McMaster University

McMaster HEALTH FORUM

EVIDENCE BRIEF

STRENGTHENING PUBLIC AND PATIENT ENGAGEMENT IN HEALTH TECHNOLOGY ASSESSMENT IN ONTARIO

8 MAY 2014

EVIDENCE >> INSIGHT >> ACTION

Evidence Brief:
Strengthening Public and Patient Engagement in Health Technology Assessment in Ontario

8 May 2014

Evidence >> Insight >> Action

McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at the regional/provincial level and at national levels, the Forum harnesses information, convenes stakeholders, and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

Authors

François-Pierre Gauvin, PhD, Lead, Evidence Synthesis and Francophone Outreach, McMaster Health Forum

Julia Abelson, PhD, Faculty, McMaster Health Forum, and Professor, McMaster University

John N. Lavis, MD, PhD, Director, McMaster Health Forum, and Professor, McMaster University

Table of Contents

KEY MESSAGES

What's the problem?

- In recent years, public and patient engagement has emerged as an imperative for more informed, transparent, accountable, and legitimate decisions about health technologies, but health technology assessment (HTA) agencies have grappled with the most meaningful ways to achieve such engagement.
- Efforts to address the challenges of strengthening public and patient engagement in HTA in Ontario will need to consider three aspects of, or contributors to, the problem:
  - o HTA agencies are under pressure (e.g., greater demands for rapid HTAs and HTAs examining multiple technologies, increased scrutiny of HTAs by various groups);
  - o current HTA processes face challenges in incorporating meaningful engagement (e.g., divergent views about what 'public and patient engagement' means, a lack of a solid body of research evidence about the effectiveness of public and patient engagement in HTA, and uncertainty about the most valid way to integrate public and patient input); and
  - o current institutional arrangements limit capacity to engage the public and patients (e.g., many HTA agencies are embedded in complex institutional arrangements contributing to a lack of public awareness about their work and how they relate to coverage decisions, and government officials may be concerned about arms-length agencies engaging the public and patients on their behalf).

What do we know about three elements of a comprehensive approach to address the problem?

- To promote discussion about the pros and cons of potentially viable solutions, we have selected three elements (among many) of a potentially comprehensive approach for strengthening public and patient engagement in HTA in Ontario.
  - o Element 1 – Create a comprehensive and flexible framework to engage the public and patients in the HTA process
    - ▪ We found a limited body of synthesized research evidence that has relevance to identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process, including two reviews focusing explicitly on HTA and 10 addressing other sectors.
  - o Element 2 – Build capacity within HTA organizations to engage the public and patients
    - ▪ We found a limited body of synthesized research evidence that has relevance to this element, most notably frameworks to understand how to promote and embed innovations within organizations, and some examples of HTA agencies that have established dedicated staff and infrastructure to strengthen organizational capacities to engage the public and patients.
  - o Element 3 – Build capacity among the public and patients to engage in the HTA process
    - ▪ We found a limited body of synthesized research evidence that revealed benefits for key components of this element, but some initiatives by HTA agencies can spur reflection about how to build such capacity (e.g., providing orientation and training for new participants and supporting the creation of a coalition of patient organizations actively involved in HTA).

What implementation considerations need to be kept in mind?

- Potential barriers to strengthening public and patient engagement in HTA in Ontario can be identified at the level of the public/patients (e.g., lack of public awareness about HTA processes), practitioners producing HTAs or making recommendations (e.g., difficulties in developing a common vision), HTA agencies (e.g., may lack champions or agents of change necessary to adopt and sustain such innovations), and health system (e.g., some policymakers may worry that public and patient engagement could undermine the efficiency of current processes).
- Efforts to address these barriers need to be attentive to potential windows of opportunity (e.g., Health Quality Ontario is currently developing a corporate public and patient engagement strategy; the Ontario Health Technology Advisory Committee established a Public Engagement Subcommittee to develop a public-engagement framework; and the Health Technology Assessment International's Interest Sub-Group on Patient and Citizen Involvement in HTA is involved in many relevant initiatives that could generate significant momentum).

REPORT

Finding better ways to manage the use and cost of health technologies is among the highest priorities for Canadian health policymakers.(1) 'Technological change,' meaning both innovation that generates new technologies and shifts in the utilization of existing technologies, continues to be a major driver of increased healthcare spending across the country, (2) and is influenced by multiple factors including demographic changes, consumer demands and major developments in fields such as genomics. Within provincial governments, a significant input to managing the health-technology portfolio is the production of health technology assessments (HTAs), which provide information about a technology's clinical- and cost-effectiveness, as well as its impacts on patients and the health system.(1;3) As health policymakers rely more heavily on this information to make difficult determinations about how and which technologies will be covered within the basket of publicly funded services, the scrutiny of the HTA activity that informs these consequential decisions has increased, as have efforts to influence it.(4-7) This has become increasingly apparent in the province of Ontario, where mounting provincial deficits are prompting major reviews of healthcare spending in search of savings, generating renewed public debate about coverage decisions.(8)

In recent years, HTA agencies in Canada and abroad have given more serious consideration to involving a broader range of stakeholders in their work, including patients and service users as well as the broader public.(4;9) However, while both public and patient engagement have gained prominence in the HTA field,(10;11) progress on this front has been slow and piecemeal.(12)

Ontario has been leading some of the experimentation with public- and patient-engagement initiatives in the Canadian HTA field.(13) More specifically, the Division of Evidence Development and Standards (EDS) at Health Quality Ontario (HQO), and the Ontario Health Technology Advisory Committee (OHTAC), which makes recommendations through the HQO board to the health system and the minister of health for the funding and use of health technologies in the Ontario health system, have invested in several collaborative research initiatives to explore different approaches to engaging various publics in their HTA recommendation-development process.(14-16) While

Box 1: Background to the evidence brief

This evidence brief mobilizes both global and local research evidence about a problem, three elements of a potentially comprehensive approach to addressing the problem, and key implementation considerations. Whenever possible, the evidence brief summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies and to synthesize data from the included studies. The evidence brief does <u>not</u> contain recommendations, which would have required the authors of the brief to make judgments based on their personal values and preferences, and which could pre-empt important deliberations about whose values and preferences matter in making such judgments.

The preparation of the evidence brief involved five steps:
1) convening a Steering Committee comprised of representatives from the partner organization, key stakeholder groups and the McMaster Health Forum;
2) developing and refining the terms of reference for an evidence brief, particularly the framing of the problem and three elements of a comprehensive approach for addressing it, in consultation with the Steering Committee and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
3) identifying, selecting, appraising and synthesizing relevant research evidence about the problem, approach elements and implementation considerations;
4) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence; and
5) finalizing the evidence brief based on the input of several merit reviewers.

The three elements of a comprehensive approach for addressing the problem were not designed to be mutually exclusive. They could be pursued simultaneously or in a sequenced way, and each element could be given greater or lesser attention relative to the others.

The evidence brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants' views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. A second goal of the stakeholder dialogue is to generate action by those who participate in the dialogue and by those who review the dialogue summary and the video interviews with dialogue participants.

each experience has yielded important insights and useful input to the health technology-advisory process, addressing the more comprehensive task of sorting out which publics to engage through which methods and at which juncture in the HTA process has been far more challenging and remains an elusive goal.

This evidence brief and the stakeholder dialogue it was prepared to inform were designed to guide the actions of those involved in strengthening public and patient engagement in HTA in Ontario. In this section of the brief, we propose key definitions to ensure a common conceptual understanding. We also highlight key goals for public and patient engagement in HTA, as well as describe the health policy and HTA context in Ontario. The second section focuses on the key challenges associated with strengthening public and patient engagement in HTA, with an emphasis on the Ontario context. In the third section we propose three elements of a potentially comprehensive approach to address the problem. Lastly, we highlight key implementation considerations for moving forward.

Within this scope, the evidence brief is focused only on the best available research evidence and (as explained in Box 1) does <u>not</u> contain recommendations. Moving from evidence to recommendations would have required the authors to introduce their own values and preferences, and this role is better suited to participants in the stakeholder dialogue. In addition, a number of issues were deemed too broad to be addressed within the scope of this brief, including public and patient engagement in primary research, as well as the engagement of certain stakeholder groups such as industry and provider organizations.

Key definitions

This evidence brief uses several key concepts that need to be defined at the outset. These concepts are: patient, public, community, stakeholder group, engagement, health technology, HTA and health literacy.

In this evidence brief we draw from the work of Facey and her colleagues who distinguished between patients and the public with regards to HTA.(12) A *patient* refers to an individual with experiential knowledge about living with an illness or condition who can provide valuable perspectives about the intended or unintended consequences of current or future health technologies. A patient's family, as well as their informal and family caregivers, are considered under the patient umbrella. These individuals also have experiential knowledge, and can make a significant contribution to understanding the patients' perspectives, especially in a context where patients are unable to communicate their values, needs and preferences.

Box 2: Equity considerations

A problem may disproportionately affect some groups in society. The benefits, harms and costs of elements of a comprehensive approach to address the problem may vary across groups. Implementation considerations may also vary across groups.

One way to identify groups warranting particular attention is to use "PROGRESS," which is an acronym formed by the first letters of the following eight ways that can be used to describe groups†:

- place of residence (e.g., rural and remote populations);
- race/ethnicity/culture (e.g., First Nations and Inuit populations, immigrant populations and linguistic minority populations);
- occupation or labour-market experiences more generally (e.g., those in "precarious work" arrangements);
- gender;
- religion;
- educational level (e.g., health literacy);
- socio-economic status (e.g., economically disadvantaged populations); and
- social capital/social exclusion.

The evidence brief strives to address all Ontarians, but (where possible) it also gives particular attention to two groups:

- those with lower health literacy; and
- those who are not organized in disease-specific organizations or consumer groups.

Many other groups warrant serious consideration as well, and a similar approach could be adopted for any of them.
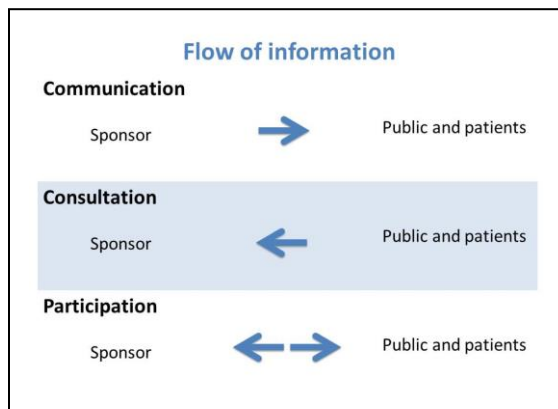
† The PROGRESS framework was developed by Tim Evans and Hilary Brown (Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. *Injury Control and Safety Promotion* 2003;10(1-2): 11–12). It is being tested by the Cochrane Collaboration Health Equity Field as a means of evaluating the impact of interventions on health equity.

The *public* (or 'publics' or 'citizens') refers here to individuals who can contribute broad social values regarding the efficiency or fairness of a technology, but who may not have specific experience with a particular technology, disease or condition.(12) The term *community* is often used interchangeably with the term *public*. However, a community refers more specifically to groups within the public who share certain characteristics (e.g., people living in the same geographic location, or people sharing a special interest, affiliation, socio-economic status, ethno-cultural identity or religious belief).(17) Members of a specific community can also contribute social values regarding the implications of a technology, and sometimes more specifically from their community's perspective.

A *stakeholder group* is defined here as a group with an organized interest in a technology, program or service, including its funding and delivery arrangements (e.g., consumer groups, provider organizations, advocacy groups and industry).

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 various typologies to illustrate different levels or types of engagement in various areas of decision-making,(18-21) which can serve as a source of inspiration for HTA decision-making. This evidence brief draws on the conceptual work of Rowe and Frewer (22) who identified three types of engagement: communication, consultation, and participation (Figure 1). These three types of engagement involve different types of 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 1. Three types of engagement (adapted from Rowe and Frewer, 2005)

Communication refers to information conveyed from the sponsor of the initiative to the public and/or patients.(22) A wide range of communication mechanisms can be used, from pamphlets and mail outs, to e-newsletters, websites and social media (e.g., Facebook, Twitter, YouTube, etc.), as well as publicity in the mass media, public meetings, drop-in centres and telephone information lines.(23) Although this type of engagement is generally passive, other types of engagement are unlikely to take place without proper communication in place, and these activities often play a central role in a more comprehensive engagement process.(20)

Consultation refers to information conveyed from the public and/or patients to the sponsor of the initiative, following a process initiated by the sponsor.(22) A variety of consultation mechanisms are commonly used to gather the public's and patients' perspectives, including interviews, focus groups, polls and surveys, and referendums, as well as soliciting feedback on consultation documents via telephone, mail, email, online forms, interactive websites and social media.(23)

Participation refers to a two-way exchange of information between the public and/or patients and the sponsor of the initiative.(22) A variety of participation mechanisms can be used, such as setting up a collaboration with a patient or public reference group that can provide guidance, appointing patient or public members to a scientific or advisory committee, using co-design approaches (e.g., web 2.0 or experience-based co-design activities), and using more intensive deliberative methods (e.g., patient/citizen panels, juries or councils, consensus conferences, deliberative polls and planning cells).(23)

The evidence brief draws on the Ontario Health Technology Advisory Committee's definition of *health technology*. 'Health technologies' refer to "a wide range of procedures, devices, and equipment applied to the maintenance, restoration, and promotion of health. They encompass interventions at any stage of health care including primary prevention, early detection of disease and risk factors, diagnosis, treatment, rehabilitation, and palliative care."(24)

The evidence brief also draws on the International Network of Agencies for Health Technology Assessment's definition of *HTA*. HTA refers to "the systematic evaluation of properties, effects, and/or impacts of health care technology. It may address the direct, intended consequences of technologies as well as their indirect, unintended consequences. Its main purpose is to inform technology-related policymaking in health care. HTA is conducted by interdisciplinary groups using explicit analytical frameworks drawing from a variety of methods."(25) Agencies have set up various processes to conduct HTAs that fit their respective mandates and institutional arrangements, but these often include variations of the following five stages: topic selection and prioritization, scoping/framing the HTA, conducting or commissioning an evidence-based analysis, formulating recommendations, and disseminating findings and recommendations. In Ontario, the process to conduct HTAs that was set up by Health Quality Ontario is known as the "evidence review process" (Figure 2).(26)

Lastly, another key concept must be defined at the outset since it can have important implications for public and patient engagement in HTA - *health literacy*. Here we draw on the work of the Canadian Expert Panel on Health Literacy, which defines health literacy as "the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course."(27)

Goals for public and patient engagement in HTA

The case for public and patient engagement in HTA is a compelling one, as it can achieve democratic, scientific, instrumental and developmental goals (Table 1).(4)

Table 1. Theorized goals of public and patient engagement in HTA

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

From a democratic perspective, public and patient engagement is central to promoting accountable health systems that are responsive to public and patients' values and expectations, and to those of taxpayers who are the shareholders in publicly financed health systems.(28-30) Indeed, public and patient engagement has been a priority for Canadian health system decision-makers for some time.(31;32) In a context of scarce resources and rapid technological change, policymakers are increasingly faced with complex and contentious coverage decisions.(5;33) This has caused public and patient engagement to emerge as a political imperative for more informed, transparent, accountable and legitimate decisions about health technologies.(4;20)

The value of public and patient engagement has also gained traction as a way of promoting a more robust and comprehensive science of HTA. Against the political and ethical backdrops of the health technology policy landscape, clinical- and cost-effectiveness evidence 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 ethical and social values into HTAs,(34) to greater patient-focused HTAs incorporating the patients' values, needs, preferences and lived experiences,(11;12;35) and also to involving a broader range of stakeholders including patients and service users as well as the broader public in conducting HTAs.(4;11;36)

Public and patient engagement in HTA can also be promoted for achieving more instrumental goals, or in other words, to make better quality decisions across all the stages of an HTA.(4) Thus, an HTA agency may be looking for the most meaningful ways to gather public and patient input to improve the prioritizing of requests, the scoping of the assessment topic, the development of recommendations, or the dissemination of findings.(12;20)

Lastly, public and patient engagement 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 health technology-policy issues.(4;20)

Key features of the health policy and HTA context in Ontario

The following key features of the health policy context are particularly relevant to health technology assessment in Ontario:
- the organization and delivery of healthcare is primarily the responsibility of provincial and territorial governments in Canada, and financing is shared between the federal and provincial/territorial governments;
- responsibility for health technologies is divided across the federal government (e.g., for assessments of safety and effectiveness that are required for pre-market approval of health technologies) and the provincial/territorial governments (e.g., for coverage decisions); and
- while some provinces rely primarily on their own HTA infrastructure (e.g., Health Quality Ontario's Evidence Development and Standards branch and Quebec's Institut national d'excellence en santé et en services sociaux [INESSS]), others depend on the pan-Canadian agency (i.e., the Canadian Agency for Drugs and Technologies in Health [CADTH]) to support and advise ministers of health and other decision-making authorities with respect to coverage decisions.

The following are key historical events related to the HTA infrastructure in Ontario and its key features at present:
- the Ontario Health Technology Advisory Committee (OHTAC) was created in 2003 as an independent advisory committee to the minister of health and long-term care, with secretariat support from the Medical Advisory Secretariat (a unit within the ministry);(37)
- Health Quality Ontario (HQO) was created in 2010 as an independent government agency established through the *Excellent Care for All Act* with the mandate to monitor and report to the people of Ontario on the quality of their publicly financed health system, to support continuous quality improvement, and to promote healthcare that is supported by the best available research evidence;(38)

- HQO's mandate covers various types of health technologies (e.g., medical devices, procedures, diagnostic, screening and monitoring tests, and services), but not pharmaceuticals;(26)
- OHTAC became a standing advisory committee of the HQO board in 2012 with the mandate to make recommendations about the uptake, diffusion, distribution or removal of health technologies;(39)
- HQO's Evidence Development and Standards branch provides secretariat support to OHTAC and conducts evidence-based reviews to evaluate the effectiveness and cost-effectiveness of health technologies;(40)
- OHTAC's recommendations are based on a careful review of results from HQO's evidence-based reviews through the lens of its decision-determinants framework that considers the overall clinical benefit, value for money, societal and ethical considerations, and the economic and organizational feasibility of the health technologies;(39) and
- using OHTAC's recommendations and advice, the HQO board formulates final recommendations about standards of care for healthcare organizations and other entities across the province, as well as funding recommendations to the minister of health and long-term care.(39)

Lastly, as mentioned earlier, Ontario has been leading some of the experimentation with public and patient engagement initiatives in HTA. The following chronology of events and initiatives describes the key aspects of this context:
- OHTAC established in 2005 a Public Engagement Subcommittee to examine various options for increasing the involvement of the general public in its process;
- OHTAC experimented with various public-engagement modalities between 2008 and 2010, namely:
  - a series of consultation mechanisms (i.e., focus groups, surveys, and polls);(14) and
  - a participation mechanism to encourage citizen deliberation about the societal and ethical values of health technologies (i.e., the Citizens' Reference Panel on Health Technologies);(16)
- 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 healthcare services and medical devices;(38)
- OHTAC re-established the Public Engagement Subcommittee in 2012 to "expand on the public-engagement framework established by the previous OHTAC Public Engagement Subcommittee in developing a comprehensive public-engagement strategy for OHTAC";(41) and
- HQO announced in 2014 the development of a public- and patient-engagement strategy across all HQO activities to ensure that 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."(42)

Current engagement efforts in HQO's evidence-review process

The evidence review process at HQO is composed of seven key steps (Figure 2). Current opportunities for public and patient engagement are available at two of these steps:
- step 4 – professional and public consultation; and
- step 6 – post-review and communication.

Figure 2. Health Quality Ontario's evidence review process (26)

1 SCOPING	2 EVIDENCE-BASED ANALYSIS	3 DRAFT OHTAC RECOMMENDATIONS	4 PROFESSIONAL AND PUBLIC CONSULTATION	5 ASSESSMENT OF COMMENTS	6 POST REVIEW AND RECOMMENDATIONS	7 FIELD EVALUATION

• HQO drafts brief overview of intervention
 	
• OHTAC determines which interventions proceed to a full review
	• HQO reviews evidence in consultation with:
	  - Clinical experts and expert panels
	  - Scientific partners
	  - Industry
	  - Government
		• OHTAC drafts recommendations based on evidence-based review	• Draft review and recommendations are posted on HQO/OHTAC website for public and professional comment	• HQO reviews public and professional comment and feedback
				
				• OHTAC modifies recommendations as required
					• HQO evidence-based review and OHTAC recommendations are published on its website and announced in e-bulletin	• OHTAC may request a field evaluation to assess effectiveness and cost-effectiveness of an intervention in the Ontario context

When OHTAC has reviewed and approved an evidence review and formulated recommendations, a 21-day consultation period is initiated (step 4). The draft review and recommendations, along with a plain-language summary, are posted on the HQO website. HQO notifies relevant stakeholders and any potentially interested parties that the materials have been posted and that they can submit comments by email. Once the 21-day period has concluded, the results of the consultation are presented to OHTAC. OHTAC may request changes to either the review or the recommendations. The report is then posted as final on the HQO website (step 6). Anyone who disagrees with the final recommendations (on the basis of omitted or misinterpreted evidence) can appeal the recommendations within 60 days of the final posting on the HQO website.(26) Thus, the current HQO's evidence-review process mostly relies on passive communication and consultation mechanisms (i.e., posting reviews and recommendations online, soliciting feedback by email, and allowing people to appeal a review or recommendation), and there are no formalized engagement opportunities earlier in the process.

THE PROBLEM

The challenges of strengthening public and patient engagement in HTA can be understood by considering three aspects of, or contributors to, the problem: 1) HTA agencies are under pressure; 2) current HTA processes face challenges in incorporating meaningful engagement; and 3) current institutional arrangements limit capacity to engage the public and patients. Most of these challenges affect the international HTA community as a whole, but whenever possible, we describe how these challenges are manifested in Ontario.

HTA agencies are under pressure

There are various pressures on HTA agencies that are challenging the feasibility and viability of public and patient engagement. These pressures include, but are not limited to: 1) greater demands for rapid HTAs; 2) greater demands for HTAs examining and comparing multiple health technologies; and 3) increased scrutiny of HTAs by patient groups, providers and technology firms.

A recent international survey of HTA agencies revealed that the issue of timeliness features prominently among the list of challenges to engaging the public.(23) Survey respondents indicated a mismatch between the demands from health-system policymakers for rapid HTAs and the time required to conduct high-quality public engagement. This is consistent with another study of international practices indicating that some HTA agencies may step back from public- and patient-engagement activities given the increased pressures for quick and efficient HTAs.(43) In Ontario, HQO is also conducting such 'rapid reviews,' usually within a two-week timeframe, in response to an urgent demand, and in some instances to inform OHTAC's recommendations.(44;45) HQO acknowledges that, given such "urgent timeframes," the usual 21-day consultation process cannot be applied to rapid reviews. However, "in the interest of transparency," HQO welcomes public comment by email at any time.(45)

While there are increased demands for rapid HTAs, there are also greater demands for HTAs that are much broader in scope. Some HTA agencies are now focusing less on single technologies that address single conditions or diseases (e.g., deep brain stimulation for treatment-resistant depression), and more on complex pathways of disease and multiple morbidities that require an array of services and programs. This is the case for HQO, which is increasingly conducting broader reviews, known locally as mega-analyses.(44) These mega-analyses examine and compare multiple health technologies for a given disease or condition (e.g., approaches to lengthening and maintaining people's ability to age in the community). Therefore, thinking about how to engage relevant members of the public and patients is becoming increasingly complex as HTA agencies are starting to address broad topic areas and multiple health technologies.

Lastly, the work of HTA agencies is carefully scrutinized, especially by disease-specific organizations, consumer groups, healthcare providers and technology firms.(5) Health-technology recommendations may be

14

Box 3: Mobilizing research evidence about the problem

The available research evidence about the problem was sought from a range of published and "grey" research literature sources. Published literature that provided a comparative dimension to an understanding of the problem was sought using three search filters (called "hedges") for health services research in MedLine, namely those for appropriateness, processes and outcomes of care (which increase the chances of us identifying administrative database studies and community surveys). We specifically conducted searches using these hedges for 'consumer participation' AND 'patient participation' (both are MeSH terms encompassing various ways to engage the public and patients in decision-making processes pertaining to health, and are used to index journal articles and books in this area) AND 'technology assessment' (the MeSH terms encompassing HTA). Published literature that provided insights into alternative ways of framing the problem was sought using a fourth hedge in MedLine, namely the one for qualitative research. Published literature was also sought by conducting specific searches in the International Journal of Technology Assessment in Health Care using various key terms, including: public/patient/consumer AND engag*/involv*/consult*/participat*. Grey literature was sought by reviewing the websites of a number of local and international organizations, such as Health Quality Ontario (HQO), Health Technology Assessment International (HTAi), and the International Network of Agencies for Health Technology Assessment (INAHTA).

appealed, as is currently allowed under HQO's evidence-review process, or challenged in courts, as we have seen in recent years in other jurisdictions (e.g., the National Institute for Health and Care Excellence's guidance regarding the use of Herceptin for breast cancer, and its guidance about restricting Alzheimer's drugs to only patients with mild-stage disease). Given the potential threat of appeals or court challenges in the background, certain members of the HTA community may become more reluctant to engage with the public and patients, and perceive it as a potential source of vulnerability for their HTA agencies.(43)

Current HTA processes face challenges in incorporating meaningful engagement

Current HTA processes face three sets of challenges in incorporating meaningful public and patient engagement: 1) there are divergent views about what 'public and patient engagement' means; 2) there is a lack of a solid body of research evidence about the effectiveness of public and patient engagement in HTA; and 3) there is uncertainty about the most valid way to integrate public and patient engagement with the other types of evidence being considered.

First, there are divergent views within the HTA community, and sometimes within the same HTA agency, about what 'public and patient engagement' means.(20) Such ambiguity is not unique to the field of HTA and can largely be explained by the highly value-laden, contextual and multifaceted nature of the term 'public and patient engagement.' It is quite common to see and hear various terms that are used inconsistently and interchangeably in the literature and during conversations, which may contribute to this ambiguity: communication, consultation, collaboration, involvement, participation, deliberation or engagement of members of the public, citizens, patients, service users, consumers or community. This ambiguity can have important consequences and lead to conflicting goals and visions for public and patient engagement in HTA,(9;20;23;46) and more practically, conflicting views about who should be engaged, who they represent, what role they should play and at what stages of the HTA process, and using what types of engagement mechanisms.(20;23;47)

Second, there is a lack of a solid body of research evidence about the effectiveness of public and patient engagement in HTA. A consequence of the lack of research evidence is that members of the HTA community are grappling with determining the most effective types of public and patient engagement that should be used, and especially for a given issue or context.(20) A recent international survey reported that among the HTA agencies with public-engagement activities, only a very small number of them have evaluated or are in the process of evaluating their activities to determine their impacts.(23) While this may be promising for the near future, this illustrates the need to encourage robust evaluations of public and patient engagement in HTA using strong theoretical foundations and rigorous methods.

Third, there is uncertainty about the most valid way to integrate public and patient engagement with the other types of evidence considered. Historically, the HTA community has been more concerned with finding and synthesizing clinical evidence (e.g. efficacy, effectiveness and safety) and economic evidence (e.g. costs, cost-effectiveness and efficiency) regarding health technologies. These types of evidence have had a privileged role in HTA in contrast with evidence about organizational issues (e.g., diffusion, accessibility and skills), patient-related issues, and broader societal and ethical issues.(43) This focus on clinical and economic evidence may explain why many HTA agencies lack expertise in public and patient engagement,(23) and in interpreting, synthesizing and weighing such input alongside other types of evidence. In recent years, OHTAC has been investing efforts in developing and refining a multifaceted decision-determinants framework that could guide its recommendations. The framework considers the clinical benefit offered by a health technology (i.e., burden of illness, need, effectiveness and safety), as well as its consistency with societal and ethical values, its value for money (i.e., economic evaluations), and its feasibility of adoption into the health system (i.e., economic and organizational feasibility). Yet, while there are rigorous processes in place to collect and assess clinical and health economics evidence, OHTAC still grapples with the most effective ways to integrate societal and ethical considerations in their advisory process alongside other forms of evidence.

Current institutional arrangements limit capacity to engage the public and patients

Two characteristics of current institutional arrangements may also limit the capacity of HTA agencies to engage the public and patients. First, many HTA agencies are embedded in complex and changing institutional arrangements. For example, the technology-advisory process in Ontario has shifted multiple times in the past years, formerly being part of the Ministry of Health and Long-Term Care and now being part of an arm's-length agency of the Ontario government.(39) A potential consequence of having complex and changing institutional arrangements is that the broader public and certain patient groups may be largely unaware of the work of HTA agencies and how they relate to coverage decisions, and thus the availability of health technologies.(43)

Second, some government officials may be concerned about having arm's-length and quasi-government agencies engaging the public and patients on their behalf. This could create public expectations that they would be unable to fulfil, and reduce their leeway when making difficult coverage decisions. Therefore, they may be apprehensive about having HTA agencies taking part in the risky business of public and patient engagement.(48)

Additional equity-related observations about the problem

An important element of the problem that requires further discussion is how the problem may disproportionately affect certain groups or communities. With respect to public and patient engagement in HTA, many groups warrant particular attention within this broad topic area. However, this evidence brief focuses on two groups for illustrative purposes: those with lower health literacy and those who are not organized in disease-specific organizations or consumer groups.

The challenges of public and patient engagement in HTA are particularly important when considering those with lower health literacy. Health literacy is an important factor enabling public and patient engagement in healthcare.(49) However, it is estimated that 60% of adults and 88% of seniors in Canada are not health literate.(50) This means that they have difficulty accessing, understanding, evaluating and communicating health information. Many groups are particularly likely to have low health literacy, including people over the age of 65, recent immigrants, those with lower income and education, those with limited cognitive and mental capacities, as well as those who are not proficient in English.(27;49) The current level of health literacy poses significant practical challenges to public and patient engagement in HTA: How can you engage patients and members of the public with lower health literacy on health-technology issues? How can you create a space where people with lower health literacy feel confident to make a meaningful contribution to HTA? Moreover, some members of the HTA community have expressed concerns about actively involving lay people in such a complex and specialized domain, and certain agencies have been relying on engagement mechanisms that exclude, de facto, anybody with lower health literacy (e.g., engaging members of the public and patients on expert advisory committees).(20)

Those who are not organized in disease-specific organizations or consumer groups are another group that warrant particular attention. In fact, past experiences suggest that HTA agencies have been more inclined to involve groups that are already organized and informed than they are to approach individual citizens and patients.(9;20;46;51) Representatives of disease-specific organizations or consumer groups are sometimes perceived as being easier to identify, having greater access to resources, and being in a higher state of readiness (and potentially having higher health literacy) to take part in HTA.(20) However, questions often remain about whose perspectives are being represented by these groups and whether they reflect a broad versus narrow set of interests. This illustrates the important challenge of how to identify and select 'representatives,' but also the critical need for HTA agencies to provide the support necessary (i.e., resources and incentives) to enable individual members of the public and patients to engage in HTA.

THREE ELEMENTS OF A COMPREHENSIVE APPROACH FOR ADDRESSING THE PROBLEM

Many elements could be selected as a starting point for deliberations. To promote discussion about the pros and cons of potentially viable solutions, we have selected three elements of a potentially comprehensive approach for strengthening public and patient engagement in HTA in Ontario.

These elements are: 1) create a comprehensive and flexible framework to engage the public and patients in the HTA process; 2) build capacity within HTA organizations to engage the public and patients; and 3) build capacity among the public and patients to engage in the HTA process.

The three elements were identified and selected through a process of consultation with the Steering Committee. The three elements were not designed to be mutually exclusive. They could be pursued simultaneously or sequentially, or elements could be drawn from each element to create a new (fourth) element. They are presented separately to foster deliberations about their respective components, the relative importance or priority of each, their interconnectedness, the potential of (or need for) sequencing, and their feasibility.

In the following section of the evidence brief, we review available research evidence about each element in turn. While some of the research evidence may not deal specifically with public and patient engagement in HTA, it was included since it can provide relevant insights and spur reflection about each element. The principal focus is on what is known about these elements based on findings from systematic reviews as well as economic evaluations or costing studies. We present the findings from systematic reviews along with an appraisal of whether their methodological quality (using the AMSTAR tool) is high (scores of 8 or higher out of a possible 11), medium (scores of 4-7) or low (scores less than 4) (see the appendix for more information about the quality-appraisal process).(52)

Box 4: Mobilizing research evidence about elements of a comprehensive approach for addressing the problem

The available research evidence about elements of a comprehensive approach for addressing the problem was sought primarily from Health Systems Evidence (www.healthsystemsevidence.org), which is a continuously updated database containing more than 3,800 systematic reviews and more than 1,900 economic evaluations of delivery, financial and governance arrangements within health systems. The reviews and economic evaluations were identified by searching the database for documents addressing features of each of the elements and sub-elements.

The authors' conclusions were extracted from the reviews whenever possible. Some reviews contained no studies despite an exhaustive search (i.e., they were "empty" reviews), while others concluded that there was substantial uncertainty about the elements based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the reviews' quality, the local applicability of the reviews' findings, equity considerations, and relevance to the issue. (See the appendices for a complete description of these assessments.)

Being aware of what is not known can be as important as being aware of what is known. When faced with an empty review, substantial uncertainty, or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an element could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a review that was published many years ago, an updating of the review could be commissioned if time allows.

Only targeted searches for additional research evidence were conducted to complement what was included in the systematic reviews. Those interested in pursuing a particular element may want to search for a more detailed description of the element or for additional research evidence about the element.

Element 1 – Create a comprehensive and flexible framework to engage the public and patients in the HTA process

This element involves the creation of a comprehensive yet flexible framework, which would allow for the engagement of relevant patients and members of the public in Ontario's HTA process depending on the types of technologies and the stages in the HTA process. Such a framework would clearly articulate the goals for public and patient engagement, and guide future decisions about when and how to engage with different publics for different technologies.

More specifically, this element could include:
1) identifying clear goals for each stage of the HTA process, and criteria to decide when and how to engage various publics for different technologies;
2) ensuring conceptual clarity and consistency in the use of public- and patient-engagement terminology so that all stakeholders have a common understanding of the terms and what they mean within Ontario's HTA context;
3) identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process, which may include:
   o models for communicating with the public and patients in relevant phases of the HTA process;
   o models for consulting with the public and patients in relevant phases of the HTA process; and
   o models allowing the public and patients to participate in relevant phases of the HTA process; and
4) identifying strategies to support evaluation and evidence-informed approaches to public and patient engagement.

As mentioned earlier, there is a lack of a solid body of research evidence about what works in terms of public and patient engagement in HTA. However, two recent international surveys (9;23) have relevance to element 1 and can provide insights into five questions about what is currently being done by HTA agencies.
- To what extent are HTA agencies engaging the public and patients?
  o the majority of HTA agencies that provided responses to these surveys indicate that they are engaging the public and patients to varying degrees, and in different phases of the HTA process.(9;23)
- Why are they engaging?
  o the vast majority of HTA agencies are engaging the public and patients to achieve instrumental goals (e.g., informing policy and procedures around HTA, informing specific HTA decisions, informing the public of decisions and their rationale) and scientific goals (e.g., informing value judgments for decision-making).(23)
- Who are they engaging?
  o the vast majority are engaging representatives of public or patient organizations and to a lesser extent individual patients and members of the public.(9;23)
- When are they engaging?
  o the majority of HTA agencies engage the public and patients in the identification of assessment topics (and to a lesser extent in topic selection and prioritization, in refining the scope and nature of HTA projects, and in developing HTA protocols, although there has been a shift away in recent years from engaging the public and patient in the identification of topics and towards greater emphasis on the other phases in the HTA process).(9)
  o the vast majority are contacting the public and patients to solicit information or opinions on the technology being assessed (and to a lesser extent for providing input to the analysis or interpreting and reviewing draft HTA reports).(9)
  o the majority are also engaging the public and patients in preparing plain-language materials (e.g., newsletters, one or two page summaries, or 'consumer versions' of HTA reports) and to a lesser extent in disseminating such materials.(9)

- What types of engagement mechanisms are used?
  - communication and consultation mechanisms are most commonly used, although some HTA agencies have experimented with (or are planning to use) more participatory mechanisms (e.g., citizens juries or councils).(23)

While these surveys provide an overview of current efforts, they do not provide an in-depth look at what specific HTA agencies are doing. Thus, we present below an overview of public- and patient-engagement activities of HQO alongside eight other HTA agencies (Table 2). Some HTA agencies have been purposefully selected because they have been pioneers in public- and patient-engagement activities, and others because they are offering a diversity of ways to engage the public across the five phases of the HTA process.

Table 2: Comparing what is currently done by select HTA agencies around the globe

HTA agencies		Stages in the HTA process				
		Topic selection and prioritization	Scoping/framing the HTA	Conducting or commissioning evidence-based analyses	Formulating recommendations	Disseminating findings and recommendations
CANADA	Health Quality Ontario (ON) (26)				• 21-day online public consultation on draft recommendations	• Evidence-based reviews and recommendations posted online • Appeal process
	Canadian Agency for Drugs and Technologies in Health (CAN) (53)		• Online submissions from patient groups requested to inform the Common Drug Review (CDR) process		• Two public members appointed to the 13-member Canadian Drug Expert Committee	• CDR Recommendations & Reasons for Recommendations published online
INTERNATIONAL	Gemeinsamer Bundesausschuss (Germany) (54)	• Patient representatives can suggest topics for technology appraisal		• Call for evidence from public via posting notice of technology selected for review for one month targeting patient and professional organizations	• Up to five patient group representatives participate in board meetings and technology appraisal committees • Draft protocols and draft reviews are posted on website for public comment	• Patient representatives can take part in a press conference following completion of technology appraisal
	Haute Autorité de Santé (France) (54)			• Public input on controversial topics via focus groups or public consultations	• Two patient representatives on two (of four) dedicated evidence-appraisal committees	• Documents summarizing stakeholder meetings are publicly available online
	Medical Services Advisory Committee (Australia) (55)				• Draft guidelines posted online for public comment; specific request for views about incomplete content	
	National Institute for Health and Care Excellence (U.K.) (56)		• Consultation with patients, carers and voluntary organizations/charities, through written comments and multi-stakeholder workshop	• Consultation with patients, carers and voluntary organizations/charities, through written evidence submissions and personal testimony	• Lay members (minimum two, often three, sometimes six) on decision-making committees and advisory groups part of each topic's 'lead team' to ensure patient evidence is presented at the meeting • Patient experts giving oral testimony at committee meeting • Citizens Council meets annually to provide input on societal values	• Patient and public versions of NICE guidance
	NIHR Health Technology Assessment Programme (U.K.) (57)	• Online form for public and patients to suggest topics	• Involving public or patient representatives on boards or panels, as well as soliciting 'public reviewers'			
	Scottish Medicine Consortium (U.K.) (53)			• Voluntary groups and health charities are invited to submit written evidence to the consortium in the form of a Patient Interest Group Submission	• Three public members are appointed to the Consortium committee • Public members present Patient Interest Group Submission at monthly consortium meetings	
	Washington State Health Technology Assessment Program (U.S.A.) (58)	• 30-day posting of proposed and final topic selections for public comment • Currently developing a process for public input into the selection of a technology for assessment		• Contribution to evidence reviews • Submission of evidence for 30 days following the announcement of selection	• 30-day period to comment on draft reports	

We found a limited body of synthesized research evidence that has relevance to element 1. Four key observations can be made:

- we found no systematic reviews that could inform how to identify clear goals for each stage of the HTA process, and criteria to decide when and how to engage (sub-element 1), how to ensure conceptual clarity and consistency in the use of public- and patient-engagement terminology (sub-element 2), and how to support evaluation and evidence-informed approaches to public and patient engagement (sub-element 4);
- we found 12 systematic reviews that have relevance to identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process (sub-element 3), two of which focus explicitly on public and patient engagement in HTA (10;59) and 10 addressing public and patient engagement to inform various health policies and decisions;(60-69)
- these reviews generally found a lack of evidence about the impacts of public and patient engagement, but suggested potential instrumental benefits (e.g., including patient preferences and patient-relevant outcomes in HTAs) and developmental benefits (e.g., raising public awareness and understanding); and
- while there is great diversity in the public- and patient-engagement strategies implemented in HTA, a recent and medium-quality review examining international experiences revealed two trends:(10)
    - consulting patients to gather evidence about their perspectives, experiences and preferences about health technologies during the evidence review phase; and
    - more active participation of public and patient representatives in other stages of the HTA process, such as defining priorities, scoping, assessing the evidence and disseminating findings.

A summary of the key findings from the synthesized research evidence is provided in Table 3. For those who want to know more about the systematic reviews contained in Table 3 (or to obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 1.

Table 3: Summary of key findings from systematic reviews relevant to Element 1 – Create a comprehensive and flexible framework to engage the public and patients in the HTA process

Category of finding	Summary of key findings
Benefits	**Identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process** *Public and patient engagement in HTA* - A recent and medium-quality review found some evidence of benefits for public and patient engagement in HTA, such as: (10) - including patients' preferences and patient-relevant outcomes in HTAs; - considering the sociopolitical context in which health technologies will be used and other important factors that may affect implementation; - refining topics and developing criteria to guide priority-setting; and - increasing overall agreement in terms of priorities between consumer groups and professionals. *Public engagement in other domains* - A recent and medium-quality review found benefits for the use of public deliberation methods (e.g., citizen panels and juries, consensus conferences, planning cells) in:(61) - bringing insights into social values; - improving understanding of complex issues (particularly ethical and social dilemmas); and - enhancing civic-mindedness. - A recent and medium-quality review found benefits for public involvement in healthcare policy, such as:(62) - enhancing awareness and understanding of healthcare issues; and - enhancing competencies among lay participants. - A recent and medium-quality review found some evidence that the use of citizen juries in health policy decision-making allowed citizens to engage with evidence, deliberate and advise.(70) *Patient engagement in other domains* - An older medium-quality review found several benefits related to patient engagement in

	the planning and development of healthcare, which include: (60)
	    • improved self-esteem for patients;
	    • rewarding experience for healthcare staff;
	    • production of updated/improved patient-information resources;
	    • improved healthcare services; and
	    • improved organizational attitudes that are supportive of patient involvement.
	  o *Public and patient communication in other domains*
	    ▪ An older high-quality Cochrane review found that the benefits of consumer involvement (as compared to no involvement) were greatest in activities related to the creation of patient-information materials.(63)

Potential harms	• **Identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process**
	  o *Public and patient communication in other domains*
	    ▪ A recent and medium-quality review highlighted concerns about user-generated content on social media and web 2.0 applications, which can be inconsistent with clinical guidelines or scientific evidence.(66)

Costs and/or cost-effectiveness in relation to the status quo	• **Identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process**
	  o *Public and patient engagement in HTA*
	    ▪ An older and low-quality review examining the NIHR's HTA program, while not explicitly providing information about costs, suggested that effective public and patient engagement required sustained efforts and resources, including payment of public participants.(59)
	  o *Public and patient engagement in other domains*
	    ▪ An older and low-quality review found that costs related to public engagement activities are rarely reported, but noted that well-structured processes range from tens of thousands of dollars to $1 million or more.(68)

Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	• Uncertainty because no systematic reviews were identified
	  o **Identifying clear goals for each stage of the HTA process, and criteria to decide when and how to engage various publics for different technologies**
	  o **Ensuring conceptual clarity and consistency in the use of public- and patient-engagement terminology so that all stakeholders have a common understanding of the terms and what they mean within Ontario's HTA context**
	  o **Identifying strategies to support evaluation and evidence-informed approaches to public and patient engagement**
	• Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review
	  o Not applicable
	• No clear message from studies included in a systematic review
	  o **Identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process**
	    ▪ *Public and patient engagement in HTA*
	      • A recent and medium-quality review (10) examining international experiences, and an older and low-quality review (59) focusing on the National Institute of Health Research's HTA program, found a lack of evidence about the impact of public and patient engagement in HTA.
	    ▪ *Public and patient engagement in other domains*
	      • Several reviews found a lack of evidence about the impact of public and patient engagement on healthcare policies (62;63;69) and healthcare priority setting,(68) most likely due to a lack of formal evaluations as well as clear outcomes and indicators of success.
	    ▪ *Public and patient communication in other domains*
	      • A recent and medium-quality review found limited evidence to support the effectiveness of web 2.0 media on health promotion, or to support such media's capacity in reaching underserved and marginalized populations.(66)

Key features of the element if it was tried elsewhere	• **Identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process**
	  o *Public and patient engagement in HTA*
	    ▪ A recent and medium-quality review revealed great diversity in the public and patient engagement activities conducted in HTA, but two trends emerged:(10)
	      • consulting patients to gather evidence about their perspectives, experiences and preferences about health technologies; and

	- public and patient participation in defining priorities, scoping, assessing the evidence and disseminating findings. - An older and low-quality review examining the experiences of the National Institute of Health Research's HTA program revealed that public involvement strategies were mainly developed in the identification of topics and mostly in prioritization processes, where it was perceived as having the greatest opportunity to influence assessments. There was also some involvement in commissioning research, but minimal involvement in monitoring and none in publication and dissemination of findings.(59) - A recent and medium-quality review found the following challenges to engaging patients and the public in HTA:(10) - recruitment is sensitive and time-consuming; - collaboration with consumer organizations may be difficult, because they may have very strongly held beliefs and could be less willing to be constrained by research evidence; - patient and public representatives may grapple with the role they have to play; - the speed at which discussions take place, unfamiliarity with the HTA process and the use of technical language and acronyms; - HTA practitioners may not be familiar with consumer organizations; - time and resources required for involving the general public; and - finding meaningful ways to integrate the public and patients' input. - Two reviews found the following facilitators to engaging patients and the public in HTA: - inviting people who have experience related to the topic (i.e., focused invitations); (10) - offering mentorship, training and support to participants;(10;59) - an open working style and innovative culture in HTA organizations;(10) - dedicated staff time and regular feedback;(59) and - payments for participants.(59) ○ *Patient engagement in other domains* - An old and medium-quality review found that training of patients and healthcare professionals is an important component for successfully involving cancer patients in research, policy, planning and practice.(67) ○ *Pubic engagement in other domains* - A recent medium-quality review outlined that the mechanisms used for public engagement need to be adapted according to the context of policy development around the issue (e.g., by forming the group in ways that are sensitive to the type of topic, history of the issue and possible power dynamics).(69) - An older medium-quality review reported on a diverse set of methods used for eliciting public values (e.g., ranking of services or programs, rating of options, making explicit choices between options, individual interviews, a Delphi process, focus groups, citizen juries and town hall meetings) to inform resource allocation decision-making, and noted that no single approach can be defined as the gold standard, and suggested that instead selection of an approach should be completed after considering population-specific factors.(65) - A recent and medium-quality review found that special attention should be paid to recruitment, independent oversight, jury duration and moderation when using citizen juries in health policy decision-making.(70)
Stakeholders' views and experience	**Identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process** ○ *Public and patient engagement in other domains* - A recent medium-quality review found that those who participate in well-designed interactive public-engagement processes report high levels of satisfaction across different components of the process (e.g., communication of objectives, adequacy of the information materials provided to inform discussions and the logistics and management of the deliberation), as well as increased levels of topic-specific learning.(69)

Element 2 – Build capacity within HTA organizations to engage the public and patients

This element involves the development of capacities within HTA organizations to engage with the public and patients. This element also highlights the need to develop a shared vision and common understanding among members of the HTA community about what 'public and patient engagement' means, learn and share best practices in order to develop expertise in this area, and ensure that these innovative practices become embedded within HTA organizations and the HTA processes.

More specifically, this element could include:
1) disseminating within the HTA community a clear and consensual public- and patient-engagement terminology so that all stakeholders have a common understanding of the terms and what they mean within Ontario's HTA context;
2) developing partnerships with other HTA agencies across Canada and internationally that have implemented public- and patient-engagement processes and that could offer advice and mentorship;
3) establishing a coordinated knowledge-translation strategy to support the communication and implementation of optimal public- and patient-engagement practices; and
4) identifying strategies for promoting and embedding- public and patient-engagement innovations.

Several initiatives can provide insights about how to build capacity within HTA organizations to engage the public and patients. Some HTA agencies are relying on dedicated staff and infrastructure that have been established with the explicit aim to strengthen organizational capacities to engage. For instance, the National Institute for Health and Care Excellence (NICE) in the United Kingdom established the Public Involvement Programme, with the mandate (among other things) to provide guidance and support about how to involve the public, and evaluate current practices.(71) Another notable example is INVOLVE, a group established and funded by the National Institute for Health Research in the United Kingdom. INVOLVE is a national advisory group with the mandate to promote and monitor public involvement in research, as well as to disseminate best practices and offer training.(72)

Another initiative that can provide insights about how to build capacity within HTA organizations is the HTAi Interest Sub-Group on Patient and Citizen Involvement in HTA. This vibrant international community of practice is dedicated to promoting and developing robust methodologies that integrate public and patient perspectives in HTA, sharing best practices, and supporting HTA organizations in engaging the public and patients. This group is currently involved in various projects that could make an important contribution, such as: developing a Patient Submission Template to enable patients to submit information for a given HTA; conducting a consensus process to formulate values and quality standards statements for patient involvement in HTA; and developing a repository of public- and patient-engagement methodologies, resources and good practices.(73)

We also found a limited body of synthesized research that can be drawn upon to inform components of element 2. Three key observations can be made:
- there is insufficient evidence to draw firm conclusions about the effectiveness of knowledge-translation strategies (sub-element 3),(74-77) but information products designed to support the uptake of research evidence may be effective under certain conditions, notably those products for which there is a single clear message, the change is relatively simple to accomplish, and there is a growing awareness by users of the evidence that a change in practice is required;(76)
- there is limited evidence about effective strategies for promoting and embedding innovations within organizations,(78;79) or alternatively to change organizational culture (i.e., beliefs, values, norms of behaviour, routines, traditions and sense-making),(80) but two reviews identified potential factors influencing the adoption of innovations (e.g., characteristics of the innovation, system antecedents for innovation, system readiness for change, characteristics of the adopter, inter-functional and inter-organizational co-ordination and collaboration, and other contextual factors);(78;79) and

24

- we found no systematic reviews that could inform how to disseminate within the HTA community a clear and consensual public- and patient-engagement terminology (sub-element 1), or how to develop partnerships with other HTA agencies across Canada and internationally that could offer advice and mentorship (sub-element 2).

A summary of the key findings from the synthesized research evidence is provided in Table 4. For those who want to know more about the systematic reviews contained in Table 4 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 2.

Table 4: Summary of key findings from systematic reviews relevant to Element 2 – Build capacity within HTA organizations to engage the public and patients

Category of finding	Summary of key findings
Benefits	- **Establishing a coordinated knowledge-translation strategy to support the communication and implementation of optimal public- and patient-engagement practices** o A recent and high-quality Cochrane review found that information products designed to support the uptake of systematic review evidence were effective under certain conditions: there is a single clear message, the change is relatively simple to accomplish, and there is a growing awareness by users of the evidence that a change in practice is required.(76)
Potential harms	- None identified
Costs and/or cost-effectiveness in relation to the status quo	- None identified

Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	- Uncertainty because no systematic reviews were identified
	  o **Disseminating within the HTA community a clear and consensual public- and patient-engagement terminology so that all stakeholders have a common understanding of the terms and what they mean within Ontario's HTA context**
	  o **Developing partnerships with other HTA agencies across Canada and internationally that have implemented public and patient engagement processes and that could offer advice and mentorship**
	- Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review
	  o **Identifying strategies for promoting and embedding public- and patient-engagement innovations**
	    ▪ An older but high-quality Cochrane review found no studies that met their quality criteria or that examined the effectiveness of strategies aimed at changing organizational culture (i.e., beliefs, values, norms of behaviour, routines, traditions and sense-making) to improve performance in healthcare settings.(80)
	- No clear message from studies included in a systematic review
	  o **Establishing a coordinated knowledge-translation strategy to support the communication and implementation of optimal public- and patient-engagement practices**
	    ▪ Several systematic reviews, including two recent and high-quality reviews, found insufficient evidence to draw conclusions about the effectiveness of interventions that have been designed for encouraging the use of research evidence by health policymakers and managers.(74-77)
	  o **Identifying strategies for promoting and embedding public- and patient-engagement innovations**
	    ▪ An old overview of systematic reviews and an older medium-quality review found limited evidence about the effectiveness of strategies for promoting and embedding innovations.(78;79)

Key features of the element if it was tried elsewhere	- **Identifying strategies for promoting and embedding public- and patient-engagement innovations**
	  o An old overview of systematic reviews identified promising tools for spreading innovations, including: (78)
	    ▪ formal published evidence;
	    ▪ decision and dissemination support tools (e.g., guidelines);
	    ▪ organizational and inter-organizational networks;
	    ▪ leadership development; and

	▪ evaluation and review.
Stakeholders' views and experience	• **Establishing a coordinated knowledge-translation strategy to support the communication and implementation of optimal public- and patient-engagement practices**
	o Several systematic reviews, including a recent and high-quality Cochrane review, have identified facilitators for policymakers' and stakeholders' use of research evidence, the most commonly cited being facilitated interactions between the users and producers of research evidence, and ensuring timely access to research evidence. Barriers included a lack of awareness and familiarity, a lack of usefulness, a lack of motivation, and other external barriers.(76;81-84)
	o A recent and medium-quality review revealed that such barriers may be overcome by adapting and presenting the findings in formats more directly tailored to their needs (e.g., providing summaries, overviews and policy briefs added value to systematic reviews, or evaluating their methodological quality and the applicability of the findings to particular settings).(82)
	• **Identifying strategies for promoting and embedding public- and patient-engagement innovations**
	o An old overview of systematic reviews revealed success factors for embedding innovations, such as:(78)
	▪ inter-functional and inter-organizational co-ordination and collaboration;
	▪ multifaceted implementation approaches facilitating interaction between the innovation, the intended audience and the context;
	▪ adapting innovations to the local context;
	▪ a receptive climate for innovation (although this may develop gradually and vary over time);
	▪ engaging users and other stakeholders as active agents of change, rather than passive recipients of innovations;
	▪ financial or other types of incentives for users and other stakeholders;
	▪ active campaigns to market the innovation and get the information out to a wider audience;
	▪ build capacity within organizations;
	▪ nurturing networks or communities of practice; and
	▪ supporting leadership and organizational connectedness at all levels.
	o The authors of an old and medium-quality review proposed a conceptual model for considering the determinants of diffusion, dissemination and implementation of innovations, which include, but are not limited to:(79)
	▪ characteristics of the innovation (e.g., relative advantages, compatibility, low complexity and risk);
	▪ system antecedents for innovation (e.g., system structure, capacity to absorb new knowledge, and receptive context for change);
	▪ system readiness for change (e.g., tension for change, power balances, dedicated time/resources);
	▪ characteristics of the adopter (e.g., needs, motivation, values, skills and social networks);
	▪ communication and influence (e.g., peer opinions, champions and change agents);
	▪ implementation process (e.g., decisions being devolved to frontline teams, hands-on approach by leaders and managers);
	▪ linkages during the design and implementation stages (e.g., effective knowledge translation, user engagement, project management support); and
	▪ outer context (e.g., sociopolitical context, incentives and mandates, political directives).

Element 3 – Build capacity among the public and patients to engage in the HTA process

This element involves raising public awareness, but also strengthening the capacity among the public and patients to be able to effectively engage in Ontario's HTA process.

More specifically, this element could include:
1) launching a public awareness campaign via mass media or social media about Ontario's HTA process, and encouraging understanding of the importance of public and patient engagement;
2) establishing a specialized service providing personal support and coaching to members of the public and patients who want to engage in Ontario's HTA process;
3) developing and sustaining a network of patients, families, caregivers, disease-specific organizations, consumer groups and other relevant publics who can be called upon to contribute to Ontario's HTA process; and
4) identifying effective strategies to engage people with low health literacy.

Several initiatives can provide insights about how to build capacity among the public and patients to engage in the HTA process. The Patient Involvement and Education Working Group, part of HTAi Patient and Citizen Involvement Interest Sub-Group, identified several initiatives led by HTA agencies to support the public and patients, including:(53)
- providing orientation and training for new participants (e.g., orientation for reviewers and new members of the Canadian Drug Expert Committee);
- conducting presentations and workshops for patient organizations (e.g., introductory courses to NICE and to health economics, and preparing for a technology appraisal course offered by NICE's Public Involvement Programme);
- creating infrastructures and dedicating staff to provide information, training and practical support to the public and patients (e.g., NICE's Public Involvement Programme in the United Kingdom and secretariat of the Scottish Medicines Consortium); and
- supporting the creation of a coalition of patient organizations actively involved in HTA (e.g., Patients Involved in NICE known as the PIN coalition in the United Kingdom).

We also found a limited body of synthesized research evidence that can be drawn upon to inform components of element 3. Four key observations can be made:
- two systematic reviews found benefits for planned mass-media campaigns and unplanned mass-media coverage on the utilization of health services (85) and using social media for health communication (sub-element 1);(64)
- a recent and medium-quality review generally found that multimedia and printed materials performed equally well to educate patients with lower health literacy (sub-element 4);(86)
- we found no systematic reviews that have relevance to establishing a specialized service providing personal support and coaching to members of the public and patients who want to engage in Ontario's HTA process (sub-element 2), or about developing and sustaining a network of patients, families, caregivers, disease-specific organizations, consumer groups and other relevant publics who can be called upon to contribute to Ontario's HTA process (sub-element 3); and
- one Cochrane systematic review that is currently being planned will examine the effectiveness of interventions for improving health literacy (sub-element 4).(87)

A summary of the key findings from the synthesized research evidence is provided in Table 5. For those who want to know more about the systematic reviews contained in Table 5 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 3.

Table 5: Summary of key findings from systematic reviews relevant to Element 3 – Build capacity among the public and patients to engage in the HTA process

Category of finding	Summary of key findings

Benefits	• **Launching a public awareness campaign via mass media or social media about Ontario's HTA process, and encouraging understanding of the importance of public and patient engagement**
	  o An old but high-quality Cochrane review found benefits for planned mass media campaigns and unplanned mass media coverage on the utilization of health services.(85)
	  o A recent and medium-quality review found benefits of using social media for health communication, such as:(64)
	    ▪ increased interactions with others;
	    ▪ increased availability of information; and
	    ▪ higher potential to make an impact on health policy.
	• **Identifying effective strategies to engage people with low health literacy**
	  o A recent and medium-quality review comparing the effectiveness of multimedia and printed materials for patient education found that both approaches performed equally well.(86)

Potential harms	• **Launching a public awareness campaign via mass media or social media about Ontario's HTA process, and encouraging understanding of the importance of public and patient engagement**
	  o A recent and medium-quality review found limitations of using social media for health communication, including concerns about:(64)
	    ▪ quality and reliability of information generated; and
	    ▪ confidentiality and privacy issues.

Costs and/or cost-effectiveness in relation to the status quo	• None identified

Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	• Uncertainty because no systematic reviews were identified
	  o **Establishing a specialized service providing personal support and coaching to members of the public and patients who want to engage in Ontario's HTA process**
	  o **Developing and sustaining a network of patients, families, caregivers, disease-specific organizations, consumer groups and other relevant publics who can be called upon to contribute to Ontario's HTA process**
	• Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review
	  o Not applicable
	• No clear message from studies included in a systematic review
	  o **Launching a public awareness campaign via mass media or social media about Ontario's HTA process, and encouraging understanding of the importance of public and patient engagement**
	    ▪ An old but high-quality Cochrane review found limited evidence about the characteristics of successful mass media campaigns, and notably about how messages should be framed.(85)
	  o **Identifying effective strategies to engage people with low health literacy**
	    ▪ An old but high-quality Cochrane review found limited evidence to draw firm conclusions about the design and delivery of interventions to improve online health literacy (i.e., the capacity to search, appraise and use online health information).(88)
	    ▪ An old and low-quality review found limited evidence to determine whether audiotapes enhance communication between "hard-to-reach" populations and health professionals.(89)
	    ▪ An old and low-quality review found a lack of evidence about the effectiveness of strategies to improve health literacy.(90)

Key features of the element if it was tried elsewhere	• **Identifying effective strategies to engage people with low health literacy**
	  o A recent and medium-quality review examining the impact of interventions aimed at mitigating the effects of low health literacy identified discrete design features of information material that improved patient comprehension, such as:(91)
	    ▪ presenting essential information by itself or first;
	    ▪ presenting information so that the higher number is better;
	    ▪ adding icon arrays to numerical information; and
	    ▪ adding video to verbal narratives.

Stakeholders' views and experience	• None identified

Evidence >> Insight >> Action

Additional equity-related observations about the three options

In our review of the research evidence, we found no systematic reviews dealing explicitly with one of the two groups prioritized in this evidence brief: people who are not organized in disease-specific organizations or consumer groups. We found a few systematic reviews that dealt explicitly with the second group: people with lower health literacy. However, the synthesized research evidence described in this brief does not allow for drawing strong conclusions about the most effective ways to engage them in HTA.

IMPLEMENTATION CONSIDERATIONS

A number of barriers might hinder the implementation of certain elements, which needs to be factored into any decision about whether and how to pursue any given element (Table 6). Potential barriers to strengthening public and patient engagement in HTA in Ontario can be identified at the level of the public/patients (e.g., lack of public awareness about the work of HTA agencies and how they relate to coverage decisions), practitioners producing HTAs or making recommendations based on these HTAs (e.g., difficulties developing a common vision for public and patient engagement), HTA agency (e.g., some organizational leaders may be unwilling to make long-term sustainable financial commitments towards building HTA practitioners' capacities due to budget uncertainties), and health system (e.g., some policymakers may worry that public and patient engagement could slow down and increase the complexity of current processes).

A detailed list of potential barriers to implementing the three elements is provided in Table 6 as a way to spur reflection about some of the considerations that may influence choices about an optimal way forward. We have listed the barriers that were identified in a range of sources (not just empirical studies) and we have not rank ordered them in any way.

Table 6:   Potential barriers to implementing the elements

Levels	Element 1 – Create a comprehensive and flexible framework to engage the public and patients in the HTA process	Element 2 – Build capacity within HTA organizations to engage the public and patients	Element 3 – Build capacity among the public and patients to engage in the HTA process
Public/Patients	None identified	None identified	The public and patients may be frustrated by past engagement efforts which they may not feel have meaningfully influenced policymaking The public and patients may not perceive value in being engaged in HTA The public and patients may have limited literacy skills or knowledge preventing them from engaging meaningfully in HTA-related capacity building The public and patients may be unaware of the existence of the HTA agency and its link to coverage decisions regarding health technologies Patient and consumer organizations may be reluctant to join a network that can be called upon to contribute to Ontario's HTA process because it may be perceived as a threat to their independence
HTA practitioners (i.e., people producing HTAs or making recommendations)	Practitioners may face difficulties in developing a shared vision for public and patient engagement in HTA	Some practitioners may be unwilling to participate in developing or implementing new practices that may challenge their professional	None identified

30

	Some practitioners may be unwilling to participate in developing or implementing new practices that could challenge their professional authority and resources (11;92;93) Some practitioners may grapple with the tensions between a traditional focus on clinical and economic evidence and pressures to incorporate patient/social values input Some practitioners may perceive that engaging the public and patients will politicize what should be a 'neutral' evidence-informed process Some practitioners may challenge the robustness of social/patient values as a valid source of evidence Some practitioners may believe that the public and patients are unable to contribute meaningfully	authority and resources (11;92;93) Some practitioners may grapple with prevalent and persistent misconceptions about what 'public and patient engagement' means Some practitioners may not be inclined to obtain additional training without tangible incentives Some practitioners may not perceive value in engaging the public and patients	
HTA agency	Some organizational leaders may worry that involving public and patient groups could threaten their scientific credibility and political autonomy (94) Some organizational leaders may worry that public and patient engagement could slow down and increase the complexity of current processes (10;43) Organizational leaders may face difficulties in developing a shared vision for public and patient engagement given their constraints and competing priorities Some HTA agencies may lack the time, resource and expertise required to support high-quality public and patient engagement	Some organizational leaders may be unwilling or uninterested in making long-term sustainable financial commitments towards building HTA practitioners' capacities due to budget uncertainties for their existing programs and services Some organizational leaders may not see value in investing heavily in education and training, especially those with frequent staff turnover and limited resources Some organizational leaders may lack the capacity to coordinate consistent educational content and activities Some HTA agencies may lack the knowledge/skills to engage with particular populations (e.g., Ontario's First Nations populations) or the infrastructure to engage particular groups (e.g., hearing-impaired patients) Some HTA agencies may lack champions or agents of change	Some organizational leaders may be unwilling or uninterested in making long-term sustainable financial commitments towards building the public's and patients' capacities due to budget uncertainties for their existing programs and services Some organizational leaders may have difficulty with multi-organizational initiatives that are subject to changes outside their control Some organizational leaders may have difficulty ensuring that educational activities reach all those who could benefit, including hard-to-reach groups Some organizational leaders may be reluctant to collaborate with patient or consumer groups, which may have strongly held beliefs inconsistent with research evidence (10)

		necessary to adopt and sustain public- and patient-engagement innovations	
Health system	Some policymakers may worry that public and patient engagement could slow down and increase the complexity of current processes Some health-system stakeholders may challenge engagement efforts on the grounds that they are not representative of Ontario's diverse population (e.g., place of residence, race, ethnicity, culture, occupation, gender, religion, educational level, socio-economic status, and level of social capital/social exclusion)	None identified	None identified

The implementation of the three elements can also be influenced by policymakers' and stakeholders' capacity to take advantage of potential windows of opportunity. These windows of opportunity could facilitate or trigger the improvement of public and patient engagement in HTA in Ontario. Some of these potential windows of opportunity apply to all elements, whereas others are element-specific. A list of potential windows of opportunities for implementing the three elements, again not rank ordered in any way, is provided in Table 7 to spur further reflection.

Table 7: Potential windows of opportunity for implementing the elements

Type	Element 1 – Create a comprehensive and flexible framework to engage the public and patients in the HTA process	Element 2 – Build capacity within HTA organizations to engage with the public and patients	Element 3 – Build capacity among the public and patients to engage in the HTA process
General	Health Quality Ontario is currently developing a corporate public- and patient-engagement strategy to increase collaborations with the public, patients and their families across all their activities.(42) Various health-system stakeholders are engaged in public- and patient-engagement activities in Ontario, which illustrates that people within and outside of the government are paying serious attention to this issue: • the Ontario Citizens' Council was established in 2009 to provide advice regarding the needs, culture and attitudes of Ontario's citizens about government drug policy;(95) • the Change Foundation recently launched its PANORAMA project, a provincial advisory panel comprised of healthcare users and caregivers;(96) • the Ontario Drug Policy Research Network, a province-wide network of researchers providing drug policy-relevant research to decision-makers, is currently involved in various public- and patient-engagement efforts (e.g., implementing citizen panels and interacting with Ontario Citizens' Council);(97) and • the McMaster Health Forum recently launched a citizen-panel program to provide the opportunity for citizens to share their views and experiences on high-priority issues.(98) There are opportunities to learn from HTA agencies in other jurisdictions that have extensive public- and patient-engagement experiences (some of which are currently evaluating their practices and can serve as models for consideration within the Ontario context). There is also an opportunity to build on past and ongoing initiatives of the HTAi Interest Sub-Group on Patient and Citizen Involvement in HTA, which constitutes a vibrant international community of practice dedicated to the issue.(73)		
Element-specific	The OHTAC Public Engagement Subcommittee is currently developing a public-engagement framework, which will be released	The Canadian Foundation for Healthcare Improvement has established a collaborative initiative entitled Partnering with	There is an opportunity to build on ongoing efforts to develop coalitions of patient organizations, such as Patients Involved in

	in the coming months.(41) The OHTAC Decision Determinants Subcommittee is currently revising its decision-determinants framework in ways that will likely give explicit consideration to societal and patient values throughout the OHTAC decision-making process.(99)	Patients and Families for Quality Improvement, which provides funding, coaching and other support for Canadian healthcare organizations that engage patients and families in designing, delivering and evaluating healthcare services.(100)	NICE,(101) the Cochrane Consumer Network,(102) or B.C. Patients as Partners | Patient Voices Network (currently on hold).(103) There is an opportunity to build on ongoing efforts to develop training opportunities for the public and patients, such as the training offered by NICE,(53) the online educational training program developed for patient advocates – eMEET (Medicine Evaluation Educational Training) developed by Eli Lilly (a pharmaceutical company) and endorsed by HTAi,(104) - or other training opportunities like those offered by the department of collaboration and patient partnership at the Université de Montréal,(105) or the European Patients' Academy.(106)

REFERENCES

1. Federal/Provincial/Territorial Health Technology Assessment Task Group. Health Technology Strategy 1.0. Final Report. Ottawa, Canada: Federal/Provincial/Territorial Advisory Committee on Information and Emerging Technologies; 2004.

2. Canadian Institute for Health Information. Health Care Cost Drivers: The Facts. Ottawa, Canada: Canadian Institute for Health Information; 2011.

3. Johnson AP, Sikich NJ, Evans G, Evans W, Giacomini M, Glendining M et al. Health technology assessment: A comprehensive framework for evidence-based recommendations in Ontario. International Journal of Technology Assessment in Health Care 2009;25(2):141-50.

4. Abelson J, Giacomini M, Lehoux P, Gauvin FP. Bringing 'the public' into health technology assessment and coverage policy decisions: From principles to practice. Health Policy 2007;82(1):37-50.

5. Chinitz D. Health technology assessment in four countries: Response from political science. International Journal of Technology Assessment in Health Care 2004;20(1):55-60.

6. Public Policy Forum. Innovating Health: Public Engagement in Health Technology Assessments and Coverage Decisions. Ottawa, Canada: Public Policy Forum; 2011.

7. Flood C. Just Medicare: What's in, What's Out and How We Decide. Toronto, Canada: University of Toronto Press; 2006.

8. Commission on the Reform of Ontario's Public Services. Public Services for Ontarians: A Path to Sustainability and Excellence - Chapter 5: Health. Toronto, Canada: Government of Ontario; 2012.

9. Hailey D, Werko S, Bakri R, Cameron A, Gohlen B, Myles S et al. Involvement of consumers in health technology assessment activities by INAHTA agencies. International Journal of Technology Assessment in Health Care 2013;29(1):79-83.

10. Gagnon MP, Desmartis M, Lepage-Savary D, Gagnon J, St-Pierre M, Rhainds M et al. Introducing patients' and the public's perspectives to health technology assessment: A systematic review of international experiences. International Journal of Technology Assessment in Health Care 2011;27(1):31-42.

11. Bridges JF, Jones C. Patient-based health technology assessment: A vision of the future. International Journal of Technology Assessment in Health Care 2007;23(1):30-5.

12. Facey K, Boivin A, Gracia J, Hansen HP, Lo SA, Mossman J et al. Patients' perspectives in health technology assessment: A route to robust evidence and fair deliberation. International Journal of Technology Assessment in Health Care 2010;26(3):334-40.

13. Levin L, Goeree R, Sikich N, Jorgensen B, Brouwers MC, Easty T et al. Establishing a comprehensive continuum from an evidentiary base to policy development for health technologies: The Ontario experience. International Journal of Technology Assessment in Health Care 2007;23(3):299-309.

14. Bombard Y. Public Engagement Pilot Study on Point-of-Care International Normalized Ratio (INR) Monitoring Devices. Toronto, Canada: Medical Advisory Secretariat, Ontario Ministry of Health and Long Term Care; 2009.

15. Bombard Y, Abelson J, Simeonov D, Gauvin FP. Eliciting ethical and social values in health technology assessment: A participatory approach. Social Science and Medicine 2011;73(1):135-44.

16. Abelson J, Bombard Y, Gauvin FP, Simeonov D, Boesveld S. Assessing the impacts of citizen deliberations on the health technology process. International Journal of Technology Assessment in Health Care 2013;29(3):282-9.

17. National Institute of Health and Care Excellence. Community Engagement. London, United Kingdom: National Institute for Health and Care Excellence; 2008.

18. International Association for Public Participation. IAP2 Public Participation Spectrum. International Association for Public Participation 2014; Available from: http://c.ymcdn.com/sites/www.iap2.org/resource/resmgr/files/iap-006_brochure_a3_internat.pdf

19. Health Canada. The Health Canada Policy Toolkit for Public Involvement in Decision Making. Ottawa, Canada: Health Canada; 2000.

20. Gauvin FP, Abelson J, Giacomini M, Eyles J, Lavis JN. "It all depends": Conceptualizing public involvement in the context of health technology assessment agencies. Social Science and Medicine 2010;70(10):1518-26.

21. Arnstein S. A ladder of citizen participation. Journal of the American Planning Association 1969;35(4).

22. Rowe G, Frewer L. A typology of public engagement mechanisms. Science, Technology & Human Values 2005;30(2):251-90.

23. Whitty JA. An international survey of the public engagement practices of health technology assessment organizations. Value in Health 2013;16(1):155-63.

24. Health Quality Ontario. Terms of Reference - Ontario Health Technology Advisory Committee. Health Quality Ontario 2014; Available from: http://www.hqontario.ca/evidence/evidence-process/about-the-ontario-health-technology-advisory-committee/terms-of-reference

25. International Network of Agencies for Health Technology Assessment. Health Technology Assessment Glossary. International Network of Agencies for Health Technology Assessment 2014; Available from: http://www.inahta.org/Glossary/

26. Health Quality Ontario. Evidence Review Process. Health Quality Ontario 2014; Available from: http://www.hqontario.ca/evidence/evidence-process/evidence-review-process

27. Rootman I, Gordon-El-Bihbety D. A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy. Ottawa, Canada: Canadian Public Health Association; 2008.

28. Wynne B. Public engagement as a means of restoring public trust in science - Hitting the notes, but missing the music? Community Genetics 2006;9(3):211-20.

29. Abelson J, Eyles J. Public Participation and Citizen Governance in the Canadian Health System. In: Forest PG, McIntosh T, Marchildon G, editors. Changing Health Care in Canada: The Romanow Papers, Volume 2.Toronto, Canada: University of Toronto Press; 2004.

30. Bovens M. Public Accountability. In: Ferlie E, Lynn LE, Pollitt C, editors. Oxford Handbook of Public Management.Oxford, United Kingdom: Oxford University Press; 2007.

31. Canadian Health Services Research Foundation, Canadian Institutes of Health Research. Listening for Direction III. National Consultation on Health Services and Policy Issues, 2007-2010. Ottawa, Canada: Canadian Health Services Research Foundation; 2007.

32. Government of Ontario. An Act Respecting the Care Provided by Health Care Organizations (Bill 46). Toronto, Canada: Government of Ontario; 2010.

33. Lehoux P. The Problem of Health Technology: Policy Implications for Modern Health Care Systems. New York, United States: Routledge: Taylor & Francis Group; 2006.

34. DeJean D, Giacomini M, Schwartz L, Miller FA. Ethics in Canadian health technology assessment: A descriptive review. International Journal of Technology Assessment in Health Care 2009;25(4):463-9.

35. Drummond M, Tarricone R, Torbica A. Assessing the added value of health technologies: Reconciling different perspectives. Value in Health 2013;16(1 Suppl):S7-13.

36. Hailey D. Consumer Involvement in HealthTechnology Assessment. Edmonton, Canada: Alberta Heritage Foundation for Medical Research; 2005.

37. Health Quality Ontario. Background and Evolution of OHTAC. Health Quality Ontario 2014; Available from: http://www.hqontario.ca/evidence/evidence-process/about-the-ontario-health-technology-advisory-committee/background-and-evolution

38. Government of Ontario. Excellent Care for All Act. Government of Ontario 2010; Available from: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_10e14_e.htm

39. Health Quality Ontario. About the Ontario Health Technology Advisory Committee. Health Quality Ontario 2014; Available from: http://www.hqontario.ca/evidence/evidence-process/about-the-ontario-health-technology-advisory-committee

40. Health Quality Ontario. Evidence Development and Standards Team. Health Quality Ontario 2014; Available from: http://www.hqontario.ca/evidence/evidence-process/evidence-development-and-standards-team

41. Health Quality Ontario. OHTAC Public Engagement Subcommittee - Terms of Reference. Toronto, Canada: Health Quality Ontario; 2013.

42. Health Quality Ontario. Public and Patient Engagement Strategy. Health Quality Ontario 2014; Available from: http://www.hqontario.ca/about-us/partnerships/public-and-patient-engagement-strategy

43. Gauvin FP, Abelson J, Giacomini M, Eyles J, Lavis JN. Moving cautiously: Public involvement and the health technology assessment community. International Journal of Technology Assessment in Health Care 2011;27(1):43-9.

44. Health Quality Ontario. Types of Evidence Reports. Health Quality Ontario 2014; Available from: http://www.hqontario.ca/evidence/evidence-process/evidence-review-process/types-of-evidence-reports

45. Health Quality Ontario. Rapid Reviews. Health Quality Ontario 2014; Available from: http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/rapid-reviews

46. Hailey D, Nordwall M. Survey on the involvement of consumers in health technology assessment programs. International Journal of Technology Assessment in Health Care 2006;22(4):497-9.

47. Menon D, Stafinski T. Role of patient and public participation in health technology assessment and coverage decisions. Expert Review of Pharmacoeconomics and Outcomes Research 2011;11(1):75-89.

48. Gauvin FP. Public Involvement in Health Technology Assessment Agencies: A Comparative Analysis of Canada, Denmark and the United Kingdom. Hamilton, Canada: Doctoral thesis, McMaster University; 2008.

49. Department of Health. Health Literacy: Enabling Communication and Participation in Health. Melbourne, Australia: State of Victoria, Department of Health; 2013.

50. Public Health Agency of Canada. Health Literacy. Public Health Agency of Canada 2014; Available from: http://www.phac-aspc.gc.ca/cd-mc/hl-ls/index-eng.php

51. Lehoux P, Williams-Jones B. Mapping the integration of social and ethical issues in health technology assessment. International Journal of Technology Assessment in Health Care 2007;23(1):9-16.

52. Shea BJ, Grimshaw JM, Wells GA, Boers M, Andersson N, Hamel C et al. Development of AMSTAR: A measurement tool to assess the methodological quality of systematic reviews. BMC Medical ResearchMethodology 2007;7(10).

53. Patient Involvement and Education Working Group. Good Practice Examples of Patient and Public Involvement in Health Technology Assessment. HTAi 2014; Available from: http://www.htai.org/index.php?id=545

54. Kreis J, Schmidt H. Public engagement in health technology assessment and coverage decisions: A study of experiences in France, Germany, and the United Kingdom. Journal of Health Politics, Policy and Law 2013;38(1):89-122.

55. Medical Services Advisory Committee. Call for Public Comment. Medical Services Advisory Committee 2014; Available from: http://www.msac.gov.au/internet/msac/publishing.nsf/Content/surveys-lp

56. National Institute for Health and Care Excellence. How We Work. National Institute for Health and Care Excellence 2014; Available from: http://www.nice.org.uk/aboutnice/howwework/how_we_work.jsp

57. NIHR Health Teachnology Assessment Programme. Public and Patient Involvement. NIHR Health Technology Assessment Programme 2014; Available from: http://www.nets.nihr.ac.uk/ppi

58. Washington State Health Technology Assessment Program. Stakeholder Engagement. Washington State Health Technology Assessment Program 2014; Available from: http://www.hca.wa.gov/hta/Pages/stakeholder.aspx

59. Moran R, Davidson P. An uneven spread: A review of public involvement in the National Institute of Health Research's Health Technology Assessment program. International Journal of Technology Assessment in Health Care 2011;27(4):343-7.

60. Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N et al. Systematic review of involving patients in the planning and development of health care. British Medical Journal 2002;325(7375):1263.

61. Carman KL, Heeringa JW, Heil SKR, Garfinkel S, Windham A, Gilmore D et al. Public deliberation to elicit input on health topics: Findings from a literature review. Rockville, United States: Agency for Healthcare Research and Quality; 2013.

62. Conklin A, Morris Z, Nolte E. What is the evidence base for public involvement in health-care policy? Results of a systematic scoping review. Health Expectations 2012.

63. Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. Cochrane Database of Systematic Reviews 2006;(3):CD004563.

64. Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication. Journal of Medical Internet Research 2013;15(4):e85.

65. Menon D, Stafinski T, Martin D, Windwick B, Singer P, Caulfield T. State of the Science Review: Incorporating Public Values and Technical Information into Health Care Resource Allocation Decision-Making. Edmonton, Canada: Alberta Innovates - Health Solutions; 2003.

66. Chou WY, Prestin A, Lyons C, Wen KY. Web 2.0 for health promotion: Reviewing the current evidence. American Journal of Public Health 2013;103(1):e9-18.

67. Hubbard G, Kidd L, Donaghy E, McDonald C, Kearney N. A review of literature about involving people affected by cancer in research, policy and planning and practice. Patient Education and Counseling 2007;65(1):21-33.

68. Mitton C, Smith N, Peacock S, Evoy B, Abelson J. Public participation in health care priority setting: A scoping review. Health Policy 2009;91(3):219-28.

69. Abelson J, Montesanti S, Li K, Gauvin FP, Martin E. Effective Strategies for Interactive Public Engagement in the Development of Healthcare Policies and Programs. Ottawa, Canada: Canadian Health Services Research Foundation; 2010.

70. Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. The use of citizens' juries in health policy decision-making: A systematic review. Social Science and Medicine 2014;109C:1-9.

71. National Institute for Health and Care Excellence. Patient and Public Involvement Programme. National Institute for Health and Care Excellence 2014; Available from: http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/ppipinvolvementprogramme.jsp

72. INVOLVE. Terms of Reference. INVOLVE 2014; Available from: http://www.invo.org.uk/about-involve/terms-of-reference/

73. HTAi. Patient and Citizen Involvement. HTAi 2014; Available from: http://www.htai.org/index.php?id=545

74. Mitton C, Adair CE, McKenzie E, Patten SB, Waye PB. Knowledge transfer and exchange: Review and synthesis of the literature. Milbank Quarterly 2007;85(4):729-68.

75. Bunn F, Sworn K. Strategies to promote the impact of systematic reviews on healthcare policy: A systematic review of the literature. Evidence & Policy 2011;7(4):403-28.

76. Murthy L, Shepperd S, Clarke MJ, Garner SE, Lavis JN, Perrier L et al. Interventions to improve the use of systematic reviews in decision-making by health system managers, policy makers and clinicians. Cochrane Database of Systematic Reviews 2012;9:CD009401.

77. Perrier L, Mrklas K, Lavis JN, Straus SE. Interventions encouraging the use of systematic reviews by health policymakers and managers: A systematic review. Implementation Science 2011;6:43.

78. Williams I, de Silva D, Ham C. Promoting and embedding innovation: Learning from experience. Birmingham, United Kingdom: University of Birmingham, Health Services Management Centre; 2009.

79. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: Systematic review and recommendations. Milbank Quarterly 2004;82(4):581-629.

80. Parmelli E, Flodgren G, Schaafsma ME, Baillie N, Beyer FR, Eccles MP. The effectiveness of strategies to change organisational culture to improve healthcare performance. Cochrane Database of Systematic Reviews 2011;(1):CD008315.

81. Wallace J, Byrne C, Clarke M. Making evidence more wanted: A systematic review of facilitators to enhance the uptake of evidence from systematic reviews and meta-analyses. International Journal of Evidence-Based Healthcare 2012;10(4):338-46.

82. Chambers D, Wilson PM, Thompson CA, Hanbury A, Farley K, Light K. Maximizing the impact of systematic reviews in health care decision making: A systematic scoping review of knowledge-translation resources. Milbank Quarterly 2011;89(1):131-56.

83. Innvaer S, Vist G, Trommald M, Oxman A. Health policy-makers' perceptions of their use of evidence: A systematic review. Journal of Health Services Research and Policy 2002;7(4):239-44.

84. Lavis J, Davies H, Oxman A, Denis JL, Golden-Biddle K, Ferlie E. Towards systematic reviews that inform health care management and policy-making. Journal of Health Services Research and Policy 2005;10 Suppl 1:35-48.

85. Grilli R, Ramsay C, Minozzi S. Mass media interventions: Effects on health services utilisation. Cochrane Database of Systematic Reviews 2002;(1):CD000389.

Evidence >> Insight >> Action

86. Wilson EA, Makoul G, Bojarski EA, Bailey SC, Waite KR, Rapp DN et al. Comparative analysis of print and multimedia health materials: A review of the literature. Patient Educ Couns 2012;89(1):7-14.

87. Sparkes L. Interventions for improving health literacy (systematic review being planned). Cochrane Database of Systematic Reviews 2013.

88. Car J, Lang B, Colledge A, Ung C, Majeed A. Interventions for enhancing consumers' online health literacy. Cochrane Database of Systematic Reviews 2011;(6):CD007092.

89. Santo A, Laizner AM, Shohet L. Exploring the value of audiotapes for health literacy: A systematic review. Patient Education and Counseling 2005;58(3):235-43.

90. Schaefer CT. Integrated review of health literacy interventions. Orthopaedic Nursing 2008;27(5):302-17.

91. Sheridan SL, Halpern DJ, Viera AJ, Berkman ND, Donahue KE, Crotty K. Interventions for individuals with low health literacy: A systematic review. Journal of Health Communication 2011;16 Suppl 3:30-54.

92. Ong BN. The lay perspective in health technology assessment. International Journal of Technology Assessment in Health Care 1996;12(3):511-7.

93. Goven J. Assessing genetic testing: Who are the "lay experts"? Health Policy 2008;85(1):1-18.

94. Moynihan R, Oxman AD, Lavis JN, Paulsen E. Evidence-informed health policy: Using research to make health systems healthier. Oslo, Norway: Norwegian Knowledge Centre for the Health Services; 2008.

95. Ministry of Health and Long Term Care. Citizens' Council. Ministry of Health and Long Term Care 2014; Available from: http://www.health.gov.on.ca/en/public/programs/drugs/councils/

96. The Change Foundation. Panorama: Our Provincial Advisory Panel of Healthcare Users and Caregivers. The Change Foundation 2012; Available from: http://www.changefoundation.ca/library/panorama-provincial-advisory-panel-healthcare-users-caregivers/

97. Ontario Drug Policy Research Network. Citizen's Panel. Ontario Drug Policy Research Network 2014; Available from: http://www.odprn.ca/citizens-panel/

98. McMaster Health Forum. Citizen Briefs and Panels. McMaster Health Forum 2014; Available from: http://www.mcmasterhealthforum.org/citizens/citizen-briefs-and-panels

99. Health Quality Ontario. Decision-making Framework (Decision Determinants). Health Quality Ontario 2014; Available from: http://www.hqontario.ca/evidence/evidence-process/evidence-review-process/decision-making-framework

100. Canadian Foundation for Healthcare Improvement. Partnering with Patients and Families for Quality Improvement. Canadian Foundation for Healthcare Improvement 2014; Available from: http://www.cfhi-fcass.ca/Elearning/partnering-with-patients-and-families-for-quality-improvement

101. National Institute for Health and Care Excellence. Patients Involved in NICE. National Institute for Health and Care Excellence 2014; Available from: http://www.nice.org.uk/PIN

102. Cochrane Consumer Network. About the Cochrane Consumer Network. Cochrane Consumer Network 2014; Available from: http://consumers.cochrane.org/healthcare-users-cochrane

103. Patients as Partners. Patient Voices Network. Patients as Partners 2014; Available from: https://www.patientsaspartners.ca/network

104. Lilly. eMeet - Medicine Evaluation Educational Training. Lilly 2014; Available from: http://www.meetforpatients.com/#0

105. Université de Montréal. **Direction collaboration et partenariat patient**. Université de Montréal 2014; Available from: http://med.umontreal.ca/la-faculte/direction-collaboration-partenariat-patient/

106. European Patients' Academy on Therapeutic Innovation. About EUPATI. European Patients' Academy on Therapeutic Innovation 2014; Available from: http://www.patientsacademy.eu/index.php/en/about-eupati

APPENDICES

The following tables provide detailed information about the systematic reviews identified for each element. Each row in a table corresponds to a particular systematic review and the reviews are organized by element (first column). The focus of the review is described in the second column. Key findings from the review that relate to the element are listed in the third column, while the fourth column records the last year the literature was searched as part of the review.

The fifth column presents a rating of the overall quality of the review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial, or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered "high scores." A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8.

The last three columns convey information about the utility of the review in terms of local applicability, applicability concerning prioritized groups, and issue applicability. The third-from-last column notes the proportion of studies that were conducted in Canada, while the second-from-last column shows the proportion of studies included in the review that deal explicitly with one of the prioritized groups. The last column indicates the review's issue applicability in terms of the proportion of studies focused on public and patient engagement in HTA. Similarly, for each economic evaluation and costing study, the last three columns note whether the country focus is Canada, if it deals explicitly with one of the prioritized groups and if it focuses on public and patient engagement in HTA.

All of the information provided in the appendix tables was taken into account by the evidence brief's authors in compiling Tables 3-5 in the main text of the brief.

Appendix 1: **Systematic reviews relevant to Element 1 - Create a comprehensive and flexible framework to engage the public and patients in the HTA process**

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
Identifying clear goals for each stage of the HTA process, and criteria to decide when and how to engage various publics for different technologies	No reviews identified						
Ensuring conceptual clarity and consistency in the use of public- and patient-engagement terminology so that all stakeholders have a common understanding of the terms and what they mean within Ontario's HTA context	No reviews identified						
Identifying promising public- and patient-engagement models that could be adapted to Ontario's HTA process	Examining the effect of engaging the public to inform policy through the use of citizen juries (70)	The review found that the citizens' jury model has been extensively adapted. Efforts to ensure inclusivity (through sampling strategies to recruit participants) have produced mixed results. The use of steering committees and facilitators promoted fair interaction between jurors. Many juries were of shorter duration than recommended, which limited the opportunity for constructive dialogue. The review revealed that special attention should be paid to recruitment, independent oversight, jury duration and moderation.	2010	4/9 (AMSTAR rating from the McMaster Health Forum)	4/28	28/28	1/28

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
	Examining the impact and utility of Web 2.0 and social media on health promotion (66)	The review revealed insufficient empirical evidence about the impact of social media and Web 2.0.

Recommended improvements included: more interventions with participatory and user-generated features, innovative study designs and measurement methods, and addressing accessibility for vulnerable populations. | 2011 | 4/10 (AMSTAR rating from the McMaster Health Forum) | Not reported in detail | Not reported in detail | Not reported in detail |
| | Reviewing the experiences with public and patient involvement in HTA internationally (10) | Public and patient involvement in HTA included gathering insight to evaluate health technologies and the need for direct participation in the HTA process.

Insufficient studies assessed experiences of involving patients and the public in HTA.

The review revealed that patient or public involvement in HTA activities was reported in two domains: research (e.g., gather evidence about their perspectives, experiences or preferences about a health technology) and HTA process (e.g., prioritization, evidence assessment,or dissemination of findings).

There is a need to employ systematic methods in examining the effect of patients' and the public's perspectives regarding HTA. | 2011 | 4/9 (AMSTAR rating from Program in Policy Decision-making) | 1/24 | 23/24 | 24/24 |
| | Examining the impact of public involvement in healthcare policy (62) | The review revealed insufficient evidence to draw firm conclusions about the effectiveness of public involvement activities for healthcare policy development.

Concepts and indicators used in the studies | 2010 | 4/9 (AMSTAR rating from Program in Policy Decision-making) | Not reported in detail – Description states: England, Canada, U.S., | Not reported in detail | 1/9 |

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
		were poorly specified and inconsistent, as was the reporting of the evidence. The review found some evidence about the developmental benefits of public involvement (e.g., enhancing awareness, understanding and competencies among lay participants), but evidence for instrumental benefits was not as well documented.			Northern Ireland)		
	Examining the use of public deliberation to increase public input on health issues (61)	The review revealed that issues that are best suited for public deliberation involve ethical and social dilemmas. The review found limited evidence about the effectiveness of one form of deliberation compared to another, on how various aspects of the deliberative process contribute to outcomes, and on the impact of applying different modes of deliberation (i.e., online versus face-to-face). There is some evidence to suggest that deliberation may provide information that may influence decision-making processes, and provide further understanding of public perception and its impact. Factors to consider during public deliberation included: establishing a clear purpose and goals for the use of public input; effective tasks and methods; ensuring transparency and adaptation to certain environments; and ensuring accessibility, expert facilitation and optimal use of technology.	2010	1/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	Not reported in detail	31/193
	Examining public involvement strategies in the	The review revealed that public-involvement strategies have evolved with the	2009	2/9 (AMSTAR rating from	Not reported in detail	Not reported in detail	Not reported in detail

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
	National Institute of Health Research HTA program (59)	development of the NIHR HTA program, but were spread unevenly across the five stages of research management. Such strategies were present in identification, strongest in prioritization, present in commissioning but minimal in monitoring, and absent in publication and dissemination of research. Further research is needed to determine where public engagement can be employed and how to ascertain its effect. The review found inconclusive findings for the impact of public involvement in the NIHR HTA program.		Program in Policy Decision-making)			
	Examining strategies for interactive public engagement in the development of healthcare policies and programs (69)	Recommendations for public engagement included adapting to the healthcare issue by engaging relevant groups, and understanding the complexity of the issue and its corresponding power dynamics. Components of public engagement with a high level of satisfaction included: well-designed processes; effectively communicating objectives; providing adequate material to inform discussions; and the logistics and management of deliberation. Increased levels of topic-specific learning are also commonly reported. Interactive public-engagement methods can influence participant views, but are less likely to change more dominant views (top rankings, highest priorities).	2009	6/9 (AMSTAR rating from Program in Policy Decision-making)	7/12	5/12	0/12

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
	Examining public engagement in priority setting and resource allocation (68)	Public engagement is most common in goal-setting for specific programs, and it is uncommon during program evaluations. There is some evidence to suggest public engagement may lead to direct impact on decisions. Identified characteristics of public engagement in priority-setting included: one-time consultations; no public engagement with decision-makers; and high costs that can range from $10,000 to more than $1 million. The review highlights the lack of practical guidance for integrating public input with other forms of evidence.	2006	3/10 (AMSTAR rating from the McMaster Health Forum)	17/190	Not reported in detail	Not reported in detail
	Examining the effects of consumer involvement, and comparing methods of involvement, in healthcare policy development and research, clinical practice guidelines and patient information material (63)	Insufficient evidence exists to determine the impact of consumer involvement on healthcare policy development and research. Patient information material with consumer involvement improved readability and relevance.	2005	9/11 (AMSTAR rating from www.rxforchange.ca)	0/6	Not reported in detail	Not reported in detail
	Examining the effectiveness of involving people affected by cancer in research, policy-planning and practice (67)	Training for patients and healthcare professionals is necessary for successful involvement of cancer patients in research, policy-planning and practice. 'Collectivism' and 'community model' are the most common rationales for public involvement in research, policy-planning and practice.	2004	4/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail - Description states: Canada, U.K., U.S.A	17/131	0/131
	Examining strategies to incorporate public values and technical information into	Sixty-nine of 117 studies presented methods for eliciting public values to inform resource allocation decision-making that included:	2002	4/10 (AMSTAR rating from the McMaster	8/117	Not reported in detail	Not reported in detail

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
	healthcare resource allocation decision-making (65)	ranking programs; utilizing Likert-type scales; explicit decision-making; conducting individual interviews through a Delphi process; focus groups; citizen juries; and town hall meetings. The 'gold standard' method was not identified. Method selection is based on population-specific factors. Regional Health Authorities (RHAs) utilized key informant interviews for the creation of advisory groups that would engage the public in priority setting. Positive impact may come from needs assessments and the awareness of public acceptability or support of a specific decision. Dissemination of priority-setting decisions included direct communication with healthcare providers, and media for the public.		Health Forum)			
	Examining the effects of patient involvement in the planning and development of healthcare (60)	Results of positive patient involvement included: improved self-esteem from patients; shifted organizational attitudes towards openness to patient involvement; and satisfaction from healthcare staff. Changes to services associated with increased patient involvement included: creation of information for patients; simplifying appointment protocols; improving patient transportation; and improving access for people with disabilities.	2002	5/9 (AMSTAR rating from Program in Policy Decision-making)	2/40	Not reported in detail	Not reported in detail

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
Identifying strategies to support evaluation and evidence-informed approaches to public and patient engagement	No reviews identified						

Appendix 2:   **Systematic reviews relevant to Element 2 – Build capacity within HTA organizations to engage with the public and patients**

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
Disseminating within the HTA community a clear and consensual public- and patient-engagement terminology so that all stakeholders have a common understanding of the terms and what they mean within Ontario's HTA context	No reviews identified						
Developing partnerships with other HTA agencies across Canada and internationally that have implemented public- and patient-engagement processes and that could offer advice and mentorship	No reviews identified						
Establishing a coordinated knowledge-translation strategy to support the communication and implementation of optimal public- and patient-engagement practices	Examining the effects of information products designed to support the uptake of systematic review evidence by health system managers, policymakers and healthcare professionals (76)	The overall quality of the included studies was very low to moderate. The findings showed that passive dissemination of an information product, based on systematic review evidence, on a national or regional basic, can be effective in instances where there is a single clear message and a growing awareness by users that changes in practice are needed. Although there is some face validity for a multifaceted intervention in development awareness for using and finding evidence, additional evidence on the effectiveness of this approach is required. Future implications for research include the challenge to classify outcome measures due	2011	9/10 (AMSTAR rating from Program in Policy Decision-making)	1/8	0/8	0/8

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
		to the variety of measures reported in the included studies. The researchers suggested that increasing awareness and accessibility to evidence for decision-making processes may lead to contamination of the delivery of interventions.					
	Examining facilitators enhancing the uptake of evidence from systematic reviews (81)	Included studies were limited in terms of the quality and generalizability of their results. They reported a number of potential facilitators to systematic review uptake, and the five most effective facilitators were: (1) the perception that systematic reviews have multiple uses for research and clinical practice; (2) a synthesized content that included benefits, harms, and costs; (3) a 1:3:25 graded entry format (i.e., one page of key messages, a 3-page summary, and a 25-page report); (4) training in use; and (5) peer-group support. There are multiple aspects that facilitate clinical practice. The review concluded that mechanisms encouraging the use of evidence from systematic reviews originate from a range of facilitators.	2010	4/10 (AMSTAR rating from Program in Policy Decision-making)	6/16	0/16	0/8
	Examining the impact of interventions encouraging the use of systematic reviews by health policymakers and managers (77)	This review showed a paucity of experimental research on interventions that encourage the use of systematic reviews by health policymakers. There is insufficient evidence to draw definitive conclusions about the effectiveness of interventions that encourage health policymakers and managers to use systematic reviews in decision-making. Implications for future research include assessing the contexts under which	2010	9/10 (AMSTAR rating from Program in Policy Decision-making)	3/3	0/3	0/3

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
		systematic reviews are most effective, which may include: (1) how systematic reviews are accessed; (2) how they are used; (3) identifying the types of reviews needed in policymaking; (4) understanding the applicability of systematic reviews in the local context; and (5) the specific characteristics that make systematic reviews easy to use.					
	Exploring knowledge-translation resources and evaluations that can surpass barriers to using systematic reviews by policymakers (82)	All included studies focused on healthcare policymakers nationally and locally. Resources used included summaries, overviews and policy briefs. Most of the included studies were conclusive on the perception that knowledge translation services are useful, and there were a few cited instances where such systematic reviews aided decision-makers in the policymaking process. The review concluded that products of systematic reviews, particularly summaries, are helpful to policy decision-makers. However, further studies evaluating their effect on meeting users' needs, their funding and their overall impact, are still required.	2009	6/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0/20	3/20
	Examining the evidence regarding knowledge transfer and exchange in the context of healthcare policy (74)	The review found that there is insufficient evidence to support knowledge transfer and exchange (KTE) in health policy decision-making. It is suggested that KTE strategies be re-evaluated, or a more comprehensive evidence base be considered for study in the future. This review was solely focused on the policy decision-making level. The majority of the studies included were classified as non-	2005	6/9 (AMSTAR rating from Program in Policy Decision-making)	44/81	0/81	0/81

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
		implementation studies. Reported facilitators to KTE were found to be personal contact with the researcher, summaries of findings with recommendations, high-quality research, and effectiveness data. Barriers included lack of interest and incentives, competing interests, information overload, and mutual mistrust. The conclusion drawn from this review is that despite the growing awareness of KTE in health services research, there is very little evidence on how KTE strategies work in different contexts.					
	Summarizing the evidence from interview studies of facilitators of, and barriers to, the use of research evidence by health policymakers (83)	The majority of included studies are qualitative, and thus are limited in their generalizability. The most commonly reported facilitators for research use were personal contact, timely relevance, and the inclusion of summaries with policy recommendations. The most commonly reported barriers were absence of personal contact, lack of timeliness or relevance of research, mutual mistrust, and power and budget struggles.	2000	No rating tool available for this type of document (overview of systematic reviews)	3/24	0/24	0/24
	Examining the factors that influence the use of research evidence in ways to improve the usefulness of systematic reviews for healthcare managers and policymakers (84)	Interactions between researchers and healthcare policymakers and timing/timeliness appear to increase the prospects for research use among policymakers. Findings from interviews with healthcare managers and policymakers suggest that they would benefit from having information	Not reported in detail	2/9 (AMSTAR rating from Program in Policy Decision-making)	1/20	Not reported in detail	Not reported in detail

Evidence >> Insight >> Action

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
		that is relevant for decisions highlighted for them (e.g., contextual factors that affect a review's local applicability and information about the benefits, harms/risks and costs of interventions), and having reviews presented in a way that allows for rapid scanning of relevance and then graded entry (such as one page of take-home messages, a three-page executive summary and a 25-page report). Managers and policymakers have mixed views about the helpfulness of recommendations. An analysis of websites found that contextual factors were rarely highlighted, recommendations were often provided, and graded entry formats were rarely used.					
	Evaluating strategies used to increase the impact of systematic review findings on policymaking (75)	The review aimed to address the concern that systematic reviews have not been maximized by policymakers and have not yielded the expected impact on policy. Strategies analyzed included dissemination strategies and knowledge transfer. The review concluded that further research is required for a full evaluation of the strategies' benefits. Discrepancies arose with regards to how policymakers used evidence from systematic reviews. Interviews with policymakers suggested that they placed a higher weight on other factors and were less influenced by research evidence. Barriers to systematic review use include	Not reported in detail	2/9 (AMSTAR rating from Program in Policy Decision-making)	10/13	Not reported in detail	3/13

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
		timeliness, availability of search results, and a lack of skills. Facilitators identified include collaboration between researchers and policymakers, dissemination strategies, and examination of applicability in reviews.					
Identifying strategies for promoting and embedding public- and patient-engagement innovations	Synthesizing evidence on the determinants of innovation within health and social care, and examining how innovation can be embedded into the National Health Service (78)	The report highlights that the evidence base on the diffusion of innovation is growing, but remains limited. Researchers suggest that the innovation process can be broken down into different components: discovery; adoption; diffusion; and routinization. The report listed promising tools for spreading innovations, including formal published evidence, decision and dissemination support tools (e.g., guidelines), organizational and inter-organizational networks, leadership development, and evaluation and review. The findings showed that there is a list of essential factors for embedding innovation in the National Health Services in the U.K., including: (1) inter-functional and inter-organizational co-ordination and collaboration; (2) multifaceted implementation approaches facilitating interaction between the innovation, the intended audience and the context; (3) adapting innovations to the local context; (4) a receptive climate for innovation (although this may develop gradually and vary over time); (5) engaging users and other stakeholders as active agents of change, rather than passive recipients of	2009	No rating tool available for this type of document (overview of systematic reviews)	Not reported in detail	Not reported in detail	Not reported in detail

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
		innovations; (6) financial or other types of incentives for users and other stakeholders; (7) active campaigns to market the innovation and get the information out to a wider audience; (8) building capacity within organizations; (9) cross-boundary networks or communities of practice; and (10) leadership and organizational connectedness at all levels.					
	Examining the effectiveness of strategies aimed at changing organizational culture to improve performance in healthcare settings (80)	Only two studies were included in this review. Although both studies reported positive effects, these results should be taken with caution due to methodological issues. The review concluded that existing evidence is limited, and does not identify strategies that change organizational culture in the healthcare setting. Evaluations must be conducted for further evidence to be gathered on this topic.	2009	5/6 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	2/2	0/2
	Exploring how innovations can spread and be sustained in health services organizations (79)	Researchers suggest that the findings presented in this review should be seen as raising areas for consideration rather than providing definitive conclusions. Researchers affirmed a number of well-described themes in the literature, such as: (1) the useful list of innovation attributes that predict (but do not guarantee) successful adoption; (2) the impact of social influence and the networks through which it operates; (3) the complex nature of the adoption process; (4) the "hard" and "soft" characteristics of organizations that encourage or inhibit innovation; and (5) the messy, stop-start process of assimilation and	2003	6/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	Not reported in detail	Not reported in detail

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
		routinization. The review found a miniscule proportion of empirical studies that acknowledged the complexities of spreading and sustaining innovation. Implications for future research suggest that the diffusion of health service innovations should be: (1) theory-driven; (2) process oriented rather than package oriented; (3) ecological; (4) addressed with common definitions, measures and tools; (5) collaborative; (6) multidisciplinary; (7) meticulously detailed; and (8) participatory.					

Appendix 3:   Systematic reviews relevant to Element 3 – Build capacity among the public and patients to engage in the HTA process

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
Launching a public awareness campaign via mass media or social media about Ontario's HTA process, and encouraging understanding of the importance of public and patient engagement	Examining the benefits and limitations of social media for health communication among publics, patients and healthcare professionals (64)	This review examined 98 studies that used a diverse range of social media tools, including Facebook, blogs, Twitter and YouTube. Health issues most frequently addressed in these studies were sexual health, diabetes, the flu (H1N1) and mental health issues. Studies showed that social media use could lead to a decrease in stigma for certain conditions. Benefits of social media included increased interactions, more available health information, and access to resources for health issues. The main limitations included quality concerns and the lack of reliability of information. Information needs to be monitored for reliability and protection of personal information.	2012	6/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	22/98	Not reported in detail
	Examining the effects of mass media on the utilization of health services (85)	Despite the limited information about key aspects of mass media interventions and the poor quality of the available primary studies, the review found that the majority of studies concluded that planned mass media campaigns and unplanned mass media coverage could have a positive influence on the utilization of health services.	1996	8/11 (AMSTAR rating from www.rxforchange.ca)	1/20	19/20	0/20
Establishing a specialized service providing personal	No reviews identified						

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
support and coaching to members of the public and patients who want to engage in Ontario's HTA process							
Developing and sustaining a network of patients, families, caregivers, disease-specific organizations, consumer groups and other relevant publics	No reviews identified						
Identifying effective strategies to engage people with low health literacy	Examining the impact of interventions aimed at mitigating the effects of low health literacy (91)	The review found multiple design features improving comprehension in one or a few studies (e.g., presenting essential information by itself or first, presenting information so that the higher number is better, adding icon arrays to numerical information, and adding video to verbal narratives). The authors concluded that multiple interventions show promise for mitigating the effects of low health literacy.	2011	6/9 (AMSTAR rating from Program in Policy Decision-making)	0/36	36/36	Not reported in detail
	Examining the effectiveness of print and multimedia health materials in improving health literacy (86)	For 54% of the total studies, there was no difference in effects between print and multimedia interventions. Future research is needed on the content of the material through patient input in order to adjust to appropriate literacy levels.	2010	4/11 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	30/30	Not reported in detail

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
	Examining the effects of strategies aimed at enhancing consumers' online health literacy (88)	A randomized controlled trial drew a comparison between patient education classes and internet information classes for participants with HIV. Positive results included self-efficacy for seeking health information, evaluation of health information and an increase in conversing with a healthcare provider. A controlled before-and-after study focused on comparing participants in online health information classes with a controlled group receiving no classes. There is evidence to suggest an increase in readiness to use internet tools for health information in the intervention group. However, the authors concluded that the evidence was too weak to draw firm conclusions about the implications for the design and delivery of interventions for enhancing online health literacy.	2008	10/11 (AMSTAR rating from Program in Policy Decision-making)	0/2	2/2	0/2
	Examining the effectiveness of interventions addressing health literacy (90)	Low literacy interventions are aimed at making health education material easier to understand for self-management of patients' conditions. Further research is needed in order to assess the effectiveness of literacy strategies and implementation processes. Positive interventions included the inclusion of nurses to develop interventions for those with low health literacy, and the need to use layman terms.	2006	2/9 (AMSTAR rating from McMaster Health Forum)	0/16	16/16	0/16
	Examining the effectiveness of audiotapes as a strategy for	No reviews addressed the "hard-to-reach" population.	2003	2/10 (AMSTAR rating from Program in	4/35	35/35	0/35

Sub-elements	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on public and patient engagement in HTA
	exchanging health information, with a particular focus on "hard-to-reach" populations (89)	Several studies indicated that audiotapes of consultations could increase knowledge in the short-term and have the potential to teach "hard-to-reach" populations. Limitations include the potential for physician opposition and generalizability of the information to the population.		Policy Decision-making)			
	Examining the effectiveness of interventions for improving health literacy (87)	A Cochrane systematic review is being planned.					