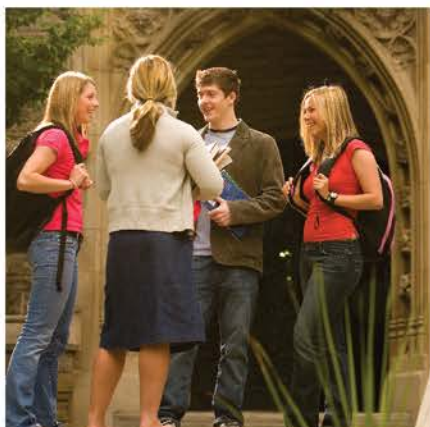McMaster University

DIALOGUE SUMMARY

# STRENGTHENING PUBLIC AND PATIENT ENGAGEMENT IN HEALTH TECHNOLOGY ASSESSMENT IN ONTARIO

8 MAY 2014

EVIDENCE >> INSIGHT >> ACTION

**Dialogue Summary:**
**Strengthening Public and Patient Engagement in Health Technology Assessment in Ontario**

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McMaster Health Forum
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Dialogue
> The stakeholder dialogue about strengthening public and patient engagement in health technology assessment was held on 8 May 2014 at the McMaster Health Forum in Hamilton, Ontario, Canada.

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# SUMMARY OF THE DIALOGUE

The deliberation initially focused on the desire of Health Quality Ontario (HQO) and the Ontario Health Technology Advisory Committee (OHTAC) to more effectively engage the public and patients after several years of related discussion and experimentation, as well as to fit together the pieces of the puzzle and to generate momentum in this area. A few dialogue participants noted that the features of the problem and its causes that were described in the evidence brief could be more helpfully considered as features of the current context for health technology assessment (HTA). One participant argued that they would like to see the 'problem' re-framed as an opportunity to drive towards more (and more meaningful) public and patient engagement in HTA in Ontario. Many participants contributed to articulating three considerations in moving ahead: 1) there are increasing expectations among the public and patients for engagement processes that can inform difficult choices about technologies; 2) many examples (if not strong research evidence) can be offered to demonstrate how such engagements leads to better decisions (and possibly better outcomes); and 3) limited resources mean that the focus needs to be on identifying where the greatest value for money can be achieved (in terms of who to engage, how to engage them, etc.).

Dialogue participants generally supported a re-framed version of the three elements of a potentially comprehensive approach, although their deliberation suggested the need for a re-ordering: 1) create a framework (or what some called a strategy) for public and patient involvement in the HTA process that has six key characteristics (although there were differences of opinion regarding whether the framework should focus on the HTA work at Health Quality Ontario (HQO) or on HQO more generally); 2) develop, monitor and evaluate a broad range of processes that contribute to engaging citizens and patients, including virtual portals and citizen/patient academies that support 'bottom-up' approaches, recruitment approaches that give voice to diverse communities, and orientation sessions and on-going support for citizens and patients who wish to get or stay involved; and 3) build capacity within HQO and the virtual community of HTA producers (or possible a much broader community of health organizations across Ontario) to use the approaches and pursue the vision described in the above framework, by disseminating and supporting the use of the framework itself, derivative products (e.g., one-page handouts) that are concise and user-friendly, and resources that are practical and easy to use.

Many dialogue participants indicated that they were willing to support the development of a public- and patient-engagement framework, processes and capacity, as well as related efforts to: 1) undertake an inventory of who is doing what in the province and beyond it that could support public and patient engagement in HTA; 2) examine the literature in other areas, such as public and patient engagement in market research, guideline development, and more broadly in research, to spur reflections about public and patient engagement in HTA; 3) develop an implementation plan (alongside the framework) to assist in achieving the objectives of the public- and patient-engagement framework; 4) develop a strategic communications plan to raise awareness among and reach different target audiences; 5) explore how to nurture 'bottom-up' efforts among the public and patients (e.g., virtual institutes/academies, networks of excellence, coaching and mentorship activities, and educational grants by industry partners); and 6) build buy-in and leadership along the way, among both internal and external stakeholders.

# SUMMARIES OF THE FOUR DELIBERATIONS

## DELIBERATION ABOUT THE PROBLEM

The deliberation initially focused on the need to more clearly position where the province of Ontario stands regarding public and patient engagement in health technology assessment (HTA). While only limited engagement opportunities are built into the evidence-review process at Health Quality Ontario (HQO) and the advisory process of the Ontario Health Technology Advisory Committee (OHTAC) – notably posting reviews and recommendations online, soliciting feedback by email, and allowing people to appeal a review or recommendation -- several participants emphasized that there is a genuine desire within HQO and OHTAC to move towards more sophisticated engagement processes.

Several participants noted that there have been prior discussions at HQO and OHTAC about public and patient engagement for quite some time, as well as some experimentation with engagement methods as part of pilot projects (e.g., polling, modified Delphi, focus groups and citizen reference panel). One participant argued that the challenge of engaging the public and patients was interconnected with the OHTAC's much-discussed challenge of integrating societal and ethical considerations into its recommendations-development process. Although societal and ethical considerations are theoretically integrated into OHTAC's decision-determinants framework, it is still grappling with the most effective ways to integrate these considerations alongside other types of evidence. The same participant viewed the stakeholder dialogue as an opportunity to fit together the pieces of the puzzle and to generate enough energy to change the status quo: "This [dialogue] is an opportunity to put the stake in the ground."

A few dialogue participants noted that the features of the problem and its causes that were described in the evidence brief could be more helpfully considered as features of the current context for HTA. For instance, they agreed that HTA agencies are under pressure in terms of greater demands for rapid HTAs and for HTAs examining multiple technologies (or 'mega-analyses' as they are called by HQO), but suggested that this is the reality that public- and patient-engagement efforts need to address (and that some HTA agencies are doing just this). One participant argued that conducting mega-analyses actually "cries [out for] the need to contextualize the evidence and bring the public into HTA."

Some participants also suggested that increased scrutiny of HTAs by various groups could stimulate engagement efforts. One such participant suggested that this increased scrutiny reflects a decline in deference to authority and trust in experts, as well as a desire for political change, for re-shaping institutions, and for the democratization of healthcare. As this participant noted, all of this should be embraced as an opportunity: "We've got a population motivated by self-interest, but with a mix of altruism. [It's] a potential source of skills and energy."

In addition, a few dialogue participants agreed that the lack of a solid body of research evidence about the effectiveness of public and patient engagement in HTA, and about the most valid ways to integrate public and patient input, complicates engagement efforts. They also agreed that current institutional arrangements, including their complexity and HQO's and OHTAC's relationship to government, can confuse the public and raise concerns about messaging among government officials. But again, dialogue participants suggested that the current state of both evidence and institutional arrangements is the reality that public- and patient-engagement efforts need to address, not a problem or the causes of a problem.

One dialogue participant argued that they would like to see the 'problem' re-framed as an opportunity to drive towards more (and more meaningful) public and patient engagement in HTA in Ontario, keeping in mind three considerations: 1) increasing expectations among the public and patients for engagement processes that inform difficult choices about technologies; 2) many examples (if not strong research evidence) can be offered to demonstrate how such engagements leads to better decisions (and possibly better outcomes); and 3) limited resources mean that the focus needs to be on identifying where the greatest value for money can be achieved (in terms of who to engage, how to engage them, etc.).

Beginning with the consideration about increasing expectations, several dialogue participants emphasized that greater public and patient engagement necessitates a paradigm shift on the part of HTA agencies, as well as a power shift from those with expertise and authority to those whose lives will be affected by HTA decisions. On the former point, some participants emphasized that meaningfully embedding public and patient engagement in HTA will involve a change in the current methodological and ideological paradigm in HTA, which currently gives significantly more emphasis to clinical and economic evidence and can be quite resistant to qualitative evidence. On the latter point, some participants emphasized that greater public and patient engagement also necessitates a new balance of power, responsibility and accountability in HTA, which could also encounter significant resistance. This discussion led one participant to caution the group to not lose sight of the fact that the challenge is about finding effective and meaningful ways to engage the public and patients in HTA, which is essentially a bureaucratic process as opposed to a democratic process: "None of us are elected decision-makers. We are starting to drift and it worries me in this discussion." However, this participant acknowledged that a paradigm shift and a power shift will probably be necessary to let the public and patients in: "[bureaucracies] are secret societies and you need admission to get in."

Turning to the consideration about the state of knowledge about public and patient engagement, dialogue participants generally recognized that there was a limited body of research evidence regarding public and patient engagement in HTA. "We have an undeveloped evidence base, a limited amount of measurement tools, and [we're] a poor cousin methodologically," as one participant declared. Nevertheless, most dialogue participants agreed that the limited body of research evidence should not be an obstacle to moving forward. One participant argued about the need "to build our evidence as we go." A second participant went further: "I'm not worried that we don't have evidence at all these steps. We need to use common sense and intuition." Other participants insisted that many examples drawn from other domains can be offered to demonstrate how public and patient engagement leads to better decisions (and possibly better outcomes).

Moving to the consideration about value for money, one participant noted that the scarcity of resources (both financial and human) forces us to think carefully about how to develop the most robust and efficient engagement process with the available resources: "For me, there are a million things that you can do. What is missing is: what is the cost and what is the benefit given our scarce resources?" Another participant expressed

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concern that the lack of cost-effectiveness evidence could pose a challenge to convincing the HTA community of the importance of public and patient engagement: "I'm worried that there is so little cost-effectiveness evidence. It's not going to be a priority for HTA people if they don't see the value for money. We need to find a way to measure that and communicate it back to people." Several participants suggested that it remains a significant challenge to identify where the greatest value for money can be achieved (in terms of who to engage, how to engage them, etc.) and expressed concern about finding effective (and cost-effective) ways to engage vulnerable populations and high-need users of the health system (e.g., people with multiple chronic conditions). One participant emphasized that engaging these populations is much more complex then engaging well-educated, articulate and socioeconomically advantaged people. Public- and patient-engagement processes often fail to integrate diverse and hard-to-reach populations, as one participant noted: "[It's] easy to define a public and patient engagement process that looks awesome from a management perspective, but it often lacks the engagement of diverse populations."

Dialogue participants concluded this first deliberation by noting the challenge of developing a clear and common vision for public and patient engagement in HTA. One participant noted that there was a need to bring coherence to the reflection about public and patient engagement: "I don't hear coherence. You need something that leads to a common understanding."

## DELIBERATION ABOUT THREE ELEMENTS OF A COMPREHENSIVE APPROACH TO ADDRESS THE PROBLEM

Dialogue participants generally supported two of the three elements of the potentially comprehensive approach identified in the evidence brief -- creating a comprehensive and flexible framework to engage the public and patients in the HTA process (element 1) and building capacity within HTA organizations to engage the public and patients (element 2) – but argued for shifting the focus from building capacity among the public and patients to engage in the HTA process (element 3) to developing, monitoring and evaluating the processes needed to engage citizens and patients.

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

The deliberation about the first element focused on the need to create a framework (or what some called a strategy) for public and patient involvement in the HTA process that:
- articulates the underlying principles, values, and goals for public and patient engagement in HTA, as well as the roles that the public and patients can play;
- establishes a common language (e.g., public vs patient vs community, and qualitative evidence vs individual experiences);
- describes a flexible array of approaches that can be used now depending on the goal, phase of the evidence-review process, and stage in a health technology life cycle (from innovation to obsolescence);
- shows the interconnections with other system and organizational strategies for public and patient engagement;
- includes measures of engagement and its outcomes that can inform adjustments over time; and
- articulates the longer-term vision (or "roadmap") for broader system change that the first, time-bound framework is a step towards.

Dialogue participants generally agreed about the importance of such framework to set clear expectations for both internal and external stakeholders, but also to establish clear measures of (what some called) 'accountability for reasonableness' for HQO - the organization leading the public- and patient-engagement activities. However, there were differences of opinion regarding whether the framework should focus on the

evidence-review process that HQO uses and the recommendation-development process that OHTAC uses or it should it be broader and guide all engagement activities across HQO.

Some participants cited two examples, both from the United Kingdom, to illustrate how such a framework could be operationalized at different levels: 1) the National Institute for Health Research (NIHR) has public- and patient-involvement framework for the period 2013-2015, which is underpinned by a clear set of principles/values and grounded in the different stages of the evidence-review process; and 2) the National Institute for Health and Care Excellence (NICE) has a public- and patient-involvement policy, which can be seen as an overarching strategy, again with clearly articulated principles/values, for the entire organization.

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

The deliberation about the second element focused on the need to build capacity within HQO and the virtual community of HTA producers to use the approaches and pursue the vision described in the above framework, by disseminating and supporting the use of:
- the framework itself;
- derivative products (e.g., one-page handouts) that are concise and user-friendly; and
- resources that are practical and easy to use.

Dialogue participants emphasized the need to build capacity both in-house and among existing groups that support HTA in the province. With regard to in-house capacity, a few participants saw a great opportunity to develop integrated capacity across the three domains of HQO (i.e., public reporting, quality improvement, and evidence development and standards), whereas others were more focused on the evidence development and standards branch that supports HTA. One participant noted that, with the recent decision of HQO to develop and implement an engagement strategy, "each domain has been asked to embrace this."

Some participants suggested the need to think even bigger and bring together organizations from across the province to best capitalize on existing resources and expertise to engage the public and patients about the full range of health-related issues (e.g., Local Health Integration Networks, healthcare provider organizations, Social Planning Network Ontario, and civil- society organizations, among). However, there was uncertainty about which organization was best positioned to be the convenor of this "collective gathering of expertise" in Ontario.

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

The deliberation about the third element involved some discussion about what was perceived by some as the unhelpful way that his element was framed and a shift in focus from building capacity among the public and patients to engage in the HTA process to developing, monitoring and evaluating the processes needed to engage citizens and patients. As one example of the first point, a few dialogue participants cautioned the group about using the term 'training' in the way it was used in the evidence brief and was sometimes being used during the dialogue. As one participant noted: "We [the public and patients] don't want to be trained. We want to be supported. You need to be careful about the language."

Dialogue participants expressed enthusiasm for a range of processes that contribute to the public's and patients' engagement in HTA, including:
- virtual portals and citizen/patient academies to learn about HTA and how to contribute and share their experiences (ideally, in the view of one participant, to be partly funded by public entities but governed by citizens/patients);
- recruitment approaches that give voice to diverse communities (and possibly social-marketing campaigns to engage those who do not normally come forward);

- orientation sessions that give citizens and patients what they need to contribute and learn in a particular process; and
- on-going support that gives citizen and patients what they need to continue contributing and learning (e.g., mentorship and peer support).

Dialogue participants debated whether we should employ a broad approach to build engagement capacity among diverse groups, or we should (at least initially) employ a more targeted approach to build engagement capacity among already interested and committed individuals. Many participants were more inclined to initially focus on those who may already be interested and committed to take part in HTA: "Most people actually don't care about healthcare until they have a personal experience. It's important to remember that." However, many indicated that if an infrastructure is put in place to recruit, orient and support participants, it will eventually grow and reach a broader audience.

Several dialogue participants also suggested nurturing 'bottom-up' approaches to recruit, orient and support participants. Examples of such approaches were offered, such as the Patients as Partners | Patient Voices Network in British Columbia, the Centre for Patient Leadership in England, virtual institutes/academies in many countries (such as Spain) and the Cochrane Consumer Network globally. As one participant noted: "It must come from committed individuals to make it grow. It needs to be bottom up." Such initiatives could create the appetite for public and patient engagement in HTA.

**Considering the full array of options**

Dialogue participants generally supported the re-framed version of the three elements of a potentially comprehensive approach, although their deliberation suggested the need for a re-ordering:
1) create a framework (or what some called a strategy) for public and patient involvement in the HTA process that has the key characteristics described above (although there were differences of opinion regarding whether the framework should focus on the HTA work at HQO or on HQO more generally);
2) develop, monitor and evaluate a broad range of processes that contribute to engaging citizens and patients, including virtual portals and citizen/patient academies that support 'bottom-up' approaches, recruitment approaches that give voice to diverse communities, and orientation sessions and on-going support for citizens and patients who wish to get or stay involved; and
3) build capacity within HQO and the virtual community of HTA producers (or possible a much broader community of health organizations across Ontario) to use the approaches and pursue the vision described in the above framework, by disseminating and supporting the use of the framework itself, derivative products (e.g., one-page handouts) that are concise and user-friendly, and resources that are practical and easy to use.

The deliberations suggested that the status quo is not an option and that there is an opportunity to build on the desire of HQO and OHTAC to move forward. Moreover, many dialogue participants shared an 'if you build it, they will come' attitude to bringing about change in this area. In other words, if the framework and processes are put in place, committed individuals will come forward to take part in HTA, and these experiences will eventually attract a broader audience, generate buy-in among internal and external stakeholders, and (if captured systematically) build the evidence base to refine the framework and processes.

## DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Dialogue participants highlighted several key factors for implementing public and patient engagement in HTA. First, leadership was emphasized by many dialogue participants as being a fundamental part of any implementation plan. While many pointed out the need to support leadership at all level of HQO and OHTAC (as the 'enablers' or 'enforcers' of the framework), others suggested that this leadership should be

more broadly distributed, including among external stakeholders. Second, and related to the notion of distributed leadership, several participants noted the importance of establishing partnerships and bringing together other organizations to pool resources and expertise on public and patient engagement. Third, strategic communications was identified as key to implementation since the public and patients are largely unaware of the work of HTA agencies and how they relate to coverage decisions, and thus the availability of health technologies. A communications strategy (informed by good market research) would help to raise awareness about the work of HQO and OHTAC so that people understand that they are participating in something critically important to society. Lastly, dialogue participants generally agreed about the importance of evaluating public- and patient-engagement activities (and building the necessary evaluation infrastructure) in order to build the evidence base and refine the processes that will be put in place in the short term. However, one participant questioned why there was so much insistence in evaluating public and patient engagement specifically, but not on evaluating the engagement of clinicians, managers, researchers and other HTA experts as well. Another pointed out that the counterfactuals can be hard to identify and that robust evidence about effectiveness "of the randomized controlled trial variety" may prove elusive, but that many complementary forms of research evidence (including lessons learned from successes and failures) can enhance our understanding in this area.

## DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

During the deliberation about next steps for different constituencies, many dialogue participants indicated that they were willing to support the development of a public- and patient-engagement framework, processes and capacity, as well as related efforts to:
1) undertake an inventory of who is doing what in the province and beyond it (in collaboration with partners such as the HTAi Interest Sub-Group on Patient and Citizen Involvement in HTA and the Guidelines International Network) that could support public and patient engagement in HTA, and enable their coming together to share resources and expertise (and possibly even their establishment of a coaching "SWAT team");
2) examine the literature in other areas, such as public and patient engagement in market research, guideline development, and more broadly in research (e.g., NIHR's 'Breaking Boundaries' report that will be released in November 2014), to spur reflections about public and patient engagement in HTA;
3) develop an implementation plan (alongside the framework) to assist in achieving the objectives of the public- and patient-engagement framework;
4) develop a strategic communications plan to raise awareness among and reach different target audiences in language that is understandable to and motivates them;
5) explore how to nurture 'bottom-up' efforts among the public and patients (e.g., virtual institutes/academies, networks of excellence, coaching and mentorship activities, and educational grants by industry partners); and
6) build buy-in and leadership along the way, among both internal and external stakeholders.
As one participant concluded: "keep moving forward and don't wait for perfection to make each step."