Practicing the Theory of Public Deliberation: Case studies from the Health Sector in Ontario and Quebec

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Abstract

Health policymakers have been turning to "deliberative public participation" with great enthusiasm recently to help them develop policies in response to morally complex and fiscally challenging issues such as large-scale health reform, resource allocation decisions, pandemic planning, health technology assessment, and controversies in bioethics. In this presentation, the experiences to date with public deliberation in the Canadian health sector will be compared and contrasted with specific discussion about the rationales for their use and impacts observed when assessed against the theoretical goals for deliberative public participation.

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Introduction

Like other policy sectors, the health sector appears to have been bitten by the deliberative democracy bug in response to calls for new governance models and more direct and meaningful ways for the public to contribute to policy processes (Inglehart, 1995; Inglehart, Nevitte, & Basanez, 1996; Graham & Phillips, 1998). These new models have resonated with health policy makers looking for less confrontational methods for consulting with citizens and health system users about some of society's most morally challenging and politically divisive issues (Lenaghan, New and Mitchell, 1996; Lenaghan, 1999; Pratchett, 1999; Simrell King, 1998; Donovan and Coast, 1996). Much of the early experimentation occurred through the 1990s, in the U.K.'s National Health Service (NHS), where a variety of methods such as deliberative polling, citizens panels and citizens juries were used by local health authorities to consult with citizens and health system users to inform health care priority setting decisions (Bowling, Jacobson and Southgate, 1993; Bowie, Richardson and Sykes, 1995; Lenaghan, New and Mitchell, 1996; Lenaghan, 1999; Coote and Lenaghan, 1997; Cookson and Dolan, 1999; Dolan, Cookson and Ferguson, 1999). More limited experimentation with these methods has taken place in Canada and other jurisdictions around the world through ad-hoc national and local deliberative public involvement initiatives initiated mostly by researchers (Abelson, Lomas, Eyles, Birch, & Veenstra, 1995; Smith and Wales, 1999; Bostwick, 1999; Stronks et al. 1997).

Over the last decade, the 'deliberative turn' in health care has been planted on even firmer footings in several high-profile areas. In 2002, for example, the principles of democratic deliberation were used to design the *citizens dialogue* sessions that were held across the country as part of the work of the Commission on the Future of Health Care in Canada (Maxwell et al. 2002). The purpose of the dialogues was to elicit, through deliberative dialogue, citizens' values toward four options for health care transformation, which would in turn be used to inform the Commission's final recommendations (Maxwell, Rosell and Forest, 2003).

At the same time, the practice of deliberation was being institutionalized in the high stakes, expert-dominated arena of health technology assessment and policy decision making. The newly established National Institute for Clinical Excellence (NICE), charged with advising the U.K.'s National Health Service about the effectiveness and cost effectiveness of health care technologies, formed a *Citizens Council* in 2002 to inform their recommendations about which new technologies should be covered by the NHS (BMJ, 2001). The 30-member council meets twice a year over several days and uses deliberative methods to address the range of topics it is assigned and produces a report based on a synthesis of their deliberations.

The Government of Ontario jumped on the deliberation bandwagon in 2006 through the establishment of an almost identical citizens council, which will provide public input into the governance of the province's pharmaceutical program (Government of Ontario, 2006). And in 2007, legislation was introduced in Quebec to create a Commissioner of Health and Well-Being to advise government on the performance of the Quebec health system. The legislation included provisions for the establishment of a 27-member citizen-expert panel to inform the Commissioner's work. In addition to these high-profile examples, the number of one-off deliberative "experiments" has been on the rise, led

mostly by researchers on different health care ethics, planning, priority setting issues (e.g., genetics and genomics, xenotransplantation, health care planning and resource allocation) (Abelson et al. 2007; Abelson et al. 2010).

So while all of this increased activity should be good news for deliberative democracy enthusiasts, the reality is that we know very little about the motivations that have led to this experimentation or how these deliberative approaches have actually been implemented in their various institutional settings. In order to determine whether these new methods are, in fact, examples of more meaningful or accountable participation, we need to better understand what their architects have set out to achieve and how they've fared in meeting these objectives. Thus, the central objective of this paper is to review selected experiences to date with public deliberation in the Canadian health sector with an emphasis on unpacking the rationales for their use and the institutional arrangements in which deliberation is being practiced. An understanding of these important contextual factors will, in our view, produce a more meaningful assessment of how the theoretical goals of deliberative public participation have been put into practice.

To undertake this analysis, we begin by summarizing some of the main arguments for deliberative participatory models and outline the core features of deliberative practice. We then use this framework to examine two case studies of public participation that we are actively researching in Ontario and Quebec where efforts have been made to incorporate deliberative ideals into the design and execution. As we reflect on some of our early findings from these two case studies, we are influenced by the work of Davies et al. (2006) who conducted one of the comprehensive evaluations of deliberative participation – an ethnographic study of the NICE Citizens Council established in 2002. Through their path-breaking work in this area, Davies et al. (2006) have encouraged empirical deliberation scholars to move beyond traditional assessments of deliberation against its theorized goals and to reflect much more broadly on the context within which deliberation takes place, taking into account the notion of deliberation as social processes and communities of practice (Davies et al. 2006).

The deliberative ideal

The essence of the deliberative ideal is rooted in democratic deliberative theory (Manin, 1987; Cohen, 1989; Fishkin, 1991; Gutmann and Thompson, 1996, Dryzek, 2000) and refers to 'a particular sort of discussion – one that involves the careful and serious weighing of reasons for and against some proposition' (Fearon, 1998). Tracing these roots back even further, deliberation theorists frequently invoke one of two traditions. In the Rawlsian tradition, one is concerned with justice and the ability to engage in public reasoning for the purposes of reaching agreement among a group of participants with diverse individual interests. In the Habermas tradition, a theory of communicative action outlines the core elements of "ideal speech" which are commonly referred to as the foundational elements of public deliberation (Habermas, 1984). Stated succinctly, it is 'problem-solving' discussion ... [which]:

allows individuals with different backgrounds, interests and values to listen, understand, potentially persuade and ultimately come to more reasoned, informed and public-spirited decisions (Abelson et al., 2003).

In their recent book *Talking Together: Public Deliberation and Political Participation in America*, Jacobs and colleagues outline the main goals of public deliberation.

First and foremost, deliberation is about *restoring the legitimacy* of political systems and improving their accountability. A core mechanism for achieving this is the emphasis on reasoning and the idea of explaining actions in ways that will foster greater public acceptability. A second goal is to *increase public understanding* of policy issues, which goes hand in hand with citizens' improving their competency and capacity to contribute to public and private decisions. A third and more instrumental goal of deliberation is to *inform and potentially improve the quality of policy making*.

The authors go on to outline 5 conditions under which deliberation would invigorate citizens, restore the legitimacy of political decisions and establish authentic democracy. The first condition - *universalism* - suggests that deliberation will be a broadly inclusive process that will provide equal opportunities for participation. The second related condition of *inclusivity* requires that a range and diversity of voices are captured. Under the third condition of *rationality*, there is an important role for evidence and claims grounded in logic and facts. A fourth condition - agreement - involves working through conflicts and competing ideas to identify common ground and practical solutions and relates to the core output of deliberation. It is important to note that this is not the same thing as consensus but a process of reasoning with the goal of identifying areas of agreement and minimizing differences. And lastly, the condition of political efficacy links deliberation to tangible outcomes that begin with building citizen confidence, encouraging learning and interest in politics that will ultimately have an effect on politics and government policy. The 3 goals and 5 conditions described in this section will be used as a framework to examine the extent to which they are present in our public deliberation case studies.

The Deliberative Ideal in Practice

Case Study #1 - Using public deliberation to inform the evaluation of health technologies in Ontario: The Citizens Reference Panel on Health Technologies (CRPHT) (see Table 1)

In 2001, the Ministry of Health and Long-Term Care (MOHLTC) established the Medical Advisory Secretariat (MAS) to conduct evidence-based analyses to help stakeholders make policy and funding decisions about health technologies in Ontario. The MAS, which is comprised of health care specialists including physicians, clinical epidemiologists, policy analysts and health economists, is committed to ensuring that residents of Ontario have access to the best available new health technologies that will improve patient outcomes (MOHLTC, 2010).

The MAS produces evidence-based analyses of health technologies that are then reviewed by the Ontario Health Technology Advisory Committee (OHTAC), an armslength expert committee established in 2003 that makes recommendations to the Ontario health care system and the Ontario Ministry of Health and Long-Term Care (MOHLTC) about the best health technologies for Ontario (MOHLTC, 2010).

MAS and OHTAC have had a long-standing interest in involving relevant stakeholders in their, particularly in the area of incorporating ethical and societal perspectives into the health technology policy analysis process. In 2007, OHTAC formed a public engagement sub-committee, which identified the need for 'added vehicles for communication and consultation' with three stakeholder groups: patients, families and caregivers; advocacy groups; and the general public and Ontario taxpayers. In December 2008, the Citizens

Reference Panel on Health Technologies (CRPHT) was formed as part of collaborative research study between the Medical Advisory Secretariat and McMaster University's Centre for Health Economics and Policy Analysis. The 14-member panel was created through a 'civic lottery' process where 3500 Ontario residents were randomly selected from a stratified sample, and mailed an invitation letter to become a member of the panel along with an information sheet describing the project and their involvement. One hundred and sixty three expressions of interest were received and 14 panel members were selected blindly from a respondent pool, stratified by geographic region, age and gender (Table 1).

The panel has met 5 times over an 18-month period between February 2009 and June 2010. Topics are selected in consultation with the research team and MAS and OHTAC representatives. Information about the topics under discussion at each meeting is precirculated in a meeting workbook which includes background information about the topic, explanation of key concepts relevant to the topic and a list of discussion questions to be addressed which form the basis of the input to be provided to the decision-maker organization. Meetings are facilitated by the research team and include a combination of large- and small-group interactions organized around a pre-circulated agenda, discussion topics and questions. The meetings are audio-recorded. Data collected include qualitative verbatim transcripts, quantitative surveys administered before and after the meeting and observation notes recorded by members of the research team (Table 1).

Case Study #2 Using public deliberation to inform Quebec's Health and Welfare Commissioner: The Consultation Forum of the Quebec Comissioner of Health and Well-Being (see Table 1)

In 2005, the Commissioner of Health and Well-Being of Quebec was established with the responsibility for:

"assessing the results achieved by the health and social services system ..., and for *providing the public with the necessary background for a general understanding* of the actions undertaken by the Government to address the major issues in the health and social services arena."

(Government of Quebec, 2005)

As part of the legislation governing the Commissioner's establishment, a Consultation Forum was also formed with a mandate to "provide the Commissioner with *its point of view* on the matters or issues the Commissioner submits to it as part of a consultation" (2005, c. 18, s. 28). The Forum is a 27-member citizen-expert panel that includes 18 citizens and 9 experts. It meets 3-4 times per year for 1.5 days. Two separate recruitment processes were used to form the panel. Citizens recruited through advertisements in local media and regional 'simulation events'. Experts were recruited through consultation with various organizations and university departments. A total of 266 citizens and 51 experts proposed their candidacy. Candidates were evaluated and selected based on a series of predetermined criteria (Table 1).

The Commissioner and his staff select the topics that will be discussed at each meeting. Information about the topics under discussion is pre-circulated to Forum members in advance of each meeting. An external facilitator runs the meetings in cooperation with the chairperson of the Forum. All discussions take place in plenary format. The meetings are audio-recorded. Data collected include qualitative verbatim transcripts, quantitative surveys administered before and after the meeting and observation notes recorded by members of the research team (Table 1).

Cross-Case Analysis

In this section we reflect on the experiences from each project through the lens of the 'goals-conditions' framework presented earlier.

The motivations for creating the deliberative forum

Table 1 describes the stated objectives for each deliberative forum. In the case of the CRPHT, the explicit focus is to provide a mechanism for OHTAC to incorporate societal and ethical values into its own deliberative process, using a deliberative public engagement methodology. Hence, the dominant focus in this project is the more instrumental goal of using the deliberative forum to *inform, and improve the quality of*, the health technology advisory process. In the case of the Quebec Consultation Forum, the motivations appear to be more aligned with the goal of *improving legitimacy and accountability* by providing the citizen-expert panel with the opportunity to 'road test' a variety of recommendations as they are being developed. In neither case does the educative goal of improving public understanding and competency emerge as an explicit motivation although it is recognized as a critical element in the design process given the highly technical nature of the topics that are put to each of the panels.

The role of institutional arrangements

Table 1 outlines the institutional features of our two case studies, which have important implications for the assessment of deliberation in each site. In particular, the legislative context within which the Commissioner of Health and Well-Being in Quebec and its Consultation Forum is situated, fosters more politicized relationships between the Commissioner and the Government, the Commissioner and his staff, and between the Commissioner's staff and the Forum members. Knowing that the Forum is a legislatively mandated body and that members are providing input to reports that are presented to the Quebec National Assembly gives members a strong sense of role legitimacy. As a result, they have high expectations for the quality of deliberations including the transparency of the Commissioner's office in explaining how their input will be used. While the citizens' panel members in Ontario have also communicated high expectations about contributing in a meaningful and transparent way, their involvement in a timelimited pilot research project appears to have dampened some of these expectations and cultivated a different set of relationships between panel members, the research team and the expert advisory committee that it is advising. These fundamentally different institutional contexts necessarily exert different shaping effects on the nature in which deliberation is implemented in each site and, in turn, how it will measure up to its theoretical goals.

Are the conditions of deliberation being met?

We now consider, in turn, each of the five conditions of deliberation summarized in Jacobs et al. (2009) in light of some early observations from our two case studies.

Universalism and inclusivity (conditions 1 & 2)

The notion that deliberative processes should be inclusive and provide for equal opportunities for participation is an iconic feature of theorized deliberation and also the easiest to dismiss through empirical observation. The reality of deliberation is that it involves social processes that are not easily managed even through the most careful design and expert facilitation. Davies et al. (2006) describe the problem as 'hegemonic discourse' which has the power to legitimate inequalities. Drawing on the work of Young (2000), they call for a more realistic theorizing of deliberation that

"address[es] the resources that citizens bring to a deliberative arena, the way in which these are already colonized by hegemonic discourses and the circumstances under which oppositional positions may be successfully articulated."

This situation was apparent in our two case studies where, from the very first meeting, influential leaders emerged within each group. In the Ontario case, one panel member wielded considerable influence by requesting additional material to inform future discussions which served as a reference point for future discussions at subsequent meetings.

[insert illustrative quotes from meeting #1 transcript here]

The same individual's ability to powerfully articulate her views toward access to screening technologies for colorectal cancer in Ontario shaped the course of ensuing discussion and the priority given to certain summary points that were reported back to the sponsoring advisory committee and subsequently incorporated into a revised screening recommendation document. What is interesting to note is that this individual does not dominate in terms of 'talk time' but behaves as a very effective informal leader and facilitator to the group, not unlike a member of the research team. Unlike other panel members whose participation routinely prompts others to take oppositional positions, this individuals' positions are rarely, if ever, challenged.

Rationality (condition #3)

A second core feature that sets deliberative methods apart from other public participation methods is the role played by evidence and claims grounded in logic and fact. The provision of information through pre-circulated material, expert presentations, and Q&A sessions is routinely described as a discrete component of the deliberative process. Scholars have long challenged the neutrality of this process given the power wielded by those who select the expert witnesses or the information to be shared with participants or who provide the information directly (insert cites). The importance of the neutral facilitator in contributing to the achievement of these goals has also been widely cited (Abelson et al. 2003). While our case study findings reinforce the challenges of trying to meet these goals, we offer a more comprehensive portrayal of what is involved and suggest that a more nuanced conceptualization of information, evidence and claims making grounded in logic is needed.

For example, in a preliminary analysis of three Ontario citizens' panel meeting transcripts we found that citizen panel members required different types of information at different points in time to provide them with the confidence required to meaningfully discuss the topics assigned. Not only do citizens interact with the information provided to

them in different ways (i.e., some relating better to written materials vs. oral presentations) and at different junctures during the meetings (e.g., during introductory presentations vs. small-group discussions), but requests for additional information are a routine occurrence and some panel members consulted varied sources of information in preparation for the meeting which were referenced during discussions (Simeonov, 2010).

A related issue concerns the appropriate time for facilitators to intervene during the deliberative process to reinforce or provide clarifying information. For some deliberation topics, there is a considerable amount of technical information required to gain a basic understanding of the problem. When citizens are deliberating among themselves, particularly in small group discussions, there can be a fine line between providing clarifying fact-based information and changing the dynamic of the discussion. Finding the right balance can be challenging and requires careful navigation. In the Ontario case study, it is probable, especially in the earlier meetings when panel members were just beginning to feel comfortable with the deliberative process that this condition of deliberation was not implemented in its fullest form.

[insert illustrate quotes here]

In the case of the Quebec Consultation Forum, some of the challenges associated with this feature related to the sheer volume of material shared with the Forum members and concerns about their ability to digest everything in a meaningful way. This raises another delicate issue of finding the right balance between providing enough information to suitably inform deliberations.

[insert illustrative quotes here]

Agreement (condition #4)

The agreement condition of deliberation involves working through conflicts and competing ideas to identify common ground and practical solutions. Meeting the agreement condition in practice is fraught with challenges even when this is a clearly identifiable design feature. But as one of our case studies illustrates, it may also be that the process falls short in this particular area. More specifically, we argue that the citizens' panel in Ontario may not be meeting this condition at all and, in fact, may never have been structured to do this in a systematic way. Rather, its focus on 'collecting' societal and ethical values that will, in turn, inform the deliberations of the provincial health technology advisory committee is more akin to a traditional public consultation process where the views of participants are solicited without any significant attempt to reconcile differences, reach common ground or find practical solutions. This is not to suggest that no effort is made to find some sense of the collective views of the group but it is the lack of a traceable, reproducible process for doing this that warrants scrutiny. At the first meeting of the Ontario citizens' panel, time was set aside to seek agreement on a set of themes that captured the essence of the discussions. This component of the agenda was formally facilitated at the end of the meeting. Subsequent efforts to reconcile competing views for the purposes of finding common ground have been much less formal and, in general, collective input is assumed to be the product of the smallgroup discussions that are built into each meeting.

In the case of Quebec's Consultation Forum, attempts to seek agreement have been more explicit but also far more contentious. At each meeting, a summary of the deliberations from the previous meeting is shared with the members as part of a vetting or member checking process. Over the two-year duration of the Forum, this aspect of the Forum's activities has been subjected to mounting criticism leading to a major overhaul of the vetting process at a recent Forum meeting. The source of concern has been the lack of transparency in how the meeting discussions are summarized and the lack of acknowledgement of differing views among Forum members. As of the last meeting of the Forum, a new process has been implemented that appears to have widespread support – time will tell if concerns about this feature have been adequately addressed.

[insert illustrative quotes here]

Davies et al. (2005) reported similar problems in the early days of the NICE Citizens Council. Mid-course adjustments were required to ensure that 'minority' views were not being glossed over in an attempt to portray the council as having reached unanimity on the issues discussed (Davies et al. 2006). The condition of 'agreement' appears to require more conceptualization to understand how this might operate adequately in practice. Our findings also suggest that the need to consider that a continuum of deliberation might be a more sensible way to categorize and understand practice with respect to certain features.

Political efficacy (condition #5)

To some deliberation scholars, political efficacy is the most important condition to be met and is, indeed, at the heart of calls for deliberative public participation. Effective deliberation, it is argued, will produce outcomes that will inform and influence policy. Along the way, and necessary to achieving the goal of informing policy, intermediate outcomes of increased public confidence, knowledge about public issues and an interest in contributing to public-spirited discussions will also be achieved. In both our case studies, the objectives of the deliberative panel were to realize some tangible output that would inform a related decision-making process. In the Ontario case, the instrumental goal of improving the quality of Ontario's health technology assessment process by incorporating the public's values were the driving force behind the project. In the Quebec case, a more general notion of incorporating Forum members' views into the Commissioner's recommendations suggests a similarly spirited emphasis.

The challenge in both cases, as it is more generally in the field, is to document these often-elusive links. But how do we map the path from deliberation to political efficacy in the context of a citizens' panel that is informing an advisory panel on health technology assessment or between a consultation forum and the work of the health and welfare commissioner that it informs? In both cases, the links between public participation and policy making are indirect, not easily perceptible, and likely to be observed, if at all, over a long time horizon usually beyond that of the participatory process. Moreover, neither of the organizations we are studying is required to demonstrate how they have considered and incorporated the input of citizens into their documents or thinking. Yet in both cases, organizational commitment and recognition of the importance of paying attention to these links appear to be sincere. Without any firm accountability requirements in place, are demonstrations of organizational sincerity enough?

In prior work in this area, we have attempted to document the links between public input and measurable outcomes and have found that the outcomes of interest are varied (Abelson et al. 2007). The conventional ways of thinking about influence are through participants themselves as they become more confident and politically interested and mobilized. However, for many of the health care organizations that are experimenting with deliberative participatory models, the path of influence is likely to be through the organization and its inner workings rather than a direct link between citizens and policy.

For example, in the evaluation of the NICE Citizens Council in the U.K., NICE as an organization struggled for some time to determine how to incorporate the input of the Citizens Council into the workings of the organization (Davies et al. 2005). This led to much soul searching within the organization which now requires the Board of NICE to respond to each Council report with a clear statement of how it has considered the Council's input in its own deliberations (Davies et al. 2006). This form of 'accountable consultation' has been discussed elsewhere (Litva et al. 2002) and is received favourably by citizens who are looking for signs that their contributions have been considered in a measured way even if they haven't had a direct influence on a policy process. Before these types of recommendations for solving the public input-policy gap can be offered, however, a much more thorough understanding of why the gaps exists in the first place, and how links that do exist might be documented more comprehensively, is required.

Some final reflections and future work

It may come as no surprise to those carrying out empirical studies of deliberation that its theorized goals fall short when put into practice. Davies et al. (2006) provocatively describes the gap as that between 'sanitized debates' vs. 'messy practice'. Through our own case studies of deliberation practice in the health sector in Ontario and Quebec we have added to the on-going discussion out what additional theorizing is required to provide a more robust framework to guide empirical work in this area. Our preliminary findings suggest that at least some of the following improvements might be considered. First, with respect to the condition of *equal participation and inclusivity*, our findings indicate that a much more sophisticated understanding of citizen participants' roles is needed given that satisfying the equal participation condition may have little bearing on the extent to which individuals use their experience and "hegemonies of discourse" to wield influence either intentionally or unintentionally. More specifically, exploring more fully how citizen participants become informal leaders within groups such as deliberative panels and how these roles affect the principles of universalism and inclusivity is an important area for additional work.

A second and equally important area for continued study is how and why citizens use, call for and independently retrieve different *forms of evidence* as sources for improved understanding and as the basis for reaching specific positions on an issue. Much of the emphasis to date has been placed on the importance of deliberation organizers carefully selecting information to provide to citizen participants; however, as citizen deliberators seek out additional information sources to augment the information provided, understanding how they use their hand picked information in relation to other sources will be important. A different angle on the rationality condition also worthy of attention is how facilitators can train themselves to avoid leading, influencing or biasing a deliberative process vs. contributing to informed and higher quality deliberations by injecting reinforcing or clarifying information into the discussion.

Perhaps the area in greatest need of additional theorizing is the fundamental question of when deliberation starts and stops, how we know that it's really happened and whether it is acceptable to have a continuum of deliberation. All of these questions bear on the *agreement* condition and are some of the most perplexing to face deliberation practitioners.

Each of the above pertains to the micro-level workings of deliberation which, independently, and taken together, are critical. But as discussed earlier, it is only through a much broader consideration of deliberation in its *political and institutional contexts* – that is in unpacking the underlying motivations for undertaking it and the institutional arrangements within which it must survive - that much progress will be made in truly understanding what shapes its design, implementation and ultimately, its influence over the policy process it seeks to inform. We look forward to the next wave of interactions between theorists and practitioners as the field of empirical deliberation research matures.

Table 1

Comparison of Key Characteristics of Deliberative Mechanism

	Ontario (Citizens Reference Panel on Health Technologies)	Quebec (Consultation Forum)
Institutional setting of deliberative body	 - initiated as a pilot research project to provide input to Ontario's provincial health technology advisory committee and secretariat 	 established in legislation to inform the Commissioner of Health and Well-Being on a range of matters relating to the performance of the health system
Objectives	 source of societal and ethical values to inform Ontario's health technology assessment processes 	- source of public consultation input on selected matters submitted by the Commissioner
Composition and size	 - 14 members selected through civic lottery - 1 representative for each local health integration network - balance of men and women and age ranges 	 27 members made up of 18 citizens and 9 experts geographic representation, men and women
Meeting structure & frequency	 1-day meetings with standard agenda items research team PI and members as facilitators combination of large and small- group discussion 	- 2-day meetings - external facilitator - large-group discussion only
Topic identification	- health technology topics identified by secretariat and advisory committee for discussion and provision of societal and ethical values input	- topics identified by Commissioner and staff
Input produced	 themes from qualitative discussion priority rankings of values pertaining to specific technologies 	- thematic summaries from qualitative discussion
How input is synthesized and reported	 thematic review of topic-specific discussions (no particular structure) "highlights" report prepared by research team and presented to advisory committee 	 forum discussions are summarized and shared with forum members for vetting not clear how summary reports are used in
Links between public input and sponsor's work	 no standard approach but elements may include: i.PI summary of themes to advisory committee ii. explicit incorporation of citizens panel input into advisory committee recommendations 	 the process for incorporating Consultation Forum input into the Commissioner's reports is not transparent Commissioner's reports are presented to the Quebec national assembly so the potential for accountable consultation is high

References

Abelson, J., Forest, P-G., Eyles, J., Smith, P., Martin, E., and Gauvin, F.-P. (2002). 'Obtaining Public Input for Health Systems Decisionmaking: Past Experiences and Future Prospects', Canadian Public Administration, 45(1): 70–97.

Abelson, J., Eyles, J., McLeod, C., Collins, P., and Forest, P.-G. (2003). 'Does Deliberation Make a Difference? A Citizen's Panel Study of Health Goals Priority Setting', Health Policy, 66(1): 95–106.

Abelson, J., Lomas, J., Eyles, J., Birch, S., and Veenstra, G. (1995). 'Does the Community Want Devolved Authority?' Canadian Medical Association Journal, 153: 03–12.

Abelson, J., Forest, P.-G., Eyles, J., Smith, P., Martin, E., and Gauvin, F.-P. (2003) 'Deliberations About Deliberative Methods: Issues in the Design and Evaluation of Public Consultation Processes', Social Science and Medicine, 57: 239–251.

Abelson, J., Forest, P.-G., Eyles, J., Casebeer, A., Martin, E., Mackean, G., and the Effective Public Consultation Project Team (2007) 'Exploring the Role of Context in the Implementation of a Deliberative Public Participation Experiment: Results from a Canadian Comparative Study', Social Science and Medicine, 64: 2115–2128.

Abelson, J. and Gauvin, F.-P. (2006) Assessing the Impacts of Public Participation: Concepts, Evidence and Policy Implications. Research report of the Public Involvement Network, Canadian Policy Research Networks, January 2006.

Baum, N., Goold, S., and Jacobson, P. (2009) ' "Listen to the People": Public Deliberation About Social Distancing Measures in a Pandemic', American Journal of Bioethics, forthcoming.

Beierle, T.C. and Cayford, J. (2002) Democracy in Practice: Public Participation in Environmental Decisions. Washington, D.C.: Resources for the Future.

Beierle, T. and Konisky, P. (2000) 'Values, Conflict and Trust in Participatory Environmental Planning', Journal of Policy Analysis and Management, 19(4): 587–602.

Bostwick, M. (1999) 'Twelve Angry Citizens: Can Citizens' juries Improve Local Democracy in New Zealand?', Political Science, 50(2): 236–246.

Bowie, C., Richardson, A. and Sykes, W. (1995) 'Consulting the Public About Health Service Priorities', British Medical Journal, 311: 1155–1158.

Bowling, A., Jacobson, B., and Southgate, L. (1993) 'Explorations in Consultation of the Public and Health Professionals on Priority Setting in an Inner London Health District', Social Science and Medicine, 37(7): 851–857.

Burstein, P. (2003) 'The Impact of Public Opinion on Public Policy: A Review and an Agenda', Political Research Quarterly; 56(1): 29–40.

Campbell, S. and Townsend, E. (2003) 'Flaws Undermine Results of UK Biotech Debate', Nature (Letter); 425(6958): 559.

Coast, J. (1996) Core Services: Pluralistic Bargaining in New Zealand. In J. Coast, J. Donovank, and S. Frankel (eds), Priority Setting: The Health Care Debate (pp. 65–82). Chichester: Wiley.

Cohen, J. (1989) Deliberation and Democratic Legitimacy. In A. Hamlin and P. Pettit (eds) The Good Polity: Normative Analysis of the State (pp. 17–34). Oxford: Basil Blackwell.

Cookson, R. and Dolan, P. (1999) 'Public Views on Health Care Rationing: A Group Discussion Study', Health Policy, 49(1–2): 63–74.

Coote, A. and Lenaghan, J. (1997) Citizens' Juries: Theory into Practice. Institute for Public Policy Research: London.

Delli Carpini, M.X., Cook, F.L., and Jacobs, L. (2004) 'Public Deliberation, Discursive Participation and Citizen Engagement: A Review of the Empirical Literature', Annual Review of Political Science, 7: 315–344.

Davies, C. Wetherll, M., and Barnett, E. (2006). Citizens at the Centre: Deliberative participation in health care decisions. Bristol, U.K.: The Policy Press.

Davies, C., Wetherell, M., Barnett, E., and Seymour-Smith, S. (2005) Opening the Box: Evaluating the Citizens Council of NICE. Open University.

Dolan, P., Cookson, R., and Ferguson, B. (1999). 'Effect of Discussion and Deliberation on the Public's Views of Priority Setting in Health Care: Focus Group Study', British Medical Journal, 318: 916–919.

Donovan, J. and Coast, J. (1996). 'Public Participation in Priority Setting: commitment or illusion?'. In J. Coast, J. Donovan, and S. Frankel (eds) Priority Setting: The Health Care Debate (pp. 203–224). Chichester: Wiley & Sons.

Dunkerley, D. and Glasner, P. (1998) 'Empowering the Public? Citizens' Juries and the New Genetic Technologies', Critical Public Health, 8(3): 181–192.

Dryzek, J.S. (2000) Deliberative Democracy and Beyond. Oxford: Oxford University Press. Editorial team (2001) In brief: NICE to Get Advice from a Citizens Council. BMJ; 323(7324): 1268.

Einsiedel, E.F. (2006) 'TransAtlantic Perspectives on Public Engagement with Science'. In J. Turney (ed.) Engaging Science: Thoughts, Deeds, Analysis, and Action. London: Wellcome Trust.

Einsiedel, E. (2002) 'Assessing a Controversial Medical Technology: Canadian Public Consultations on Xenotransplantation', Public Understanding of Science, 11: 315–331.

Fearon, J.D. (1998) 'Deliberation as Discussion'. In J. Elster (ed.) Deliberative Democracy (pp. 44–68). Cambridge: Cambridge University Press.

Fishkin, J.S. (1991) Democracy and Deliberation. New Haven: Yale University Press.

Fishkin, J.S., Luskin, R.C., and Jowell, R. (2000) 'Deliberative Polling and Public Consultation', Parliamentary Affairs, 53(4): 657–666.

Forest, P.-G., Gauvin, F.-P., Martin, E., Perrault, C., Abelson J., and Eyles, J. (2004) Une expérience de consultation publique délibérative dans Charlevoix. Recherches Sociographiques, 2004; XLV(1): 77–104.

Government of Quebec. 2005. An Act respecting the Health and Welfare Commissioner. L.R.Q. Bill 38 (2005, chapter 18).

Graham, K.A. and Phillips, S.D. (1998) 'Making Public Participation More Effective: Issues for Local Government'. In: K.A. Graham and S. D. Phillips (eds) Citizen Engagement: Lessons in Participation from Local Government. (pp. 1–24). Monographs on Canadian Public Administration, No. 22. Institute of Public Administration of Canada: Toronto.

Gutmann, A., and Thompson, D. (1996). Democracy and disagreement. Cambridge: Harvard University Press.

Habermas, J. (1984) The Theory of Communicative Action I: Reason and the Rationalization of Society. Boston: Beacon Press.

Inglehart, R. (1995) 'Changing Values, Economic Development and Political Change', International Social Science Journal, 47(3): 379–403.

Inglehart, R., Nevitte, N., and Basanez, M. (1996) The North American Trajectory: Social Institutions and Social Change. New York/Berlin: Aldine de Gruyter.

Jacobs, L., Lomax Cook F., and Delli Carpini, M. (2009). Talking Together: Public Deliberation and Political Participation in America. Chicago: University of Chicago Press.

Lenaghan, J., New, B., and Mitchell, E. (1996) 'Setting Priorities: Is There a Role for Citizens' Juries?' British Medical Journal, 312: 1591–1593.

Lenaghan, J. (1999) 'Involving the Public in Rationing Decisions. The Experience of Citizens' Juries', Health Policy, 49(1–2): 45–61.

Leroux, T., Hirtle, M., and Fortin, L.-N. (1998). 'An Overview of Public Consultation Mechanisms Developed to Address the Ethical and Social Issues Raised by Biotechnology', Journal of Consumer Policy, 21(4): 445–481.

Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J., and Morgan, K. (2002). 'The Public is Too Subjective': Public Involvement at Different Levels of Health-Care Decision Making', Social Science and Medicine, 54(12): 1825–1837.

Manin, B. (1987) 'On Legitimacy and Political Deliberation', Political Theory, 15(3): 338–368. Maxwell, J.S., Rosell, S., and Forest, P.-G. (2003) 'Giving Citizens a Voice in Health care Policy in Canada', British Medical Journal, May, 326: 1031–1033.

McIver, S. (1998) Healthy Debate? An Independent Evaluation of Citizens' Juries in Health Settings. London: King's Fund Publishing.

Mullen, P. (2000) 'Public Involvement in Health Care Priority Setting: Are the Methods Appropriate and Valid?' In C. Ham, and A. Coulter (eds) The Global Challenge of Health Care Rationing (pp. 163–174). Buckingham, UK: Open University Press.

National Institute of Clinical and Health Excellence. 2002.

Nevitte, N. (1996) The Decline of Deference: Canadian Value Change in Cross-National Perspective. Peterborough, ON: Broadview Press.

Richardson, A., Charny, M., and Hanmer-Lloyd, S. (1992) 'Public Opinion and Purchasing', British Medical Journal, 304: 680–684.

Romanow (2002) Building on Values: The Future of Health Care in Canada – Final Report. Commission on the Future of Health Care in Canada. Ottawa.

Rowe, G. and Frewer, L.J. (2000) 'Public Participation Methods: A Framework for Evaluation', Science, Technology and Human Values, 25(1): 3–29.

Rowe, G. and Frewer, L. (2004). 'Evaluating Public Participation Exercises: A Research Agenda', Science, Technology and Human Values, 29(4): 512–556.

Rowe, G. and Frewer, L.J. (2005) 'A Typology of Public Engagement Mechanisms', Science, Technology and Human Values, 30(2): 251–290.

Royle, J., & Oliver, J. (2004). Consumer involvement in the health technology assessment program. International Journal of Health Technology Assessment in Health Care, 20(4), 493–497.

Simeonov, D. and Abelson, J. Citizens' use of information in the public deliberation process on health technology assessments. Presentation to the Department of Clinical Epidemiology and Biostatistics Research Day, April 23, 2010.

Simrell King, C. (1998) 'The Question of Participation: Toward Authentic Public Participation in Public

Administration', Public Administration Review, 58: 317-326.

Smith, G. and Wales, C. (1999) 'The Theory and Practice of Citizens' Juries', Policy and Politics, 27(3): 295–308.

Stronks, K., Strijbis, A., Wendte, J.F., and Gunning-Schepers, L.J.G. (1997) 'Who Should Decide? Qualitative Analysis of Panel Data from Public, Patients, Health Care Professionals, and Insurers on Priorities in Health Care', British Medical Journal, 315: 92–96.

Wiseman, V., Mooney, G., Berry, G., and Tang, K.C. (2003) 'Involving the General Public in Priority Setting: Experiences from Australia', Social Science & Medicine, 56(5): 1001–1012.