the HTA field specifically. Terms such as *the public*, *patients*, and *stakeholders* are often used interchangeably and with little precision. To address these conceptual weaknesses in the literature and practice, we propose the three broad categories of perspectives presented in Figure 2. (15, 16)

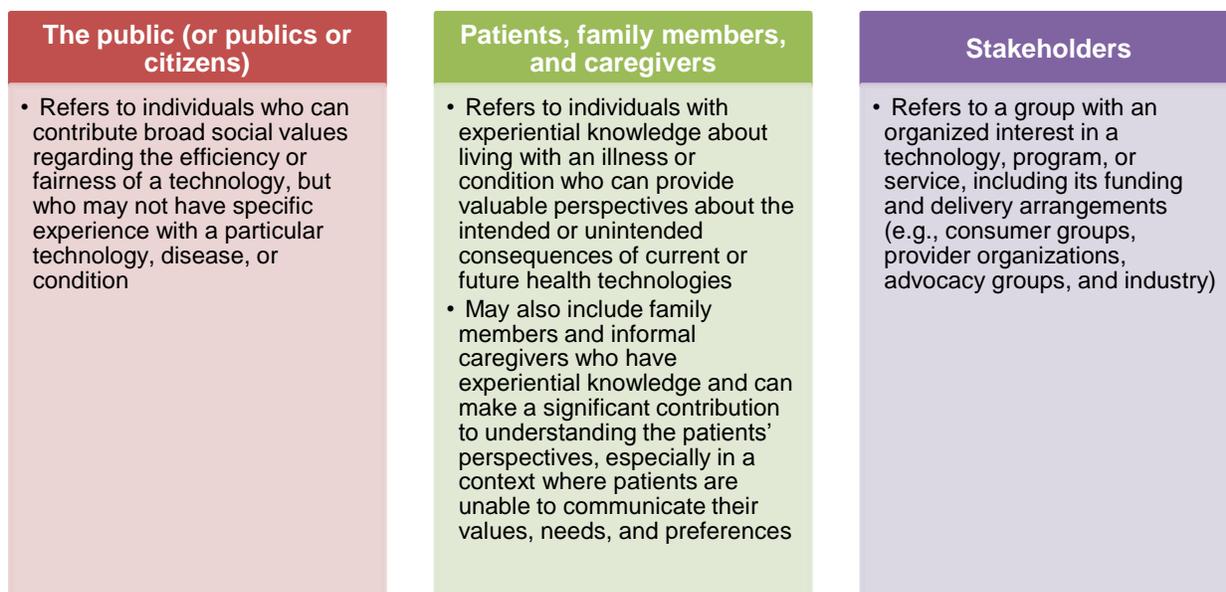
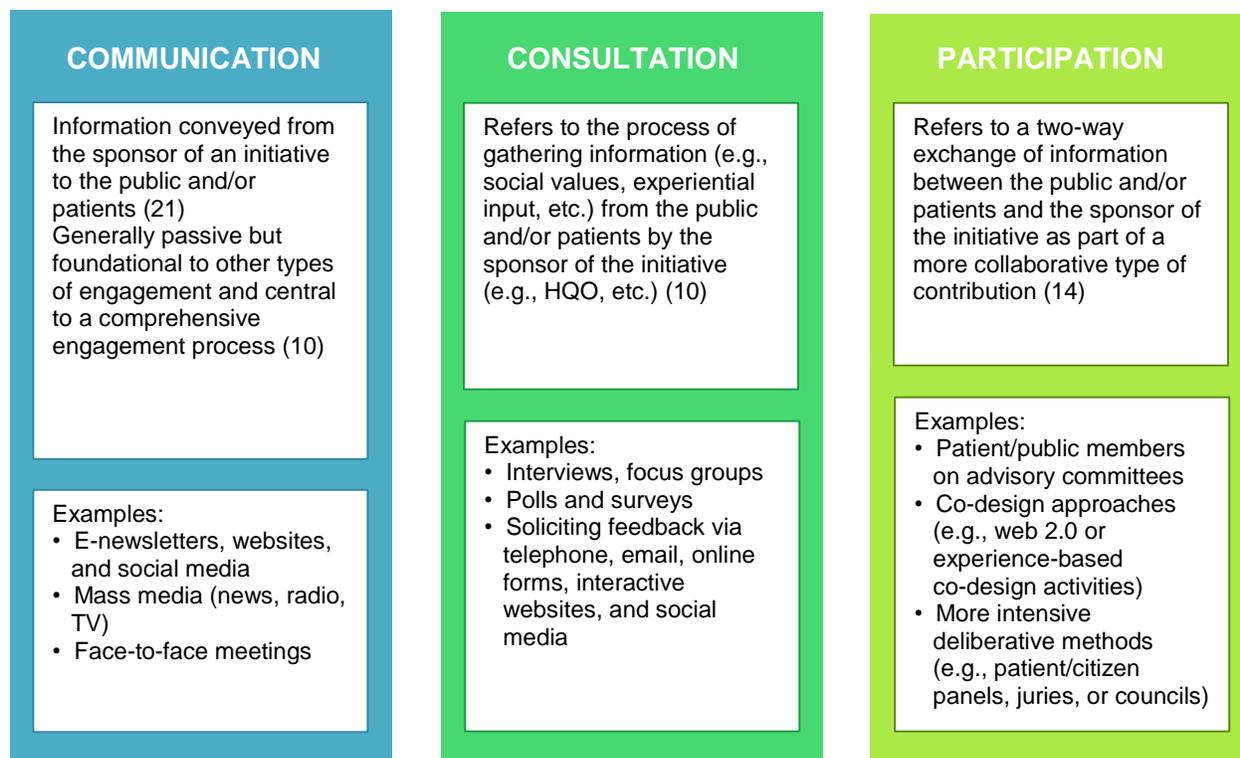


Figure 2: Categories of Public and Patient Perspectives

### Public and Patient Engagement

The concept of *engagement* captures a range of efforts used to involve the public and patients in various domains and stages of HTA decision-making. Many researchers and organizations have developed typologies to illustrate different levels or types of engagement in various areas of decision-making that can serve as a source of inspiration within the HTA community. (17-20) In particular, we have drawn on the conceptual work of Rowe and Frewer, (21) who identified three types of engagement: communication, consultation, and participation (Figure 3 (10, 14, 21)). These three types of engagement involve different flows of information between the sponsor of an engagement activity and the participants. This typology incorporates core elements of many widely used typologies and was chosen for its simplicity and its capacity to encourage a meaningful dialogue among a broad range of stakeholders.



**Figure 3: Typology of Engagement**

Abbreviations: HQO, Health Quality Ontario.

## Goals for Public and Patient Engagement

The case for PPE in HTA is a compelling one. Numerous goals for involving the public and patients at various levels and stages of decision-making have been theorized in the public participation literature. More recently, these have been considered in the context of assessing and appraising health technologies (Table 1). (22)

**Table 1: Theorized Goals of Public and Patient Engagement in Health Technology Assessment**

Democratic	Achieving more informed, transparent, accountable, and legitimate decisions about health technologies
Scientific	Promoting a more robust and comprehensive approach to HTA that incorporates social values and ethics, as well as patients' problems, lived experiences, outcomes, and preferences
Instrumental	Making better-quality decisions across all stages of the HTA process
Developmental	Increasing public understanding of health technologies and HTA, and strengthening the public's and patients' capacity to contribute to health technology policy issues

Abbreviations: HTA, health technology assessment.

From a *democratic* perspective, PPE is central to promoting accountable health systems that are responsive to the values and expectations of patients and the public, including taxpayers, who are the shareholders in publicly financed health systems. (23-25) Indeed, PPE has been a priority for Canadian health system decision-makers for some time. (4, 26) In a context of scarce resources and rapid technological change, policymakers are increasingly faced with complex and contentious decisions regarding coverage. (27, 28) This has caused PPE to emerge as a political imperative for more informed, transparent, accountable, and legitimate decisions about health technologies. (18, 22)

The value of PPE has also gained traction as a way of promoting a *more robust and comprehensive approach to HTA*. Against the political and ethical backdrops of the health technology policy landscape, evidence regarding clinical and cost-effectiveness alone appears inadequate to determine which technologies a publicly funded health plan can justify morally, afford economically, and use to good purpose. In recent years, researchers and HTA agencies have given more serious consideration to incorporating social values and ethics into HTAs (29); to a greater patient focus in HTAs, incorporating patients' values, needs, preferences, and lived experiences (15, 30, 31); and to involving a broader range of stakeholders including patients and service users as well as the broader public in conducting HTAs. (22, 30, 32)

Public and patient engagement in HTA can also be promoted for achieving more *instrumental* goals or, in other words, making better-quality decisions across all the stages of an HTA. (22) Thus, an HTA agency may be looking for the most meaningful ways to gather public and patient input to improve the prioritization of requests, the scoping of the assessment topic, the development of recommendations, or the dissemination of findings. (15, 18)

Lastly, PPE can be promoted for achieving *developmental* goals, such as increasing public understanding of health technologies and HTA, as well as strengthening the public's and patients' competence and capacity to contribute to issues regarding health technology policy. (18, 22)

## Guiding Principles

The PE Subcommittee refined the guiding principles outlined in the 2007 PE Subcommittee Final Report (2) to provide broader, more overarching guidance to HQO as it develops its strategy of determining when and how to engage patients and the public in its processes. These guiding principles are articulated in Table 2.

**Table 2: Guiding Principles**

Purposeful	Engagement activities will be aligned with clearly stated goals and rationales.
Fair and equitable	Engagement activities will be designed in a manner that ensures the inclusion of a broad range of perspectives determined by those most affected or potentially affected by the relevant condition or technology being reviewed.
Transparent	Processes and decisions will be clearly described and communicated to ensure a broad understanding among interested constituencies (e.g., patients, interested members of the public, stakeholder groups) that facilitates their engagement.
Proportional	The degree of public and patient engagement is proportional to the nature and purpose of the technology, size and demographics of the targeted patient population, and disease incidence and prevalence.
Pragmatic	Methods of engagement will, to the extent possible, take into account the level of rigour, time, resources, and effort required.
Evidence-informed	Engagement approaches and methods will be informed by the best available evidence.

## Parallel and Complementary Initiatives

In addition to the guiding principles identified above, the committee's work was informed by several parallel and complementary initiatives. These include the development of HQO's corporate PPE strategy, the development of a revised Decision Determinants framework for OHTAC, and a Canadian Institutes of Health Research (CIHR)-funded research grant led by Dr. Julia Abelson from McMaster University, each of which is briefly discussed below. In addition to these specific activities, the committee deliberations were also informed through invited presentations from the Ontario Drug Policy Research Network and the Ontario Citizens' Council.

## Health Quality Ontario's Corporate Public and Patient Engagement Strategy

In early 2014, HQO began the process of developing a PPE strategy (5) built on the premise that the public, patients, and families need to have a strong voice in shaping the health care system and in setting the quality agenda in the province of Ontario. Literature and jurisdictional reviews as well as interviews with key informants and stakeholders informed the development of the strategy. An advisory committee of patients, caregivers, HQO staff, researchers, and members of the OHTAC PE Subcommittee oversaw the development and refinement of the strategy to ensure that it was informed by the most current best practices, was aligned with complementary activities, and reflected patient and caregiver perspectives. The strategy was presented to the HQO Board at its June 2014 meeting and is composed of overarching principles and an associated framework and objectives for both internal and externally facilitated components of the strategy. In the fall of 2014, HQO hired a Director of Patient, Caregiver and Public Engagement to support patient engagement at HQO throughout our activities, and to help build the capacity within the system for patients and providers to engage with each other.

## Decision Determinants: Social Values and Ethics

The OHTAC Decision Determinants framework is the decision guide used by OHTAC to assess technologies under review. The framework, which is currently being revised by the Decision Determinants Subcommittee, has four key attributes: overall clinical benefit, value for money, consistency with expected societal and ethical values, and feasibility of adoption into the health system. Revisions to these categorizations have been drafted as follows: benefit and harm, economics, and patient-centred care. As one of the attribute-assigned groups within the

Decision Determinants Subcommittee, the Social Values and Ethics working group (working on the new patient-centred care domain) has been engaged in a four-step approach to its task of more fully developing and operationalizing its attribute within the framework:

1. Identify the social values and ethics that should be used to inform questions relevant to all stages of the assessment process, and to weigh and balance the implications of the use or non-use of the technology
2. Pose evaluative questions that can be used to identify ethical issues in all stages of the assessment process, or in the use or non-use of the technology
3. Develop processes that identify opportunities to integrate other perspectives and new information and evidence into the HTA process
4. Identify criteria for determining the scope and depth of an ethics-based assessment

This initiative is closely aligned with the work of the PE Subcommittee, and both incorporate the current stage-specific HQO-OHTAC evidence review process as an organizing framework.

### **Strengthening Governance and Accountability in Ontario’s Health Technology Assessment Process**

The CIHR-funded research study by Dr. Julia Abelson and colleagues explores the challenges of engaging the public and patients in the evidence-based, value-laden arena of HTA. Results are used to inform efforts to support and strengthen the role of PPE in Ontario’s HTA process, with HQO as a knowledge user partner. The project includes several phases of data collection and synthesis drawing on a range of evidentiary sources, including grey and published literature, interviews, and a stakeholder dialogue (see the Evidence Review section for more details regarding study methods and findings).

## EVIDENCE REVIEW

The PE Subcommittee’s work was informed by a number of evidentiary sources. These include published literature, websites, and grey literature documents; key informant interviews and presentations to the committee; and the deliberations from a stakeholder dialogue— Strengthening Public and Patient Engagement in Health Technology Assessment in Ontario— that was convened by the McMaster Health Forum on May 8, 2014. The material reviewed in this section was collected and synthesized by Dr. J. Abelson and her research team through a CIHR-funded health care policy analysis grant, Strengthening Governance and Accountability in Ontario Health Technology Assessment. An evidence brief (16) was also prepared for the stakeholder dialogue convened by the McMaster Health Forum that drew on the evidence synthesized by Dr. Abelson’s research team as well as a broader range of relevant sources from Health Systems Evidence ([www.healthsystemsevidence.org](http://www.healthsystemsevidence.org)), a database of systematic reviews and economic evaluations of delivery, financial, and governance arrangements within health systems.

The review was guided by the following question:

What is the international experience with PPE in HTA processes?

- Why are HTA organizations engaging the public and patients? (goals and rationales)
- How are they doing this? (descriptive evidence)
- What are their results? (evaluative evidence)
- What are the barriers to and facilitators of PPE in HTA processes?

The questions outlined above were addressed by two main sources (Table 3): (a) a website scan of international HTA agencies; and (b) a synthesis of published and grey literature reviews, empirical studies, and conceptual analyses of PPE related to HTA (detailed methods are reported in Appendix 4). The timeframe for the review was 1990 to present. Only English-language literature and English-language and English-accessible websites were reviewed.

A high-level summary of the sources gathered to address our primary review question is provided in the following sections of the report.

**Table 3: Sources of Evidence**

Data Source	Types of Evidence Reviewed	Number of Sources
Websites and organizational documents of international HTA agencies	<ul style="list-style-type: none"> <li>• Organizational mission (e.g., goals and rationales for PPE)</li> <li>• Organizational structures and methods for PPE (which publics? at what stage in HTA process?)</li> <li>• Examples of PPE experiences, projects</li> <li>• Evaluation of PPE activities?</li> </ul>	53 websites (English language or translated) across 34 countries and HTAi website for “good practice” submissions
Published literature—review articles and surveys, empirical studies, and conceptual analyses of PPE related to HTA	<ul style="list-style-type: none"> <li>• Goals or rationales for PPE in HTA (why should we engage?)</li> <li>• How are patients and/or publics contributing to HTA? (descriptive, evaluative)</li> <li>• How could patients and/or publics be contributing? (ideal directions)</li> <li>• What are the barriers, challenges, or facilitators for PPE in HTA?</li> </ul>	4 surveys of international HTA practice 30 empirical articles 12 conceptual articles

Abbreviations: HTA, health technology assessment; HTAi, Health Technology Assessment international; PPE, public and patient engagement.

## High-Level Summary of Website Scan and Literature Synthesis Results

Scan and synthesis results are organized according to the following broad themes:

- The goals or rationales provided for PPE
- The approaches employed to engage the public and patients
- The evidence of effectiveness or the impact of engagement
- Feasibility considerations including barriers to and facilitators of PPE

The general messages extracted from these sources are highlighted in Box 1. In addition, a more detailed set of messages tailored to each of the stages of a typical HTA process (e.g., topic selection, scoping, evidence analysis, and appraisal) is highlighted in Box 2. (A detailed summary of these stage-specific findings is available in Appendix 5 [Tables A4–A8] and in the McMaster Health Forum evidence brief. (16))

### Box 1: Key Messages from Website Scan and Literature Synthesis of PPE in HTA

- Between one third and two thirds of HTA organizations report some level of PPE activity
- The most commonly stated goals for incorporating PPE into HTA processes are to (a) improve the quality and relevance of assessments and the recommendations they inform; (b) incorporate the perspectives of the main beneficiaries of the assessments by complementing the expertise of scientific experts and health care professionals; (c) and improve the legitimacy of the recommendations that arise from HTAs
- There has been a steady increase in the level of reported PPE activity over time, but the scope of this activity is limited
- Common approaches used include communicating and soliciting information (through the Internet), consulting with patient groups (through feedback on draft documents and focus groups), and including the direct participation of patients and public members on advisory and decision-making committees
- There is some reporting of PPE activity related to specific HTA stages, but only a small number of HTA organizations have developed a comprehensive approach to PPE that covers the full scope of their activities
- There has been minimal evaluation of the effectiveness of specific PPE mechanisms or their impacts on HTA decision-making, and the evaluations that do exist are primarily descriptive and drawn from case studies
- The literature highlights numerous cultural, organizational, and patient- and public-recruitment challenges to implementing PPE in HTA organizations, as well as enablers for addressing these challenges that include the commitment of organizational resources

Abbreviations: HTA, health technology assessment; PPE, public and patient engagement.

### Goals and Rationales for Public and Patient Engagement

A review of 53 HTA websites identified only a small number ( $n = 5$ ) of organizations that articulated a clear set of goals or rationales for engaging the public or patients in their activities. (33-37) Three main goals of PPE were cited:

1. As a means for *improving the relevance of assessments* (34-36)
2. To *strengthen the research and complement the expertise* of health care professionals and researchers (33, 34, 36)
3. For more *procedural goals*—to enhance the openness and inclusiveness of the decision process (37)

Findings from the published literature echo and build on these goals and rationales. The broad aim of making the work of HTA agencies relevant to the public was cited as *necessary to gaining public support for funding*. (38, 39) Menon and Stafinski (39) noted that patients should be involved in every step of the HTA process *to ensure that the assessment adopts a broader health condition perspective*, rather than the stricter technology perspective characteristic of

more traditional HTAs. They further argued that traditional types of clinical assessment are no longer sufficient for decision-makers since most new technologies offer only incremental health gains. As such, the insights from patients and the public are increasingly important to inform the decision-making process.

Gagnon et al (40, 41) cite three key rationales for PPE:

1. PPE provides context to the research, which *improves the usefulness of assessments* for decision-makers. In turn, this improves the appropriateness and applicability of the recommendations
2. *Patient engagement might contribute to better acceptability, adoption, and implementation of the recommendations*
3. *PPE focuses on the primary beneficiaries of the decisions*

## **Public and Patient Engagement Approaches**

The website scan found that 13 of the 53 HTA agencies reviewed had documented approaches to PPE. (33, 34, 37, 42-51) This finding is roughly consistent with previous surveys of international practice, which found that one third to two thirds of agencies reported or documented PPE activities. (52, 53) The website scan results suggested that the most commonly used PPE approach (n = 8) was to have patients and/or members of the public directly participate on committees of the agency. (33, 35, 43, 45, 48, 50, 54) This contrasted with the results of a self-reported survey of HTA agencies, which identified a much stronger emphasis on communication and consultation mechanisms. (53) The most commonly used mechanisms reported in the survey included communicating through public meetings, or consulting through the use of documents or focus groups (53); very few responding agencies indicated that they had engaged the public through more participatory approaches. (53, 55) Many of the agencies facilitated communication by preparing plain language versions of their reports to increase accessibility of the assessment. (55) Findings of HTAs are also increasingly disseminated through patient organizations, particularly for controversial technologies. (55)

### *Stage-Specific Approaches to PPE*

Public and patient engagement approaches are employed at a variety of stages in the HTA process. Our website scan revealed that HTA agencies most frequently favoured soliciting input through a “public comment” stage toward the end of the HTA process (n = 54). At the topic selection stage, six agencies invited the general public to submit assessment requests. (34, 42, 43, 45, 48, 50) Only a small number of agencies reported engaging the public and patients to help define the research questions that would guide the HTA process, or in the evidence collection and analysis process (n = 3). This contrasts with our literature review findings that noted a trend among HTA agencies toward increased efforts to involve the public and patients in the early stages of HTA (e.g., topic selection and prioritization, and scoping stages) while also valuing the importance of PPE in the evidence analysis process to capture patient values and experiences. (8, 52, 56) Reviews of draft documents, surveys, and face-to-face discussion are most regularly documented at the appraisal and draft recommendation stage. (53)

## **Evidence of Effectiveness**

We found minimal evaluation of the effectiveness of PPE or the impacts of engagement on the HTA process reported on agency websites. This gap was reinforced in the published literature, where only a few efforts have been made to assess the effectiveness or trace the impacts of PPE on decision-making in the HTA arena. (8, 39, 57, 58) These efforts document potential instrumental benefits (e.g., including patient preferences and patient-relevant outcomes in HTAs) and developmental benefits (e.g., raising public awareness and understanding). (41, 59)

A small number of ethnographic evaluations have sought to document the impacts of a particular type of PPE mechanism—face-to-face citizen deliberations—and how these impacts are facilitated and constrained. (58, 60)

## Feasibility Considerations

Websites of HTA agencies were not a source of information about feasibility considerations related to PPE. However, cultural, organizational, and recruitment challenges were a significant theme in the published literature reviewed. (38, 39, 61) Cultural challenges include tensions between the traditional focus within HTA agencies on clinical and economic evidence, and pressures to incorporate input regarding patient and social values. Public engagement initiatives must combat beliefs that patient views are an anecdotal and biased source of evidence, and perceptions that the public and patients are unable to contribute meaningfully to the process. (38, 39, 61) Some papers also noted perceptions that engaging patients and publics would politicize what should be an evidence-informed process. (39)

The time, resources, and expertise required to support high-quality PPE are key organizational challenges. Organizational commitment is necessary to ensure capacity is built. Recruitment challenges involve struggles to obtain “representative” input and concerns that public and patient involvement will allow narrow interests to trump fairness considerations. Enablers to meaningful PPE include a supportive organizational culture, appropriate supports for patient and public committee members and those interacting with them, dedicated time devoted to patient perspectives on meeting agendas, and strategic use of new and existing networks of patient organizations for external consultations. (15, 39)

### Box 2: Key Messages from Review of Stage-Specific PPE in HTA

- The literature does not explicitly link the goals for PPE to PPE approaches or HTA stages; however, the goals of incorporating patient perspectives and achieving an accountable, legitimate process are regularly cited
- HTA organizations are increasing their efforts to engage the public and patients in the early stages of HTA (e.g., topic selection and prioritization, and scoping stages) and recognizing the importance of PPE in the evidence-analysis process to capture patient values and experiences (recommendations 2, 3, and 4, pp. 32–34)
- HTA organizations have been moving away from using online topic suggestion templates as a source of PPE due to a lack of specificity of input (recommendation 2, p. 32)
- The authors of a comprehensive case study of an organization’s PPE activities found that the clearest evidence of public and patient input into the UK HTA program was in the scoping stage (56)
- Involvement of the public and patients in the appraisal and recommendations stage is done widely, but the literature provides little guidance about which approaches are most effective
- A commonly used approach involves a combination of having public and patient members participate on advisory committees at the scoping and appraisal stages, and support from various consultation mechanisms to obtain condition- and/or technology-specific input from specific groups (recommendations 3, 5, and 6, pp. 33–35)
- A variety of consultation mechanisms are used, but reviews of draft documents, surveys, and face-to-face discussion are most regularly documented at the appraisal and draft recommendation stage (recommendations 5 and 6, pp. 34–35)
- Online and social media approaches are not well documented but are seen as an area for future development (recommendation 6, p. 35)
- There are feasibility considerations at each stage of the HTA process; common challenges cited include how to seek a set of “representative” perspectives from a broad array of patient organizations, charities, and user groups through the consultation process and how to balance broad public interests with the narrower interests of organizational representatives (recommendations 3, 5, and 6, pp. 33–35)

Abbreviations: HTA, health technology assessment; PPE, public and patient engagement.

## Stage: Topic Selection and Prioritization

### Goals for Public and Patient Engagement

The website scan and literature review documented considerable PPE activity in the early stages of the HTA process. Oliver et al (56) contended that PPE at the stage of topic selection and prioritization leads to better oversight and accountability to those affected by HTA decisions and, in the case of public health systems, to taxpayers. In the United Kingdom, engagement at this stage is conceptualized as an ethical obligation, with an emphasis on democratic citizenship and stakeholders as part owners of the system. (59) Actively involving patients and those with relevant conditions in the identification and selection of technologies allows HTA to become more of an “enabler” of effective new technologies than a “gatekeeper.” (39)

### Approaches to Public and Patient Engagement

Approaches to PPE for topic identification span passive solicitation through organization websites (e.g., online submission forms) to proactive engagement with other research organizations, user groups, and charities. (59) Prioritization and selection of identified topics can occur through public consultation (e.g., reviewer comments on pre-circulated briefs), public representation on advisory committees, (59) or collaborative participation through citizens’ juries. (39)

### Evidence of Effectiveness

In one case, staff reported that public suggestions were often disregarded because they were “too vague or described a service provision problem without specifying the research uncertainty that needed to be resolved in order to improve the quality of the service.” (56) Topics were also discarded because they could not be readily translated into the conventional framework of a research question.

There is some evidence of the impact of engaging public members on committees to prioritize topics. Moran and Davidson reported that public members’ feedback resulted in the development of user-friendly documentation and highlighted a need for a clearer discussion of the importance of proposed topics to the UK National Health Service (NHS), rather than just on scientific quality. (59) Engaging other research organizations, user groups, and charities has been relatively successful: 8% to 9% of their suggestions have led to commissioned research, which represents more than twice the success rate from other sources. (56)

### Feasibility Considerations

Oliver et al (56) reported that working with affiliated organizations nurtured and fostered relationships, which led to better suggestions. We found several challenges to engaging publics at the topic selection and prioritization stage:

- The use of HTA websites as a means for suggesting topics requires knowledge of this opportunity, which is unlikely without pre-existing connections (59)
- It can be difficult to identify the appropriate research organizations, user groups, and charities with which to consult
- There can be challenges in translating the problems of people’s daily lives into a clear, researchable question (56)
- Finally, HTA organizations’ internal procedures and protocols can impose constraints, such as limits of public membership on advisory panels

## Stage: Scoping

### Goals for Public and Patient Engagement

Patient input at the scoping stage helps to identify questions to be addressed that differ from those typically formulated by HTA agencies, governments, and payers. (15) Patients' views on what constitutes "value" may not be the same as those of clinicians or those who conduct clinical trials. Thus, a lack of patient input may lead to the identification and selection of outcome measures that do not capture critical aspects of "benefit" to patients (e.g., preferences regarding the management of a condition). (38, 39)

### Approaches to Public and Patient Engagement

We found several examples of PPE at the scoping stage in the literature. In Australia and France, there is patient representation on the committees tasked with defining the scope of an assessment. In the United Kingdom, the National Institute for Health and Care Excellence (NICE) includes formal stakeholder consultation as part of its scoping process. (62) Collaborative participation can also be employed through citizens' reference panels. (8)

### Evidence of Effectiveness

Oliver et al (56) found that consulting the public to shape research questions was more influential to the HTA process than having the public identify possible research topics. In the UK HTA program, the clearest evidence of public input (through consultation) and greatest influence was in the preparation of vignettes. Routine records indicated public involvement in 54 of the 323 vignettes (17%) prepared since 1999. (56)

The public provides unique contributions both as external experts and as panel members. (56) Staff and panel members have acknowledged the value and influence of many of the public contributions. These contributions resulted in some important changes, such as making patient and caregiver perspectives explicit, changing the focus of the research, adding new outcomes, refuting the need for the planned research, providing up-to-date prevalence data, and providing plain language background text. (56) Conversely, Abelson et al (8) have suggested that collaborative participation (through a citizens' reference panel) is less amenable to direct impacts at the scoping stage than at the recommendation stage.

### Feasibility Considerations

The scoping stage presents a similar challenge to that in topic selection and prioritization: how to identify from an array of options the appropriate research organizations, user groups, and charities with which to consult. Balancing broad public interests with the narrower interests of organizational representatives can be difficult. (56)

## Stage: Evidence Development

### Goals for Public and Patient Engagement

Two reasons cited for engaging patients at the evidence-based analysis stage are that patients can (63-65):

1. Provide a unique source of evidence on the personal impact of a disease and how a technology can make a difference, which may help to contextualize clinical and economic evidence
2. Identify shortcomings in the published research

## **Approaches to Public and Patient Engagement**

Health technology assessment agencies in Canada, France, and the United Kingdom allow submissions describing patient experiences from any patient or carer group. In New Zealand, these submissions are solicited by request only. In Australia, a patient representative is included on the advisory panel overseeing the assessment. In Scotland, there is a dedicated patient and public subcommittee that includes three members of the general public. (39)

### **Evidence of Effectiveness**

Menon and Stafinski (39) describe an example where patient views from website blogs were compared with those identified through peer-reviewed literature to inform the assessment of a diagnostic test for the detection of diabetic retinopathy. The blogs contained information not presented in the published literature, suggesting that social media may prove to be an important tool for efficiently capturing the views of patients.

### **Feasibility Considerations**

Incorporating public perspectives in the evidence stage often involves qualitative synthesis. These syntheses can be difficult to conduct within the limited time and resource constraints faced by most HTA agencies. (39) Several sources highlighted the importance of drawing on social science and qualitative expertise in the gathering of robust evidence about patients' perspectives, and its presentation and interpretation in the HTA through either in-house capacity or collaborations with relevant researchers. (15)

## **Stage: Recommendation Development and Public/Professional Consultation**

### **Goals for Public and Patient Engagement**

Consulting the public on draft recommendations ensures accountability to health system users as taxpayers and consumers. (66) It can also inform key HTA decisions. (53)

## **Approaches to Public and Patient Engagement**

Health technology assessment organizations in Australia, France, and Germany include patients on committees that draft and finalize recommendations. These representatives are generally recruited through patient/carers organizations. Another approach used is to consult directly with relevant patient/carers organizations during the drafting process or after the recommendation has been drafted, either by invitation (Australia, the Netherlands) or at the request of the patient organization (United Kingdom). In Ontario, citizens have been consulted on draft recommendations through a collaborative citizens' reference panel. A more passive approach used by a number of organizations (HTA agencies in Ontario, Oregon, and Washington) involves posting draft guidance online for a specific consultation period.

### **Evidence of Effectiveness**

We found evidence that consulting with patients and users brings new ideas about how to formulate recommendations in a way that reflects the users' perspectives. (41) In the case of the Ontario citizens' reference panel, there were traceable changes at the draft recommendations stage that were attributable to the PPE. (8)

The integration of public comments in the final recommendations is one measure of the impact of consultation on the draft. In an international survey of PPE in HTA organizations, the majority of respondents (18 [69%]) indicated that their organization integrated the findings of PPE activities with other forms of evidence (e.g., scientific evidence) to inform health technology

decisions or recommendations. Five (19%) indicated that their organization did not integrate the findings, and three (12%) indicated that they did not know whether this was the case. (53)

## **Feasibility Considerations**

Collaborative participation methods require periodic exchanges between the public and the HTA agency to clarify roles, foster accountability, and build trust. (8)

## **Stage: Post-Review and Recommendations**

### **Goals for Public and Patient Engagement**

Engaging publics post-review and recommendations can increase knowledge and capacity through well-designed dissemination strategies. (56) Increased communication between researchers and journalists might also generate long-term “knowledge benefits” for the public. (67)

### **Approaches to Public and Patient Engagement**

Health technology assessment agencies use both active and passive approaches to disseminate information to relevant groups (e.g., sending plain language HTA reports by mail, posting information on agency websites, and presenting at public board meetings). (18) The National Institute for Health and Care Excellence ensures that full guidance is published in two forms: one for the public, and one for health care professionals. (62) Furthermore, members of the public can appeal for a review or a reversal of recommendations, and agencies are required to respond to those appeals. (18) In Germany, the HTA agency reports its binding decision in a public session. If the patient representatives’ position differs from the board’s decision, this is noted in the final documentation, and patient representatives may take part in the press conference and explain their position. (62)

### **Evidence of Effectiveness**

The content of press articles was compared with the content of three HTA reports on the same technologies in Quebec. Results revealed good alignment of content between the two sources, with some differences in emphasis and a loss of nuance in the media coverage. (67)

### **Feasibility Considerations**

Mechanisms must be in place to address appeals to the recommendations, if these are solicited. An HTA agency’s governance structure can affect the mechanisms available. (18)

## FRAMEWORK FOR PUBLIC AND PATIENT ENGAGEMENT FOR THE HQO-OHTAC PROCESS

In the following sections, we propose a comprehensive and flexible framework for engaging the public and patients in the HQO-OHTAC process. The framework builds on the recommendations of the inaugural PE Subcommittee and is further informed by a synthesis of international practice and published research evidence, as well as the outputs of a stakeholder dialogue convened by the McMaster Health Forum in May 2014. (16, 68) The key elements of the framework, described in detail in the sections below, are as follows:

- Articulate the underlying principles, values, and goals for PPE in HTA
- Establish a common language to support PPE efforts
- Describe a flexible array of approaches that can be used depending on the goal and phase of the evidence review process
- Develop methods for evaluating PPE that can inform adjustments over time

The framework described in the sections below is accompanied by a set of recommendations that appear in the next section of this report.

### Principles, Values, and Goals for Public and Patient Engagement in HTA

As outlined on pp. 15 and 16, we have articulated the following set of guiding values and principles that we encourage HQO and OHTAC to embrace as they improve the HQO-OHTAC evidence review process: *purposeful, fair and equitable, transparent, proportional, pragmatic, and evidence informed*. These principles have guided PE Subcommittee discussions and have informed the development of the framework and accompanying recommendations, which appear in the following section of the report. Many of these principles are common to the values identified in the recently released Health Technology Assessment international (HTAi) document titled *Values and Quality Standards for Patient Involvement in HTA*, based on an 18-month Delphi consensus process conducted with input from 150 respondents in 39 countries worldwide. (69)

Linked to these overarching principles is a set of more operational goals that are specific to the HQO-OHTAC evidence review process and that provide the foundation for the PPE framework:

1. PPE will be strengthened and supported:
  - To improve the quality of the outputs that arise from each stage of the HQO-OHTAC process
  - To create more informed, transparent, accountable, and legitimate processes for deliberating about health technologies and interventions
  - To promote a more robust and comprehensive science of HTA that incorporates social values and ethics, as well as patients' problems, lived experiences, outcomes, and preferences
  - To increase public and patient understanding of health technologies and HTA, and to strengthen the public's and patients' competence and capacity to contribute to various stages of the HTA process
2. PPE efforts will be informed by evidence (where possible), best practice in the absence of evidence, and sound principles

3. (Formative) evaluation will ideally be embedded in all aspects of HQO’s PPE activities, given both the lack of a strong evidence base in this area and HQO-OHTAC’s emphasis on it
4. PPE efforts will support and be supported by HQO’s Decision Determinants framework and the specific domain of social values and ethics

## Establishment of a Common Language to Support Public and Patient Engagement Efforts

Conceptual and empirical studies have noted divergent views within the HTA community, and sometimes within the same HTA agency, about what *public and patient engagement* means. (18) This ambiguity can lead to conflicting goals and visions for public and patient engagement in HTA (18, 52, 53, 55) and, more practically, conflicting views about who should be engaged, who they represent, what role they should play at what stages of the HTA process, and what types of engagement mechanisms should be used. (18, 39, 53) In addition to the principles, values, and goals described in the previous section, our framework includes a common language to effectively support efforts to engage the public and patients in the HQO-OHTAC process. Key concepts and terms used to define the *who* and *what* of public engagement have been described (see Figures 2 and 3, pp. 13 and 14). These are linked in Figure 4 to illustrate the early but critical step in any PPE strategy where key decisions are made about which publics to involve and how, a step that is guided by explicitly stated goals.

Goals for Public and Patient Engagement			
<ul style="list-style-type: none"> <li>• Improved quality of OHTAC recommendations</li> <li>• Improved transparency and accountability</li> <li>• Increased knowledge and awareness of HQO-OHTAC work</li> </ul>			
Which Groups?	What Type of Activity?		
	Communication	Consultation	Participation
The public (i.e., citizens, interested members of the general public without direct experience with a specific technology or condition)			
Patients, families, caregivers (who have experience with a specific technology or condition)			
Stakeholder group (has an organized interest in a technology or condition)			

**Figure 4: Building a Common Language for Public and Patient Engagement**

Abbreviations: HQO, Health Quality Ontario; OHTAC, Ontario Health Technology Advisory Committee.

## Flexible Menu of Public and Patient Engagement Approaches

In this section, we present a menu of mechanisms and tools for engaging the public and patients in each stage of the HQO-OHTAC process, informed by our review of international practice and the descriptive and evaluative evidence in this area (see the Evidence Review section, above, and Appendix 5). A key message from this review is that there is no one-size-fits-all or single “optimal” approach to PPE. Rather, the choice of method needs to be matched to the context of the technology or condition, the characteristics of the populations affected by the technology or condition, and the motivation or central concern for incorporating public and/or patient perspectives into the process. These ethical considerations bear heavily on the complementary work of the Social Values and Ethics working group of HQO’s Decision Determinants Subcommittee (see pp. 16–17). In particular, some of the approaches described in the sections below may be triggered by the evaluation questions posed to identify ethical issues in various stages of the assessment process, and by the criteria set out to determine the

scope and depth of an ethics-based assessment. In this way, the range of approaches put forward for engaging relevant groups and perspectives to gather and synthesize their values also contributes to fulfilling the broader social values and ethics goals of HTA decision-making.

Here, we present a series of three visuals that feature the following:

1. A newly configured HQO-OHTAC evidence review process that includes a new stage where PPE should be incorporated (and excludes the appeal and field evaluation stages which are not relevant to our framework) (Figure 5)
2. A statement of the goals or rationales for each stage of the HQO-OHTAC process (Figure 6)
3. A depiction of the newly configured HQO-OHTAC process with the different group(s) that may be involved in each stage, mapped onto a menu of engagement mechanisms and tools that could be used (Figure 7)



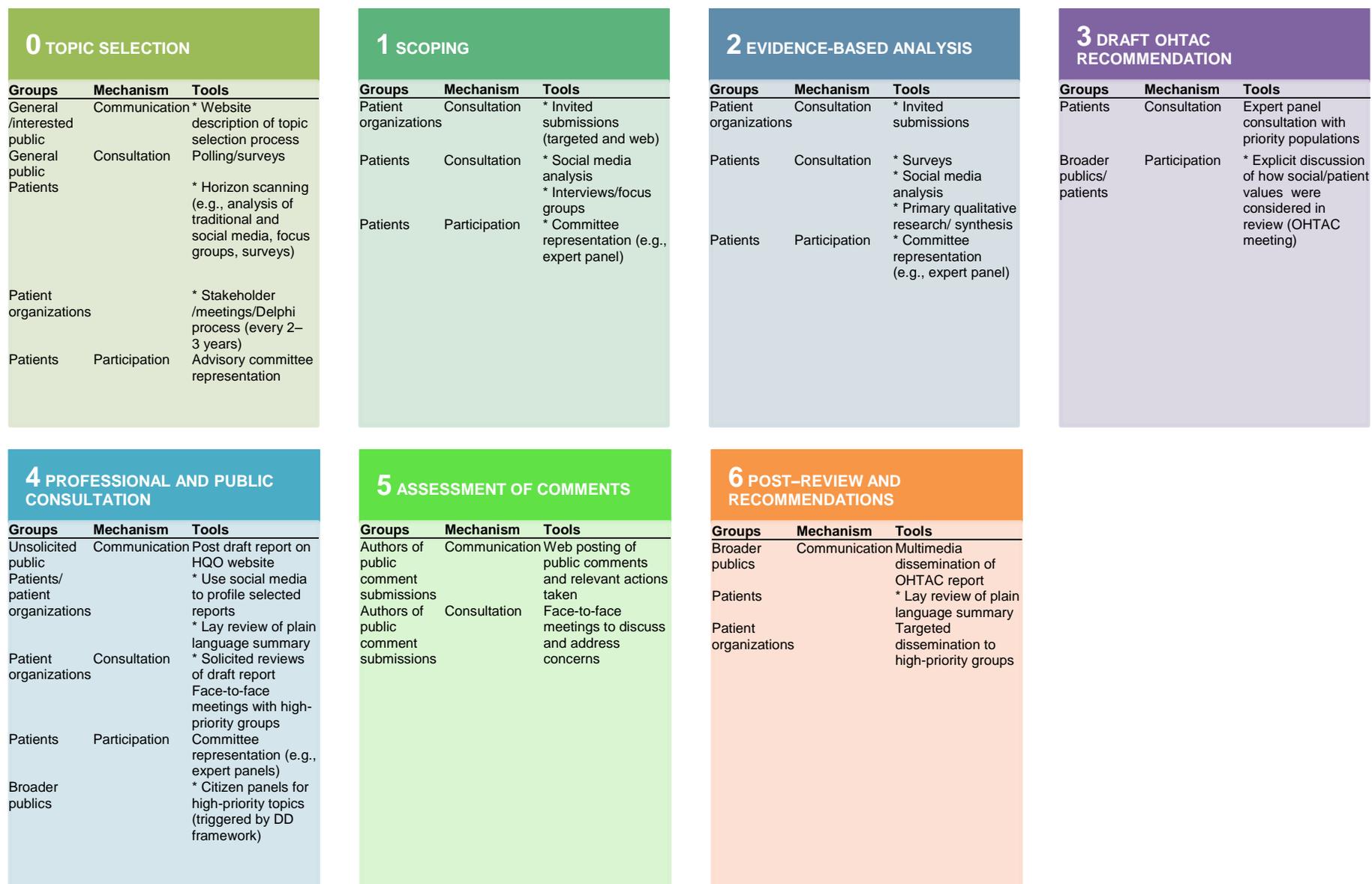
**Figure 5. HQO-OHTAC Evidence Review Process**

Adapted to include a new stage for public and patient engagement.  
 Abbreviations: HQO, Health Quality Ontario; OHTAC, Ontario Health Technology Advisory Committee.



**Figure 6. Rationales and Goals for Public and Patient Engagement by Stage in the HQO-OHTAC Evidence Review Process**

Abbreviations: HQO, Health Quality Ontario; OHTAC, Ontario Health Technology Advisory Committee.



**Figure 7. Who to Engage and How, by HQO-OHTAC Stage**

\* Indicates link to recommendations.

Abbreviations: DD, decision determinants; HQO, Health Quality Ontario; OHTAC, Ontario Health Technology Advisory Committee.

## Measurement and Evaluation

Given the weak evidence base for PPE in HTA and related fields, the development of this framework and its associated recommendations provides a unique opportunity for HQO and OHTAC to embed evaluation into the initiation of new PPE activities, and to provide leadership on the PPE evaluation front. Efforts in this regard should initially focus on basic formative evaluation metrics to determine whether the intended goals of the PPE activities are being achieved, including basic process and impact measures, such as numbers and types of consultations, how different types of PPE input are being used in various HQO-OHTAC stages, and the resources that are required to carry out relevant activities. These will provide valuable information to inform mid-course adjustments to approaches. Over time, more robust evaluation metrics could be developed, allowing the possibility to compare different PPE approaches using trial or quasi-experimental designs consistent with several recently published high-quality public engagement evaluation studies in related fields. (70, 71)

## RECOMMENDATIONS

The recommendations presented in this section flow from the previous section, where the range of clearly articulated approaches for engaging the public and patients is presented, with an emphasis on those that most robustly meet our guiding principles and that are informed by best practices and available evidence. The PE Subcommittee recommendations represent potential enhancements to OHTAC's current public engagement activities and focus special attention on the early stages of the HQO-OHTAC process, where the need for more direct involvement from the public and patients is most pronounced and where the HTA and PPE in the health research field has much to offer in the way of "tried-and-true" methods.

Recognizing the complexity involved and HQO's limited capacity in the area of PPE, each recommendation listed below is supported by one or more implementation mechanisms that provide specific suggestions about how to move forward, as well as an assessment of the degree of implementation difficulty with regard to available resources and capacity. While some recommendations will require more effort and resources than others, overall we view these recommendations as feasible to implement.

### Stage: Topic Identification and Prioritization

#### Rationale

Engaging patients and the public early on in the HQO-OHTAC evidence review process provides opportunities to gather a broader range of perspectives on what OHTAC reviews.

#### Recommendation 1

HQO should increase the transparency of the evidence review process to facilitate a fuller understanding among interested patients, broader publics, and stakeholder groups of how topics are selected and referred to OHTAC.

**Principles supporting this recommendation:** transparency, pragmatism

#### Mechanisms for implementing this recommendation:

- Simplify the description of the HQO-OHTAC evidence review process on the public website  
*Degree of difficulty to implement: low*
- Establish a dashboard on the HQO website that indicates:
  - Topics that have entered into the HQO-OHTAC evidence review process
  - Where the topics originated, including applicants, sponsors, and organizations
  - Decisions taken by OHTAC (including whether to prioritize), what types of products will be developed, and approximate timelines for public posting*Degree of difficulty to implement: low*

#### Recommendation 2

HQO, with the assistance of OHTAC, should increase the relevance and responsiveness of its work by undertaking a range of horizon-scanning and consultation activities to prospectively identify potential review topics and emerging issues of concern to patients and priority populations.

**Principles supporting this recommendation:** transparency, fairness, pragmatism, evidence informed

**Mechanisms for implementing this recommendation:**

- Establish linkages with patient organizations to increase the awareness of the HQO-OHTAC process and to solicit, on a periodic basis, through robustly designed consultation processes, ideas for topics to be reviewed  
*Degree of difficulty to implement: medium*
- Establish linkages with external organizations that conduct horizon scanning (e.g., Canadian Network for Environmental Scanning in Health) to identify and share information on new and emerging health technologies  
*Degree of difficulty to implement: medium*
- Dedicate HQO resources to horizon scanning, which could include such activities as:
  - Scanning Internet blogs using established methods
  - Analyzing traditional and social media, as well as crowdsourcing, using established methods
  - Creating focus groups with representatives of the patient/public perspective
  - Employing polls/surveys, especially for high-priority issues*Degree of difficulty to implement: medium*

## Stage: Scoping

### Rationale

Public and patient engagement at the scoping stage ensures that the evidence analysis:

- Is oriented more broadly to health conditions and the range of approaches for addressing these, rather than having a narrow focus on the technologies to treat a condition
- Emphasizes the input of relevant and priority populations to identify pertinent outcomes
- Articulates research questions that are important to the public and patients

### Recommendation 3

Public and patient engagement should be embedded in the scoping of all review topics. One or both of the following criteria should be used to justify PPE *not* being triggered:

- The topic under review concerns technologies with no direct patient interface
- The focus of the review is exclusively on the technical aspects of the technology

**Principles supporting this recommendation:** transparency, fairness, proportionality

**Mechanisms for implementing this recommendation:**

- Expert panels, which oversee the scoping of review topics, include a minimum of three patients/public members (two full members plus one alternate); this is becoming standard practice in the field. Public/patient members on these panels are identified through and supported by central capacity within HQO or through linkages with relevant patient organizations as determined by the topic under review. Efforts are made to avoid “tokenism” and to demonstrate a commitment to considering a broad range of public perspectives  
*Degree of difficulty to implement: low*

- HQO solicits patient input regarding the technology or condition that is to be reviewed actively, through a range of consultation activities (e.g., interviews, focus groups, solicitation of input on draft documents, surveys), and passively, through the HQO website

*Degree of difficulty to implement: low to medium*

## Stage: Evidence Development

### Rationale

Patient input at the evidence development stage can provide a unique source of evidence about the personal impact of a disease/condition and how technologies can make a difference. Patient input can also identify gaps or limitations in the published research (e.g., outcome measures that do not reflect what is important to patients).

### Recommendation 4

On the advice of HQO's expert panels, HQO should draw on a range of sources for incorporating societal and patient values into the evidence-based analysis stage. This could include input from patient members of expert panels, consultations with individual patients and/or patient groups, and the synthesis of primary qualitative research studies.

**Principles supporting this recommendation:** proportionality, pragmatism, evidence informed

#### Mechanisms for implementing this recommendation:

- HQO invests in capacity and professional development for staff around PPE  
*Degree of difficulty to implement: low to medium*
- Patient input is sought through the patient membership on the expert panel and through other consultation vehicles; both are described in recommendation 3  
*Degree of difficulty to implement: medium*
- HQO identifies skills in qualitative research and ethics as an asset in future hiring processes  
*Degree of difficulty to implement: low*
- HQO hires or seconds (in a manner similar to that used for health economic expertise from Health Technology Fund Program organizations) an individual(s) with skills in qualitative research and ethics to provide in-house capacity  
*Degree of difficulty to implement: medium*

## Stage: Recommendation Development and Public/Professional Consultation

### Rationale

Patient/public input at the recommendation development and public/professional consultation stage ensures that the patient/public perspective has not been lost through the formal report writing and evidence appraisal stages, and provides opportunities for improving the quality of the recommendations through patient/public feedback.

### Recommendation 5

OHTAC should identify dedicated agenda time at its monthly meetings for the explicit consideration of societal and patient values relevant to all evidence reviews that are being presented for OHTAC recommendations.

**Principles supporting this recommendation:** transparency, fairness, proportional, pragmatic, purposeful

**Mechanism for implementing this recommendation:**

- An explicit standing agenda item is included as part of all reviews of HQO reports and draft recommendations that is focused on identifying how public or patient values were reflected in the review process (e.g., through the scoping or EBA stage, consultation with priority populations, etc.)  
*Degree of difficulty to implement: low*

**Recommendation 6**

HQO, with OHTAC’s assistance, should enhance its public and patient consultation process at the post-appraisal stage to develop increased awareness of its work and to encourage broader input on its draft recommendations.

**Principles supporting this recommendation:** transparency, fairness, pragmatism, proportional, purposeful

**Mechanisms for implementing this recommendation:**

- HQO uses in-house social media expertise to disseminate and seek broad-based input during the public comment period  
*Degree of difficulty to implement: low*
- HQO uses and enhances existing email lists to seek targeted input during the public comment period  
*Degree of difficulty to implement: low*
- HQO expands current efforts to write in plain language and include lay-member review in the drafting of plain language materials  
*Degree of difficulty to implement: medium*
- HQO dedicates resources to polling or deliberative methods (e.g., citizen panels) for high-priority issues that have broad social, ethical, and economic impacts  
*Degree of difficulty to implement: medium*

## CONCLUSIONS

The PE Subcommittee has met its objectives of expanding on the PPE framework established by the previous OHTAC PE Subcommittee, and advising OHTAC on a comprehensive but flexible set of approaches to PPE guided by a clear set of principles and goals. Through its work, the subcommittee has also taken important steps toward systematically identifying and linking the PPE goals, groups, mechanisms, and tools for each stage of the HQO-OHTAC process and identifying where PPE is most warranted and likely to add the greatest value.

The framework and corresponding recommendations presented in this report focus on enhancing the transparency, legitimacy, and overall quality of the outputs at the front end of the HQO-OHTAC process, especially in the topic selection and scoping stages. In addition, they seek to strengthen the communication and consultation activities already present in the later stages (e.g., professional and public consultation, assessment of comments).

The framework and recommendations are consistent with the mission of HQO and OHTAC, and with the Decision Determinants framework and its four attributes:

1. Overall clinical benefit
2. Value for money
3. Social values and ethics
4. Feasibility

We expect the recommendations of the PE Subcommittee to be highly synergistic with the efforts of the Social Values and Ethics working group being undertaken with the Decision Determinants Subcommittee. The combined efforts of these groups will bring greater rigour and sophistication to the task of gathering and integrating patient-level and social value judgments with clinical and economic evidence in the HQO-OHTAC process.

Recognizing the reality of limited resources and capacity within HQO, the subcommittee's recommendations are designed to make measurable progress toward achieving HQO's goals for PPE over a short period of time and without significant resource investments. While some recommendations will require more effort and resources than others, overall we view these recommendations as feasible to implement.

The framework and accompanying recommendations presented in this report have been developed for implementation in the unique context of the HQO-OHTAC process; however, we believe that the framework's core elements are applicable to HTA agencies in Canada and abroad, as well as other health system organizations pursuing health quality agendas with strong evidentiary support.

## ACKNOWLEDGEMENTS

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Susan Harrison

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## APPENDICES

### Appendix 1: Recommendations from the September 2007 Report to OHTAC

1. We recommend that stakeholder categories be established in consultation with the MOHLTC's Communications and Information Branch. In phase one of the engagement process, we recommend that stakeholders be assigned to the appropriate stakeholder category as outlined below. The output of this process is intended to inform the consultation plan which becomes part of the vignette.
  - a. We recommend the following stakeholder categories be used as a method of prioritizing the engagement effort in circumstances where time and available resources are limited during an analysis period.
  - b. These categories are also intended as a checklist mechanism to aid MAS staff in their effort to ensure that all relevant stakeholders are considered for consultation. The subcommittee recognizes that staff of the Medical Advisory Secretariat already engages many professional stakeholder groups. This prioritized list is intended as a means of guidance in identifying appropriate public stakeholders. (See Table A1.)

#### Stakeholder Engagement Categories

- I. Patients and Families/Caregivers
- II. Advocacy Groups/Patient and Caregiver Organizations
- III. General Public/Ontario Taxpayers

See Table A1 for examples.

**Table A1: Stakeholder Engagement Categories**

Stakeholder Category	Examples/Notes
Patients/Health Care Consumer	Elderly, Epileptics, Diabetics, etc/Bring experiential knowledge
Family/Caregivers	Consultation, Comments on draft recommendations. Solicit input from lay groups
Advocacy Groups	Heart & Stroke Foundation, MS Society. National and Provincial Organizations. Self-identified or externally identified
General Public Citizens/Taxpayers	Friends, neighbours of patients, employers, members of local or cultural communities, citizens. Input through interviews, workshops, surveys, focus groups

- c. We recommend the creation and regular updating of a list of National/Provincial Stakeholder Groups for Stakeholder identification and for possible consultation. This effort should lead to a list of "recognized groups". In association with Communications and Information Branch, stakeholder identification methods would be improved to ensure that the relevant bodies and individuals are identified for inclusion in engagement process.

These may include but not be limited to the following:

- I. National and provincial groups representing patients and caregivers
  - II. Public Agencies
2. We recommend that MAS consider a sliding timeline for select technologies in order to accommodate the elongated evaluation and public engagement of some specialized review projects such as the proposed mega-HTAs and those single technologies which may require a more time-intensive deliberative public engagement process.

Some select technologies may require more deliberative engagement strategies to ensure that all information critical to a more comprehensively-informed decision process can be obtained. In these special instances it may be necessary to consider an extended timeline to complete the analyses.

A set of predetermined threshold values could be used by MAS as a mechanism to decide when to expand the 16 week analysis period in order to accommodate the more time-intensive deliberative engagement efforts.

**Proportionality Principle**

Analogous to research ethics protocol review in which the degree of review is proportional to the extent of risk to the research participants, the subcommittee recommends that the proportionality principle guide the degree of stakeholder engagement in relation to the nature and purpose of the technology, size and demographics of the targeted patient population, and disease incidence and prevalence. See Table A2.

Note: Part of the rationale of the sliding timeline is to respect the timeline and resource constraints of the existing 16 week review process, while allowing provision for those instances in which more steps are required in order to guarantee a thorough and responsible review of a technology topic.

**Table A2: Proportionality Principle**

Consideration	Surpasses 2 or More of the Following Thresholds	Engagement Action
Incidence/Prevalence of indication	Qualitative Threshold	Recommend more deliberative engagement strategy (Survey, focus groups, etc)
Invasiveness of intervention	Qualitative Threshold	
QALY	Qualitative Threshold	
Demographics/Potential marginalization of patient group	for Qualitative Threshold	

3. We recommend the development of a methodology based on Health Related Quality of Life Measures as highlighted in the series of questions below which are intended to help estimate the societal impact of the technology:

Because this remains a highly contested area in evidence based assessments, we recommend further discussion on what criteria would be admissible for submission of “social value evidence,” i.e., What kind of evidence would we accept? (Principles, criteria, weights) What does societal value evidence look like? Is this a technology that will have a significant

impact on how people care for themselves or how others care for them? Or, at a broader public level, will this technology have a broader societal impact/profound effect on society?

Health-Related Quality of Life Measures expressed as outcomes that are relevant to patients, families, and caregivers could include:

- Physical mobility/reduction of impairment/handicap
  - Ability to self-care
  - Ability to carry out activities of daily living
  - Absence of pain and discomfort
  - Absence of anxiety and depression
  - Financial economic burden/benefit
4. We recommend that the level of weight that public input is to be given in the final recommendation be debated and informed by the work of the Decision Determinants Subcommittee, based on the importance of the health care outcomes as determined by the above criteria. In this way we will begin to integrate patient evidence in our recommendations.
  5. We recommend that consistent with the principle of transparency, we identify and include the stakeholders consulted in the final recommendation document.
  6. We recommend that MAS consider the production of guideline materials advising the public on how to engage with OHTAC (i.e., helpful engagement information, training and support to patients, caregivers, and members of the public).
  7. We recommend that draft analyses and draft OHTAC recommendations be posted on the OHTAC website for an agreed upon period of time in an effort to seek public input on these documents as part of the public engagement process. (The subcommittee acknowledges that MAS has already begun undertaking the implementation of this recommendation by agreeing to post the draft document on the OHTAC website for no less than 21 days.)
  8. We recommend that MAS undertake the evaluation of any input, which meets the criteria for consideration, received during the consultation period in order to ascertain whether the items need to return to OHTAC for further deliberation. (The subcommittee acknowledges that MAS has already begun undertaking the implementation of this recommendation by agreeing to evaluate the public input received during the consultation period.)
  9. We recommend to MAS that a page be added to the OHTAC website which outlines the OHTAC public engagement strategy and a link to the public engagement guideline document stipulated above.
  10. We recommend that OHTAC consider adding vehicles for communication and consultation in addition to the existing strategies which rely primarily on web-based methods.
    - a. In light of the heavy emphasis placed on use of the OHTAC website for the public engagement efforts (<http://www.health.gov.on.ca/mas> is the sole vehicle for public comment on draft recommendations and analyses), the subcommittee recommends that steps be taken to ensure that the OHTAC website can be easily located/accessed by both providers and the general public.

11. We recommend that an evaluation mechanism for the OHTAC public engagement process be considered, so that we know if/when OHTAC has done a good job. This would provide valuable feedback on the degree of effectiveness of OHTAC's public engagement efforts.

## Appendix 2: OHTAC Public Engagement Subcommittee Terms of Reference

### Definitions

<b>Health technology</b>	Encompasses interventions targeted at all stages of health care, from primary prevention, early detection of disease, and risk factors to diagnosis, treatment, rehabilitation, and palliative care. Health technologies may include existing diagnostic and treatment-related medical devices and services, approaches to diagnostics and treatments, equipment and supplies, laboratory tests, and clinical procedures used in any health services delivery setting
<b>HQO</b>	Refers to Health Quality Ontario
<b>OHTAC</b>	Refers to the Ontario Health Technology Advisory Committee
<b>MOHLTC</b>	Refers to the Ministry of Health and Long-Term Care
<b>Subcommittee</b>	Refers solely to the OHTAC Public Engagement Subcommittee

### Background

The subcommittee has been established to advise HQO on approaches to PPE in order to foster transparency, awareness, legitimacy, acceptability, and trust in OHTAC recommendations arising from the OHTAC review process.

### Subcommittee Objectives

The subcommittee's primary objective will be to expand on the PPE framework established by the previous OHTAC PE Subcommittee in developing a PPE strategy for HQO.

Health Quality Ontario will provide secretarial support to the subcommittee in support of its deliberations and deliverables.

### Role of the Subcommittee

- The subcommittee will develop and propose a PPE strategy to enhance the overall existing HTA process
- The subcommittee will propose a revised PPE framework that includes evaluative criteria to measure the impact of PPE on the OHTAC process. The framework will include mechanisms for evaluating and considerations of the impact on the public, society, health care sectors and professions, relevant stakeholders, and associated ethics
- The subcommittee will explore and recommend mechanisms to engage the general public in OHTAC's activities
- The subcommittee will recommend a PPE mechanism that involves disseminating information to the public in an easily accessible manner
- The subcommittee will determine which public voices are of most relevance to OHTAC and clearly define how those voices will be considered in OHTAC recommendations (and in the process leading up to recommendations). Key points of deliberation will include the following:
  - What types of health technology questions warrant PPE?
  - What methodologies for seeking public input does OHTAC want to use?
  - When/where in the health technology recommendation process might PPE enrich the process?

- In the development of a PPE model, the subcommittee will explore multifaceted PPE approaches (e.g., using social media) tailored to the needs of specific publics
- The subcommittee will suggest ways in which PPE can be used to promote accountability in decisions about health care technology resource allocation

## **Membership**

The members of the PE Subcommittee are as follows:

Frank Wagner (chair)  
Charles Wright  
Dorothy Pringle  
Julia Abelson  
Murray Krahn  
Pat Campbell  
Renata Axler  
Sally Bean  
Shirlee Sharkey  
Anthony Easty

## **Reporting**

The subcommittee reports to OHTAC.

## **Project Deliverables**

The subcommittee's deliverables include these:

- Regular updates to OHTAC on actionable items
- Minutes of meetings available to OHTAC
- A report to OHTAC on the subcommittee's recommended model for PPE by OHTAC, complete with implementation considerations, by June 2014

## **Meeting Frequency, Duration, Rules of Order, and Subcommittee Lifespan**

The subcommittee will meet 7 to 12 times a year for 1 year at the direction of the chair. Each meeting will take place at a location determined by the secretariat of the subcommittee (HQO). Meetings will be no more than 3 hours long.

When feasible, procedural policies of the subcommittee will mirror OHTAC, including but not limited to:

- The conflict of interest policy
- The confidentiality policy
- The communications protocol
- Decision by consensus; if consensus is not possible, a simple majority vote

Members of the subcommittee are expected to attend meetings in person; however, accommodations for remote participation will be made if required.

## **Secretariat Support**

Health Quality Ontario will provide secretariat support for the subcommittee. The secretariat:

- Monitors and evaluates efficiency and effectiveness of the subcommittee
- Coordinates preparation of information including but not limited to agendas, minutes, records of proceedings, and reports, and maintains information for the work of the subcommittee
- Carries out additional duties such as risk assessment and risk mitigation strategies, as necessary

## **Subcommittee Expenses**

Health Quality Ontario will reimburse travel expenses incurred by subcommittee members in accordance with its Travel Meal and Hospitality Policy.

## **Indemnification**

All members serve on the subcommittee on a volunteer basis and by virtue of acting on behalf of HQO, the members are afforded a statutory indemnification under Section 11 of the *Excellent Care for All Act, 2010*, as follows:

*No personal liability*

*11. No action or other proceeding for damages may be instituted against any member of the Council or anyone acting on behalf of the Council for any act done in the execution or intended execution in good faith of the person's duty or for any alleged neglect or default in the execution in good faith of the person's duty. (4)*

## Appendix 3: Summary of Public Comments on a Sample of OHTAC Reports

**Table A3: Summary of Public Comments on a Sample of OHTAC Reports**

Technology/ Intervention	Report Type	Consultation Start	No. of Comments	Commenters
Epilepsy surgery	Evidence summary	Nov 8, 2011	~150	Sample: <ul style="list-style-type: none"> <li>• Mostly members of the public</li> <li>• OMA</li> <li>• Epilepsy Ontario</li> <li>• Hospital scientist</li> </ul>
Metal-on-metal hip resurfacing	EBA	Jul 16, 2012	1	<ul style="list-style-type: none"> <li>• OMA</li> </ul>
Deep-brain stimulation for depression	PER	Feb 15, 2013	2	<ul style="list-style-type: none"> <li>• Physician</li> <li>• Academic</li> </ul>
Optimizing chronic disease management in the community setting	Mega-analysis	Feb 27, 2013	3	<ul style="list-style-type: none"> <li>• Ministry of Health and Long-Term Care</li> <li>• Ontario Lung Association</li> <li>• Respiratory Therapy Society of Ontario</li> </ul>
Photoselective vaporization of the prostate	Field study	Feb 27, 2013	1	<ul style="list-style-type: none"> <li>• Staff surgeon</li> </ul>
Deep-brain stimulation for epilepsy	EBA	Apr 29, 2013	1	<ul style="list-style-type: none"> <li>• Medtronic of Canada</li> </ul>
Vitamin B <sub>12</sub> and cognitive function	EBA	Apr 29, 2013	2	<ul style="list-style-type: none"> <li>• OMA</li> <li>• OAML</li> </ul>
Pressure ulcer multidisciplinary teams via telemedicine	Field study	May 23, 2013	2	<ul style="list-style-type: none"> <li>• Academic</li> <li>• Administrator</li> </ul>
Urea breath test for detection of <i>Helicobacter pylori</i>	EBA	Jun 27, 2013	5	<ul style="list-style-type: none"> <li>• OMA (2)</li> <li>• OAML</li> <li>• LASER ANALYTICA</li> <li>• Paladin Labs</li> </ul>
Hysteroscopic tubal sterilization	EBA	Jul 22, 2013	3	<ul style="list-style-type: none"> <li>• OMA</li> <li>• 2 physicians</li> </ul>

Abbreviations: EBA, evidence-based analysis; OAML, Ontario Association of Medical Laboratories; OMA, Ontario Medical Association; PER, preliminary evidence review.

## Appendix 4: Evidence Review Methods

We conducted a systematic website scan of selected international HTA agencies in August 2013. Eighty-three HTA agencies from 46 countries were identified through member lists of umbrella organizations (European Network for Health Technology Assessment [EUnetHTA], the International Network of Agencies for Health Technology Assessment [INAHTA], EuroScan, and organizations reporting to the HTA Database). We included agencies with English-language websites ( $n = 17$ ) or translation capabilities ( $n = 36$ ), which narrowed the sample to 53 HTA agencies across 34 countries. We scanned the websites for relevant links, followed by a keyword search using the terms *public participation*, *public engagement*, *public involvement*, *consumer involvement*, and *patient involvement*. Data were extracted using a template and summarized in Excel. In addition to HTA producer agencies, the Patient and Citizen Involvement section of the Health Technology Assessment international (HTAi) website was searched for relevant documents.

Findings from the website scan were complemented by four published surveys of international HTA practice (39, 52, 53, 55) retrieved from the authors' personal files. We were aware of a small but highly relevant set of reviews of empirical studies and conceptual analyses of PPE in HTA. (18, 22, 41) To identify recent empirical studies and conceptual analyses relating to PPE in HTA, we used the search strategy developed by Gagnon et al (41) for PubMed. The search strategy retrieved 360 potentially relevant articles published from February 1, 2009, to September 25, 2013. We reviewed titles and abstracts and discarded articles that did not address PPE or were not related to HTA. The final set included 30 empirical articles and 12 conceptual articles for full-text review. We combined a qualitative content analysis of these recent articles with the previous reviews to capture evidence published from 1990 to 2013.

## Appendix 5: Evidence Summary Tables

**Table A4: Evidence Summary Table for Topic Selection and Prioritization Stage of Health Technology Assessment**

Aspect	Details
Goals/rationales for PPE at this stage	<p><i>Accountability</i> to those being served and, in the public sector, to those meeting the costs</p> <p><i>Better-quality decisions that reflect patient and public preferences and values</i></p> <p><i>Increased knowledge and capacity</i> through well-designed dissemination strategies</p> <p>HTA as an “enabler” of effective new technologies rather than a “gatekeeper” (39)</p>
Approaches to PPE	<p><b>Topic identification</b></p> <ul style="list-style-type: none"> <li>• <i>Passive communication</i> through organization website (online form)</li> <li>• <i>Proactive activity</i> through networks and forums with other research organizations</li> </ul> <p><b>Prioritization and selection</b></p> <ul style="list-style-type: none"> <li>• <i>Public consultation</i> through reviewer comments on pre-circulated briefs</li> <li>• <i>Public representation</i> on priority-setting advisory committees</li> <li>• <i>Collaborative participation</i> through citizens’ jury</li> </ul>
Evidence of effectiveness/impact	<p><i>Public suggestions</i>—“too vague or described a service provision problem without specifying the research uncertainty that needed to be resolved in order to improve the quality of the service” (56); not readily translated into the conventional framework of a research question</p> <p><i>Participation of public members on committees to prioritize topics</i>—led to user-friendly documentation; highlighted need for a clearer discussion on the importance of proposed topics to the NHS, rather than just on scientific quality</p> <p><i>Involvement of affiliated organizations</i> relatively successful; 8%–9% of their suggestions led to commissioned research, at least twice the success rate from other sources (56)</p>
Feasibility considerations: barriers, challenges, and enablers	<p><b>Enablers</b></p> <ul style="list-style-type: none"> <li>• Working with affiliated organizations leads to better suggestions (56)</li> </ul> <p><b>Barriers/challenges</b></p> <ul style="list-style-type: none"> <li>• Use of HTA website for topic suggestions requires knowledge of the opportunity, which is unlikely</li> <li>• How to select from large number of voluntary organizations/charities/patient groups for consultation</li> <li>• Balancing broad public/patient interests with narrower interests of organizational representatives</li> <li>• Difficult to translate the problems of people’s daily lives into a topic that supports a well-structured research question</li> <li>• Constraints imposed by HTA program and internal procedures</li> </ul>

Abbreviations: HTA, health technology assessment; NHS, UK National Health Service; PPE, public and patient engagement.

**Table A5: Evidence Summary Table for Scoping Stage of Health Technology Assessment**

Aspect	Details
Goals/rationales for PPE at this stage	<p>To ensure that HTA adopts a health condition perspective, rather than a technology perspective</p> <p>To identify questions to be addressed that differ from those typically formulated by HTA agencies, governments, or payers</p>
Approaches to PPE	<p><i>Public/patient consultation</i> in scoping and review of draft protocols—consultation methods used not identified (United Kingdom)</p> <p><i>Patient representation on committees</i> tasked with defining the scope of the assessment (Australia and France)</p> <p>Formal <i>stakeholder consultation</i> described as part of NICE’s scoping process</p> <p><i>Collaborative participation</i> through citizens’ reference panel</p>
Evidence of effectiveness/impact	<p><i>Public input (through consultation)</i> into shaping research questions more influential than role in suggesting research topics. Clearest <i>evidence of public input (through consultation)</i> in UK HTA program was in the preparation of vignettes</p> <p><i>Public provided unique contributions both as external experts and as panel members.</i> Their contributions resulted in some important changes, including making patient and carer perspectives explicit, changing the focus of the research, adding new outcomes, refuting the need for the planned research, providing up-to-date prevalence data, and providing plain language background text (56)</p> <p><i>Collaborative participation (through the citizens’ reference panel)</i> at the vignette stage, where the parameters of the evaluation are still being defined, was less amenable to direct impacts than in the recommendation stage (8)</p>
Feasibility considerations: barriers, challenges, and enablers	<ul style="list-style-type: none"> <li>• How to select from the vast array of voluntary organizations/charities/patient groups to consult with them about vignettes</li> <li>• How to balance broad public/patient interests with narrower interests of organizational representatives</li> </ul>

Abbreviations: HTA, health technology assessment; NICE, National Institute for Health and Care Excellence; PPE, public and patient engagement.

**Table A6: Evidence Summary Table for Evidence-Based Analysis Stage of Health Technology Assessment**

Aspect	Details
Goals/rationales for PPE at this stage	<p>Identification and selection of <i>outcome measures that capture critical aspects of “benefit” to patients</i> (e.g., preferences regarding management of condition)</p> <p>Patients can:</p> <ul style="list-style-type: none"> <li>• Provide a <i>unique source of evidence on the personal impact</i> of a disease and how a technology can make a difference</li> <li>• <i>Identify shortcomings in the published research</i></li> </ul>
Approaches to PPE	<p><i>Patient/carer organization group submissions</i> (open invitation) (Canada, France, United Kingdom); by request only (New Zealand)</p> <p><i>Patient representative to the advisory group</i> overseeing the assessment (Australia)</p> <p>Dedicated <i>patient/public involvement in subcommittee</i> that included 3 members of the general public (Scotland)</p>
Evidence of effectiveness/impact	<p>Comparison of different sources of patient/public input noted differences in “content” across various information sources (e.g., patient blogs vs. academic literature)</p>
Feasibility considerations: barriers, challenges, and enablers	<ul style="list-style-type: none"> <li>• Methodological challenges of identifying and synthesizing patient information</li> <li>• Little guidance about rigorous approaches to accomplish this, given the time and resource constraints faced by most HTA agencies</li> </ul>

Abbreviations: HTA, health technology assessment; PPE, public and patient engagement.

**Table A7: Evidence Summary Table for Draft Recommendations Stage of Health Technology Assessment**

Aspect	Details
Goals/rationales for PPE at this stage	<p><i>Accountability</i> to users as taxpayers, voters, and consumers (66)            To <i>inform</i> key HTA decisions (53)</p>
Approaches to PPE	<p><i>Patient/public representation</i> on relevant committee(s) where recommendations are being drafted and finalized (generally recruited through patient/carer organizations) (Australia, France, and Germany; in Germany, patients are non-voting members)</p> <p><i>Direct consultation</i> with relevant patient/carer organizations during the drafting process or after the recommendation has been drafted (by invitation—Australia, the Netherlands; or at the request of the patient/carer organization—United Kingdom)</p> <p><i>Internet consultation</i> (draft guidance is posted for specific consultation period) (Ontario, Oregon, Washington)</p> <p><i>Collaborative participation</i> through patient/citizens’ reference panel (Ontario—citizens’ panel pilot)</p>
Evidence of effectiveness/impact	<p><i>Consultation with service users</i> through focus groups and through <i>user representation on HTA working group</i> “brought new ideas on how to formulate recommendations in a way that reflects users’ perspectives” (40)</p> <p><i>Collaborative participation</i> (e.g., through citizens’ panels) produced traceable impacts at the draft recommendations stage; concerns about loss of choice and patient autonomy associated with population-based colorectal cancer screening programs and perceived pressure to be screened were considered by OHTAC and resulted in changes to the final recommendation (Ontario) (8)</p> <p>In an international survey of PPE in HTA organizations, the majority of respondents (18 [69%]) indicated that their organization integrated the findings of public engagement activities with other forms of evidence (e.g., scientific evidence) to inform health technology decisions or recommendations. Five (19%) indicated that their organization did not integrate the findings, and 3 (12%) indicated that they did not know whether this was the case (53)</p>
Feasibility considerations: barriers, challenges, and enablers	<p><i>Collaborative participation</i> methods require periodic direct and brokered exchange between the panel members and the expert advisory committee to clarify roles, foster accountability, and build trust</p>

Abbreviations: HTA, health technology assessment; NICE, National Institute for Health and Care Excellence; PPE, public and patient engagement.

**Table A8: Evidence Summary Table for Post–Review and Recommendations Stage of Health Technology Assessment**

Aspect	Details
Goals/rationales for PPE at this stage	<i>Increased knowledge and capacity</i> through well-designed dissemination strategies (56) Increased communication between researchers and journalists may generate long-term “ <i>knowledge benefits</i> ” for the public
Approaches to PPE	Active or passive dissemination of HTA reports (through websites and/or plain language communication) <i>Real, relevant, and realistic public involvement cannot take place without more sophisticated public information mechanisms</i> Full guidance published in 2 abbreviated forms (for health care professionals and the public) (62) Public appeals for a review or a reversal of an agency recommendation
Evidence of effectiveness/impact	The content of press articles was compared with the content of 3 HTA reports on the same technologies in Quebec; results revealed good alignment of content between the 2 sources, with some differences in emphasis and a loss of nuance in the media coverage (67)
Feasibility considerations: barriers, challenges, and enablers	Mechanisms must be in place to address appeals to recommendations, if these are solicited; an HTA agency’s governance structure can affect the mechanisms available (18)

Abbreviations: HTA, health technology assessment; NICE, National Institute for Health and Care Excellence; PPE, public and patient engagement.

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