

**Health Technology Assessment**

**PRACTICES FOR IMPLEMENTING EFFECTIVE  
PUBLIC ADVISORY GROUPS OF LAY PEOPLE  
OR MEMBERS OF THE GENERAL PUBLIC**

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INSTITUTE OF  
HEALTH ECONOMICS  
ALBERTA CANADA

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# Health Technology Assessment

## **PRACTICES FOR IMPLEMENTING EFFECTIVE PUBLIC ADVISORY GROUPS OF LAY PEOPLE OR MEMBERS OF THE GENERAL PUBLIC**

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## **Corresponding Author**

Please direct any inquiries about this report to Christa Harstall at: [charstall@ihe.ca](mailto:charstall@ihe.ca)

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## TARGETED SCAN OF THE LITERATURE

### Background

A lay person is a non-professional or non-specialist or an amateur.<sup>1</sup> This definition has been largely adopted by the health services.<sup>1</sup> Lay people are those who have not gone through the training or socialization into the particular profession under discussion and are assumed to have retained the ordinary norms and values of their society. In contrast, health professionals acquire new norms, assumptions, values, and ways of behaving during their training and professional practice.<sup>1</sup> Members of the public are not expected to be objective scientific experts, but rather to participate in value-based deliberations.<sup>2</sup> They are experts in the living experience of using the health care system and offer insight into the values and beliefs of the public at large.

The public is considered the most important stakeholder in the health care system.<sup>2</sup> Interest is growing in scientific research and public policy for engaging the public in consultation and, furthermore, to involving the public in deliberation that will lead to a more transparent, accountable, responsive, and therefore legitimate outcome, with the ultimate goal in the healthcare field of improving healthcare outcomes.<sup>3</sup> A deliberative approach asks the public to do more than just give their views, but also to participate in the task of deliberating over these views using dialogue, and to work through the issues together with the sponsoring organization through a collaborative process that includes bringing a measure of discipline and accountability into the discussion. At the end of the deliberative process, the sponsoring organization usually makes the final decision.

A public engagement and knowledge translation environmental scan<sup>4</sup> was conducted in 2011 that aimed to determine the best models/frameworks, tools, techniques, and practices related to public engagement, including lay committees, and to understand the current Alberta landscape regarding knowledge translation in public engagement. The work was initiated by the Collaborative Health Innovation Network (CHIN), an Alberta forum through which ten organizations in the province, including the Institute of Health Economics (IHE), could cooperate to improve the link between evidence and decision-making and to increase the speed and impact of research investment through effective knowledge translation.<sup>4</sup> The review contributed to a better understanding of public engagement aspects. The summary of findings stated there is no “best practice” method for a specific purpose and the techniques used to engage the public were dependent on the purpose of engagement, the issues to be discussed, the time frame, the number of participants, and the funds available. Increasing literacy of the participants does improve the outcomes and engagement; clarity of requirements and of questions for discussion is essential. The size of committees doesn’t matter and no best-practice approach is evident for achieving sustainability in public engagement, according to the literature scan results. In Alberta, several initiatives exist for engaging the public at a variety of levels and in multiple sectors, and the scan report states that a consistent, unified approach could improve the effectiveness and efficiency of these forms of engagement.

The IHE Layperson Advisory Committee was established in the fall of 2009 and started to function in the spring of 2010. Its aim was to reflect on IHE research activities and priorities and provide feedback and ideas about how to improve IHE products and programs. Currently, the committee involves eight members, including the chair. Members have no direct connection with IHE programs and are diverse with respect to age, gender, occupation, and ethnic and political background. The committee meets twice a year; each meeting includes an informal dinner and a 6-hour meeting the next day. A senior IHE manager, in collaboration with the chair, prepares for the meetings in advance, and agendas, including documents for discussions, are distributed by email or

postal mail in advance of the meeting. The meetings include information about programs and research activities at IHE and consultation about various topics such as IHE final health technology assessment reports. Topics are typically presented by IHE staff and members of the management team and, on a few occasions, by external professionals. At the end of each meeting participants prepare and share with the IHE management team a report that highlights the committee's feedback and suggestions resulted from their discussions. Participants receive an honorarium and compensation for their travel and accommodation expenses.

Early in 2013, the IHE management team initiated an evaluation of its Layperson Advisory Committee. This evaluation aimed to provide insights and feedback on past processes and activities, and to obtain fresh ideas on how the IHE could improve its work with the committee. Part of the evaluation included conducting a targeted scan of the literature published about other practices for implementing effective public advisory groups or committees composed of lay people or members of the general public.

## Scope and Objective

The objective was to perform a review of practices of engaging committees composed of lay people or members of the general public at international, national, provincial, and regional levels.

## Research questions

The review attempts to address the following questions:

- What scientific evidence is available about committees composed of lay people or members of the general public that are similar to the IHE Layperson Advisory Committee?
- What best practices models/options/bodies/applications for implementing effective committees of lay people or members of the general public are available (such as how best to inform the committee, process considerations, effective advice characteristics, areas for improvement, best structures, and governance)?
- What has been shown to work and what lessons have been learned?

The methodological approach to answering these questions was established a priori and included a synthesis review of the scientific research about practices of engaging committees composed of lay people or members of the general public with processes that are similar to those used for the IHE Layperson Advisory Committee.

- Appendix A provides detailed descriptions about the literature strategy (data sources, dates searched, and search terms) and the literature selection (inclusion and exclusion criteria) used.
- Appendix B provides a list of excluded publications.
- Appendix C provides a synopsis of characteristics of the included publications.
- Appendix D provides an example of a Canadian citizens' panel on health technologies, as published by the Canadian Institutes of Health Research (CIHR) in the *Citizen Engagement in Health Casebook*.

## Results

### Selection of publications and reasons for inclusion

A comprehensive literature search of electronic databases for articles published between April 1998 and April 2013 (see Appendix A) identified 1926 citations. One reviewer conducted the screening and selection of studies for inclusion. After screening of titles and abstracts, the full text of 76 potentially relevant articles and documents from the grey literature review were retrieved and evaluated for eligibility in the review. The searches included publications from healthcare and non-healthcare fields.

As anticipated, the literature addressing layperson committees with structures and processes similar to the IHE Layperson Advisory Committee was very limited; only five committees were found with structures and functions more or less similar (see Figure 1).

The included publications provided descriptions of structures and processes of committees whose members were entirely lay people or members of the general public, were not affiliated with government organizations, or were not considered experts in the field where their involvement was required.

Among exclusion criteria were publications about committees composed of patients, special groups of populations with interest in a specific topic, committees composed of lay people or members of the general public involved in activities connected to primary research, committees that included a mix of lay people/members of the general public and experts, and committees whose meetings were open to the general public.

Appendix A provides a detailed description of the selection procedure and Appendix B lists the excluded studies and the reasons for exclusion.

Relevant information contained in some of the excluded papers was included in the background and discussion sections of the review.

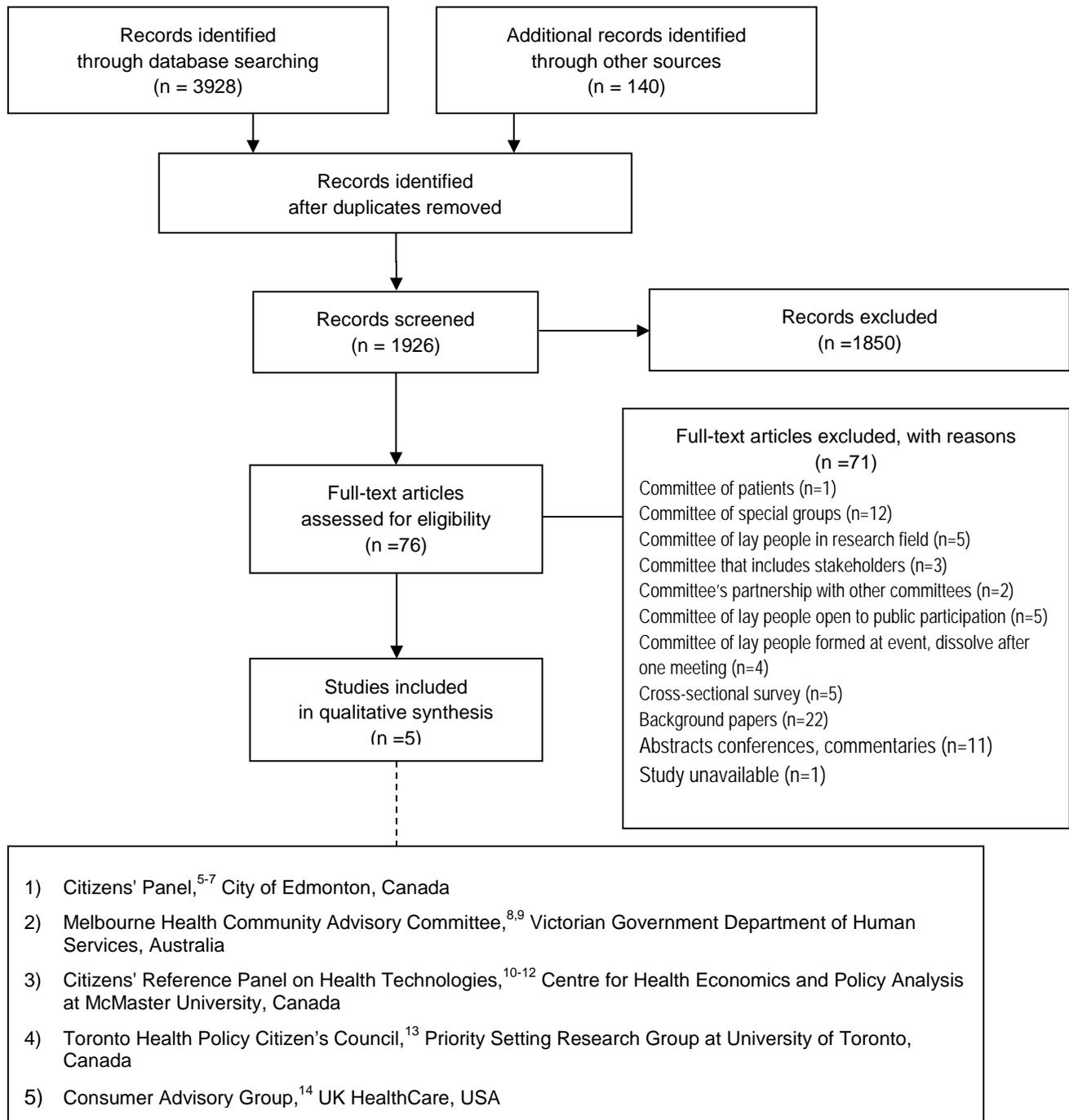
### Study characteristics

#### *General aspects*

The five committees were established between 2006 and 2012 and all but one<sup>5-7</sup> were active in the healthcare field. Two committees<sup>10-13</sup> were set up at the provincial level while the other three committees were active at the local levels. One guideline manual was found that provides directions for public health services to develop effective community advisory committees at all levels within the public health services of Australia.<sup>9</sup> All but one of the committees were established to function with support from universities: University of Alberta,<sup>5</sup> McMaster University,<sup>10</sup> University of Toronto,<sup>13</sup> and University of Kentucky.<sup>14</sup>

Although the committees involve lay public individuals, they are not all the same. They vary greatly in terms of occurrence in different fields (healthcare and non-healthcare fields), selection of participants and membership, structure, and participants' roles, commitment, and levels of involvement (see Tables 1 and 2 and Appendix C.1, Table C.1).

**Figure 1: Selection of included publications**



### ***Selection processes and membership***

Lay people or members of the general public included in committees do not need to represent all sectors of their communities. Committees should consist of a balanced and representative group of members<sup>15</sup> selected on the basis of specific inclusion criteria that reflect the scope/goals, intended functions, and purpose of the committee. Generally, members are selected either by special invitation or through a competitive application process by inviting a diverse and balanced group to serve on the committee. An appropriate representation may be ensured by recruitment of minorities and people from low-income populations. A group having 10 to 15 members is considered large enough to allow a diversity of viewpoints, while simultaneously keeping meetings manageable. Having an option for members to cycle on and off the committee is also important.<sup>16</sup> The findings of the public engagement and knowledge translation environmental scan<sup>4</sup> indicated that the size of a public engagement committee does not matter and success can be achieved from a small or a very large number of participants.

The size of the five committees included ranged between eight and 57 members, depending on the scope of the engagement project. The four healthcare committees consisted of between eight and 30 volunteer members, not representative of any healthcare organization (see Table 2 and Appendix C.1, Table C.1).

Recruitment strategies varied, and the committees that engaged participants in deliberations benefited from a more rigorous and systematic process of selection of participants in an attempt to ensure a reliable representation of various groups from the society. Recruitment strategies included:

- selection of members through the use of a computer-generated list of names and addresses selected randomly from “white pages” listings, outreach at inner-city agencies, advertisements in community newspapers and on online bulletin boards, to ensure a cross-section of communities and representation of demographic targets such as both genders, those of aboriginal origin, and persons with disabilities and from visible minorities (citizens’ panel<sup>6</sup>)
- use of a “civic lottery” from a geographic region and stratification by gender and age (citizens’ panel<sup>10-12</sup>)
- random selection by an independent company to approximate the age, gender, educational level, socio-economic status, ethnic background, and health status distribution (citizens’ council<sup>13</sup>)
- recruitment from a marketing database, respondents to patient satisfaction surveys, health lectures attendees, and referrals from current members (consumer advisory group<sup>14</sup>)
- recruitment from recommendations of peak bodies, direct approach of individuals with experience as consumers, carers or community members, and open advertisements (advisory committee<sup>8,9</sup>)

In a community advisory committee, members were appointed as individuals, had to contribute with their knowledge and expertise and not to represent any organization, preferably were active in the community and had strong community networks, and had a sound understanding of local or regional issues. A community advisory committee emphasized consumers, carers and communities who were not health care providers.<sup>8,9</sup> Exclusion criteria for membership in two of the committees included providers of health services, employees or peoples engaged in provision of health services,<sup>8,9</sup> health care professionals, employees of health care professionals, employees or directors

of pharmaceutical companies, individuals owning significant equity in pharmaceutical companies, members or employees of political action groups (such as patient advocacy groups), members of provincial parliament and other elected officials, employees of the Ministry of Health and Long-Term Care, and individuals affiliated with marketing research, marketing, advertising, public media, or public relations companies.<sup>13</sup> Full functional literacy was not a requirement for membership in one committee.<sup>6</sup>

The reported lifetime/tenure of members ranged from 2 to 3 years,<sup>8,9,13</sup> with a commitment to five 1-day meetings during a period of 17 months,<sup>10-12</sup> to as short a duration as 6 days (that is, six Saturdays) for a citizens' panel<sup>5-7</sup> (see Table 2 and Appendix C.1, Table C.1).

### ***Objectives and roles***

Clearly defined roles and responsibilities of committee members are essential for an effectively functioning group.<sup>16</sup>

In the five committees, the roles of the members varied as follows (see Table 1):

- informing<sup>10-12</sup>
- providing qualitative reflections<sup>10-12</sup> and feedback/opinion/input/advice/direction<sup>5-7, 8,9, 10-12,13,14</sup>
- deliberating<sup>13</sup> and brainstorming ideas on new programs and developments<sup>14</sup>
- developing recommendations<sup>5-7,13</sup>
- providing leadership in an advisory capacity and monitoring of performance indicators without having an executive authority<sup>8,9</sup>

**Table 1: Committees, background information, roles, and objectives**

Committee	Background information, roles, and objectives
<p><b>Citizens' Panel</b><sup>5-7</sup> City of Edmonton Canada</p>	<p><i>Background:</i> Pilot project was organized collaboratively by the City of Edmonton and the University of Alberta in 2009 with the aim to learn about and discuss the City's budget priorities.</p> <p><i>Objectives and roles:</i> To provide recommendations to Edmonton City Council (Pilot project, Panel 2009); to advise the City on how to shape future energy use and to develop recommendations (Panel 2012).</p>
<p><b>Melbourne Health Community Advisory Committee (CAC)</b><sup>8,9</sup> Victorian Government Department of Human Services Australia</p>	<p><i>Background:</i> CACs were established in 2000 in metropolitan health services to foster consumer participation. By 2001, CACs were operating in 14 metropolitan health services with TOR, membership, and priority activities identified.</p> <p><i>Objectives and roles:</i> To increase consumer, carer, and community participation in public health services. Role: to provide direction and leadership in relation to the integration of consumer, carer, and community views into all levels of health services operations, planning, and policy development; to advocate to the board on behalf of the community, consumers, and carers. It is a high-level committee appointed in an advisory capacity to the public health service board as a legislated advisory committee of the board, but it has no executive authority.</p>
<p><b>Citizens' Reference Panel on Health Technologies, Ontario</b><sup>10-12</sup> Centre for Health Economics and Policy Analysis at McMaster University Canada</p>	<p><i>Background:</i> Established in Dec 2008 through a research collaboration between McMaster University and the Medical Advisory Secretariat (MAS) of the Ontario Ministry of Health and Long-Term Care.</p> <p><i>Objectives and roles:</i> To inform the work of the MAS and the Ontario Health Technology Advisory Committee (OHTAC). Role: to make qualitative reflections on a set of pre-circulated questions designed to elicit societal and ethical values related to the technology under review; to provide input to OHTAC deliberations at various stages in the HTA process—review of selected health technologies at various stages in the MAS-OHTAC review process (that is, vignette stage, draft recommendation stage, and public comment stage).</p>
<p><b>Toronto Health Policy Citizen's Council</b><sup>13</sup> University of Toronto, Priority Setting Research Group Canada</p>	<p><i>Background:</i> Established in 2007 by the University of Toronto Priority Setting in Health Care Research Group as part of a research agenda to explore public deliberation and “learn public opinion about complex health care issues as they pertain to the residents of Ontario.”</p> <p><i>Objectives and roles:</i> To have ordinary citizens deliberate about complex health care issues as they pertain to the residents of Ontario, to comment and make recommendations about these issues; to study priority-setting in health policy using public engagement.</p>
<p><b>Consumer Advisory Group</b><sup>14</sup> UK HealthCare USA</p>	<p><i>Background:</i> UK HealthCare is the clinical enterprise of the University of Kentucky.</p> <p><i>Objectives and roles:</i> To brainstorm ideas and obtain feedback on new programs and market industry developments from patients and nonpatients; to evaluate current and proposed marketing initiatives; to provide context to consumer perceptions.</p>

### *Levels of involvement*

The International Association for Public Participation<sup>17</sup> has developed a spectrum of five levels of public participation/engagement (inform, consult, involve, collaborate, and empower), in order to demonstrate the possible types of engagement with stakeholders and communities. The model shows the level of public impact from “inform”—a very low level of public impact—to “empower”. In January 2011 Canada was formally accepted into the Federation of IAP2, joining over 25 other countries. The infrastructure created aims to support members, extend the practice, and further develop and lead public participation in Canada.

An advisory committee could fall in the full range of public impact categories from “inform,”—meaning no influence and input, a very low level of public impact—to “empower,” meaning the highest involvement and input, functioning in a partnering role with the sponsoring agency. Often a lay committee could meet with the intent of hearing information (“inform”) or providing individual input and feedback (“consult”). Members could serve in an advisory role and provide information, guidance, or suggestions from the community, although the sponsoring agency may choose to accept or reject the advisor’s input.

The level of participation was considered to be at the “consult” level in four committees<sup>8-14</sup> and on the continuum between “consult” and “collaborate” in one citizen’s panel.<sup>5-7</sup> The information about the level of participation in the five committees lacked clarity due to unavailability of terms of reference in the documents studied; the level of involvement seems to be context-dependent, and to include a mixture of “consultation” and “involvement” in most of the committees (see Table 2). Two of five committees are advisory committees; one of them functions at a high level and is appointed in an advisory capacity as a legislated advisory committee but without having executive authority.

**Table 2: Committee characteristics**

Committee organization	Setting	Accountability	Level participation (IAP2)					Membership	Number members	Meeting structure	Lifetime committee	Formal evaluation	Outputs
			Inform	Consult	Involve	Collaborate	Empower						
Citizens' Panel <sup>5-7</sup>	Local	Edmonton City Council	○	●	●	●	○	General public	57	Six days (Saturdays)	Six days	● Surveys	Recommendations; overview of discussions on website
Melbourne Health Community Advisory Committee <sup>8,9</sup>	Local	Public health service board	●	●	●	○	○	Consumers, carers, community, board members	8 to 12	At least bimonthly; min. six per year, two to three hours each	Two to three years	● Biennial review ● Independent	Minutes meeting; report activities
Citizens' Reference Panel on Health Technologies, Ontario <sup>10-12</sup>	Provincial	OHTAC	○	●	○	○	○	General public	14	Two or three per year	Five one-day meetings	● Independent (CIHR)	Thematic summaries
Toronto Health Policy Citizen's Council <sup>13</sup>	Provincial	University of Toronto, Priority Setting Research Group	○	●	○	○	○	General public	26 (24 after fourth meeting)	Two weekend days	2-year; seven meetings	● Satisfaction survey	Recommendations and reports after each meeting
Consumer Advisory Group <sup>14</sup>	Local	NR, manager marketing research	○	●	?	○	○	Community Former & present patients	30	Bimonthly, average one every two months; two hours each	No commitment	● NR	NR
IHE Laypeople Advisory Committee	Local	IHE management team	●	●	●	○	○	General public	8	Twice a year; Informal dinner plus a six-hour formal meeting the next day	NR	● Independent	Minutes meeting, feedback on various topics

\* Non-healthcare field, topics—budget priorities, energy & climate change; <sup>†</sup>HTA field.

CIHR – Canadian Institutes of Health research; HTA – Health Technology Assessment; IAP2 – International Association for Public Participation; IHE – Institute of Health Economics; NR – not reported; OHTAC – Ontario Health Technology Advisory Committee

Level of participation: ● = yes; ○ = occasionally; ○ = no; ? = not clear

### *Committees' composition and structure of meetings*

The composition and structure of meetings may vary widely in formality and each committee's autonomy.<sup>15</sup> The meeting organizer could be the sponsoring agency or an independent organization.<sup>18</sup> Meetings could be run by a chairperson with assistance from the sponsoring agency or other independent staff. The chair should be an individual with a commitment to public life and reputation for being impartial, committed, and neutral.<sup>18</sup>

A typical meeting agenda covers the following items:<sup>15</sup>

- 1) introduction and welcome of newcomers
- 2) opportunity to amend or review the agenda
- 3) discussion of agenda items
- 4) presentation of specific information, as necessary
- 5) identification of consensus on each item or outstanding issues on each item.

Members' participation is likely to be effective when a committee is cohesive, energetic, and develops an internal consensus.<sup>19</sup> Clarity and relevance of debate questions are critical to a meeting's success.<sup>18</sup> Frequency of meetings and attendance at meetings are indicators of effectiveness, as is access to a higher authority.

The Melbourne Health Community Advisory Committee (CAC), a high-level committee, was appointed in an advisory capacity by a board that included volunteer members who did not represent any organization. The guidelines for establishing the CAC stipulated that the members should preferably have established some connections with formal or informal community or consumer networks. The other four committees that were active in the healthcare field included participants who were not healthcare providers, not individuals connected with healthcare activities, not other employees connected with pharmaceutical or device companies, not elected officials or their employees, and not employees of disease-focused groups. Meetings of one consumer advisory committee<sup>14</sup> were chaired by a senior manager of marketing research.

Selection of topics for discussion at meetings in the Citizens' Reference Panel on Health Technologies<sup>10-12</sup> were made by the research team, the Medical Advisory Secretariat staff, and OHTAC members. Background documents about each topic, such as research and topic summaries, media articles, and discussion questions, were circulated 1 week prior to each meeting. Meetings included an introduction to each topic, a brief presentation about the topic of discussion by the meeting facilitator or guest expert, and a question-and-answer session, followed by discussion in small groups or plenary, externally or self-facilitated, of the questions sent prior to the meeting.

In one citizens' panel<sup>5-7</sup>, over six full-day sessions, the panelists were introduced to the topic of discussion and learned about the processes and approaches, heard and responded to presentations and asked questions, and worked in small groups or plenary toward achieving common ground and consensus and developing recommendations.

In the five committees, meeting frequency ranged from a sequence of weekend meetings (six full-day sessions)<sup>5-7</sup> to two weekend days,<sup>13</sup> to bimonthly meetings (six two- to three-hour meetings per year),<sup>8,9,14</sup> to two to three meetings per year<sup>10-12</sup> (see Table 2 and Appendix C.1, Table C.1).

In one community advisory committee<sup>8,9</sup> the CEO or an alternate executive was in attendance at each meeting, either as a member or as a resource to the committee. Another committee<sup>13</sup> reported

that meetings were closed to the public, although backgrounders, agendas, and reports were posted to the council’s website and reports were disseminated to appropriate people.

### ***Accountability and reporting***

Reporting directly to the governing body increases the impact of the consultation and recommendations provided by the committee. An important aspect is also to create “point persons” within the agency to answer critical questions as well as to set clear guidelines and goals and check them to make sure the committee is on track”.<sup>16</sup>

The reporting process consisted of development of recommendations and reports after each meeting<sup>13</sup> or at the end of the project,<sup>5-7</sup> publication of an overview of the discussion on the website,<sup>5-7</sup> development of minutes from the meetings,<sup>8,9</sup> and thematic summaries of the panel discussions<sup>10-12</sup> (see Table 2 and Appendix C, Table C.1).

### ***Sponsoring agency’s responsibilities/Sustainability***

Adequate orientation and training of new members, opportunities for social interaction and participation, adequate support, access to information and resources, and recognition of the contributions of time, resources, and expertise through some type of compensation (remuneration; flat *per diem*; reimbursement of expenses including transportation, meals, accommodation and special expenses; help for individuals with disabilities) ensure retention and satisfaction of committee members and promotes continued engagement and participation.<sup>20,18</sup> Other worthwhile activities include development of a new member’s guide or manual that outlines terms of reference, processes of and conduct at meetings, and a history of the committee activities; a short training to provide orientation for new members; and working with committee members on team development and with the chairperson to develop his or her abilities and skills.<sup>16,18</sup>

Key informants for the public engagement and knowledge translation environmental scan<sup>4</sup> report indicated that flexible, simple, easy-to-use tools for knowledge translation, together with conversation, are more likely to be effective in helping people understand the information provided, while use of sophisticated tools is not a requirement for obtaining positive outcomes.

In the five selected committees, the following supporting actions were identified:

- providing training activities for members that included provision of a handbook summarizing processes and dialogue with resource people and presenters, with the aim of providing information and answering questions (citizens’ panel<sup>5-7</sup>)
- making use of the sponsoring agency management team as an important resource; provision of in-house, formal orientation and training; appropriate professional advice; mentoring; attendance of relevant training sessions and workshops (community advisory committee<sup>8,9</sup>)
- having the agency’s representatives provide a description of the agency’s processes, an explanation of the rationale for creating the panel, and answers to questions from panel members (citizens’ reference panel<sup>10-12</sup>)
- using team-building exercises at the onset of council formation and presentations made by experts during the council meetings to provide a better understanding of the topics (citizens’ council<sup>13</sup>)
- providing an orientation, including a short overview of the agency marketing plan and current goals (consumer advisory group<sup>14</sup>)

Various ways to reimburse members were reported in publications: reimbursement of costs of participation (travel, accommodation),<sup>8-12</sup> an honorarium after attending each meeting<sup>10-13</sup> or a number of meetings,<sup>6</sup> or offering small gifts of appreciation.<sup>14</sup>

### *Evaluation, reviews, and outputs/outcomes*

Various methods are employed to collect qualitative and quantitative evaluation data, such as key informant interviews, meeting observations, focus groups, study of documents and reports of activity, or members' surveys.<sup>20</sup> Information considered in evaluations may include whether a sponsoring agency seeks out members' opinions, approaches members for help with specific tasks, and provides pride and recognition; review of turnover rate of committee's members; level of success in recruiting members with specific skills and/or connections to influential leaders; members' perceptions of the benefits and costs of participation; and the degree to which members perceive the partnership to be effective and sustainable over time. Reviewers should be neutral and independent.<sup>18</sup>

The effectiveness of lay committees could focus on:

- process effectiveness (the mechanism that encourage meaningful participation)
- outcome effectiveness (the actual evaluation and implementation of recommendations)<sup>16</sup>

Regarding outcome effectiveness, a highly effective committee would be defined as one in which members felt their input was sought early in the planning or policy-making process, where they had timely access to important information in order to accomplish their tasks, and where their recommendations were reviewed and implemented.

Information from four committees showed that committee members evaluated positively their involvement and participation. Although the committees had a different structure and mandate, the degree of satisfaction and appreciation with members' involvement and participation was determined by the use of appropriate processes to involve the members in the committees. This is in line with the public engagement literature, which recognizes that form should follow function, and that the most effective strategy for engaging the public should be chosen based on the underlying goal of the original project or endeavour.<sup>21</sup>

- Through its design and management, the citizens' panel pilot project<sup>6</sup> conducted in 2009 offered the potential for achieving a highly valid outcome and encouraged informed, values-based discussion by citizens through providing broad-based direction to the City Council. The results were used to support, inform, correct, or shape policy-making decisions. Reflections collected at the final session from the participating panel members of the citizens' panel pilot project<sup>6</sup> about their experiences during the six sessions indicated members were content with their participation, and found working in a team to be a worthy and enriching experience. The meetings were considered a good forum in which to exchange ideas and come to a common ground, although participants were from various/diverse backgrounds and had different opinions at the beginning of the process.
- Appointed in an advisory capacity to the public health service board, as a legislated advisory committee, the Melbourne Health Community Advisory Committee (CAC)<sup>8,9</sup> develops an annual work plan and its activity is reviewed biennially. The annual review focuses on the level of achievement of major goals and objectives of the work plan in the time-frames, determines whether the advice of the committee has been sought by the board, whether the board has benefited from the advice, whether the committee made recommendations and whether they have been considered and responded to, and whether the recommendations

resulted in changes in practice in the public health service. The board conducts annual evaluations of members' attendance at meetings (at least 75% of scheduled meetings), participation, and quorum. An independent evaluation of the CAC was conducted in 2008, using a self-evaluation tool for health services and consultations with board members, CAC members, and executive management from 14 metropolitan and five rural services. The evaluation concluded that CACs had contributed significantly to progressing the role and profile of community participation among health service boards and their senior executives, had been a catalyst for community participation and had contributed to a cultural change within health services.

- The Citizens' Reference Panel on Health Technologies<sup>10-12</sup> was created to provide new insights into the social values and ethics data related to five technologies reviewed by the Medical Advisory Secretariat (MAS) and the Ontario Health Technology Advisory Committee (OHTAC). The outputs of the meetings were qualitative reflections on questions and pre- and post-meeting survey results of panel members' rankings of the societal and ethical values. Most panel participants felt that their input was valued by OHTAC. Attendance of senior MAS and OHTAC officials at two panel meetings and the open invitation for panel members to attend an OHTAC meeting so they could provide their input on the value of the panel model increased the confidence among participants about the panel's perceived value to the two organizations. Other members felt they had a minimal influence; however, the creation of the panel was an important step toward increasing the awareness of MAS and OHTAC about the importance of incorporating public values into their decisions.

The panel was assessed by the Canadian Institutes of Health Research (CIHR) and the following strengths were identified<sup>10-12</sup>:

- incorporating input from various perspectives, including citizen input to provincial policy-making; providing citizen input on societal and ethical issues; raising awareness of the importance of incorporating public input into the HTA process; creating a model for public involvement in health technology assessment
- facilitation of meetings kept participants on track and encouraged participation in the deliberations; use of small groups provided a platform for input from all participants
- arm's-length relationship between the panel and MAS/OHTAC; MAS/OHTAC attendance at panel's meetings re-affirmed panel's role and contributions

The CIHR assessment identified challenges, such as:<sup>10-12</sup>

- informational requirements; existence of a large quantity of information to take in during the session; discussions "meandered" or were "monopolized" at times; challenges to feel part of the panel again at each meeting, given the time lapse between meetings; size and representativeness of panel; role confusion; communication between citizens' panel and MAS/OHTAC
- The deliberative process of the Toronto Health Policy Citizen's Council<sup>13</sup> was effective to the extent that it helped citizens clarify their positions on different health policy topics. It was apparent that citizens were satisfied with the citizens' council model being used to elicit the public's values. Citizens were generally positive about the Council's process, as indicated by the results of the satisfaction survey. Their top two reasons for continuing participation in

the Council were the fact that they learn a lot about health care and its ability to make a difference to health policy in Ontario, and they enjoyed the experience.

### *Lessons learned*

Members from the Melbourne Health Community Advisory Committee<sup>8,9</sup> participated in other committees and projects and in this way contributed to the increase of scope of consumer and community involvement across the organization, enabling CAC members to "get to know" their health service. Clear communication pathways with the board and other committees have been considered important. The key lesson was the need for the CAC agenda to be driven by consumers on the basis of their perspectives and experience, and for a health service to put its own perceptions to one side and really listen to what consumers have to say.

The Citizens' Reference Panel on Health Technologies, Ontario<sup>10-12</sup> showed that success factors include having a carefully designed panel with a clear purpose and coordinated linkages to an expert advisory body. Suggestions for improvement included:

- increasing the frequency of meetings
- considering alternative and additional communication vehicles
- ensuring adequate attendance at each meeting
- expanding the size and reach of the panel
- improving the clarity of roles and activities for panel
- clarifying and strengthening the supporting infrastructure of the panel and the interface between panel and sponsoring organizations

The selection and dimension of the group of the Toronto Health Policy Citizen's Council<sup>13</sup> ensured variation of opinion among participants and facilitated deliberations. For public engagement to be successful, participants should be involved in all aspects of the process. They need to feel respected and know that their views will be heard. Successful public engagement should also ensure that topics are timely and questions are conducive to deliberation.

Lessons from various UK HealthCare customer advisory groups<sup>14</sup> included: the need for buy-in and approval from management; the need to remind the group regarding the expected level of participation and, if the group is advisory, to remind members that not all their suggestions will be implemented; and the need to freshen the group and bring in individuals representing a different segment of the public. It usually takes at least three meetings before a group begins to become comfortable with each other and their roles.

In a survey of citizen advisory committees in the budget process of local governments,<sup>19</sup> conducted with citizens and municipal managers on the utilization and effectiveness of committees' recommendations, 30% of the municipal managers indicated that citizen recommendations were acknowledged but rarely enacted.

A summary of criteria from other background documents for improving the quality of citizen/public participation and engagement in committees to achieve productive, long-term, trusting relationships with sponsored agencies include:

- representativeness of participants,<sup>22</sup> a broad sample of the population,<sup>23</sup> participants appointed by a democratic process<sup>19</sup>

- early involvement in the process<sup>23</sup>
- transparency and access to processes<sup>22</sup> that are viewed as legitimate by decision-makers and the wider public<sup>21</sup>; an effective public participation process attracts a wide range of people to the process, allows participants to have independent views and influence decisions, and ensures that the entire process is open and that decisions resulting from the process are transparent<sup>22</sup>
- access to credible information and resources, well-organized to assist with informed decision-making<sup>22,21, 23,18</sup> and enabling participants to fulfill their tasks<sup>23</sup>; procedural rules that promote power-sharing and information-sharing among and between participants and decision-makers<sup>21</sup>
- a clear mandate and instructions about participants' roles, clearly stated context,<sup>23</sup> scope,<sup>23</sup> goals,<sup>22,21</sup> objectives,<sup>22</sup> expectations,<sup>19</sup> outputs,<sup>23</sup> and rationale for participation,<sup>23</sup> an indication of how the consultation fits into the larger decision-making process<sup>21</sup>
- clear timeliness for the entire process from start to finish<sup>18</sup>
- that the issues to be discussed must be of importance to the participants and stakeholders<sup>18</sup>
- opportunities for mutual learning;<sup>22</sup> collaborative, consensus-based decision-making<sup>22</sup>
- greater involvement and commitment by the governing body,<sup>19,18</sup> clear links between the consultation and the decision outcome,<sup>21</sup> trust in decision-makers<sup>22</sup>
- comfort and convenience of meetings<sup>22</sup>
- education and training opportunities—two types of training were identified: a) general communication and facilitation skills, consensus building, and b) specific training relative to the type of committee,<sup>19</sup> value of other forms of knowledge<sup>19</sup>
- appropriate technical, administrative, and staff support<sup>19,18</sup> and high-level commitment from the sponsoring agency<sup>18</sup>
- effective and regular communication about processes and goals<sup>19,22,21</sup>
- visioning and championing<sup>22</sup>
- conflict resolution<sup>22</sup>
- support; incentives; reasonable compensation, reimbursement, and recognition for participation, such as tax breaks, stipends, respect, and public acknowledgement<sup>19,18</sup>
- cost-effectiveness—there should be a cost-benefit; the process should be cost-effective from the point of view of the sponsoring agency<sup>23</sup>

Most of above-mentioned criteria are in line with the lessons learned from the five committees and could be implemented without the need for additional resources or the reallocation of staff.

## DISCUSSION

The targeted review of practices of engaging committees composed of lay people or members of the general public that are similar in processes and structures with the IHE Layperson Advisory

Committee provided very limited results, showing the unique aspects of the IHE Committee and the difficulty in comparing its structure and processes with that of other committees, each of them tailored and implemented to respond to the very specific tasks and agendas of the sponsored agencies by which they were established.

Five examples of committees, four of them in the healthcare field, are included in the targeted review, one in Australia,<sup>8,9</sup> three in Canada,<sup>5-7,10-12,13</sup> and one in the United States.<sup>14</sup> Although they are different in many aspects related to structures, processes, and mandate, their common aspects were inclusion of members who were lay people—representatives of the general public, consumers, and former or current patients with had no interest in any specific disease or condition. Members did not represent other organizations nor were they affiliated with government organizations. All but one committee functioned with support from universities— as pilot or research projects, and in partnership with other organizations showing the engagement of various sectors and stakeholders and the role of networking for improvement of these forms of public engagement. Two committees were set up at the provincial level and three committees at the local level. The level of involvement on the IAP2 model spanned from “inform,” to “collaborate” in rare cases, while all committees were fully represented in the “consult” level.

The committees vary in structure and processes.

- Roles—these ranged from informing to providing qualitative reflections, opinions, and feedback, deliberating and brainstorming on new programs and developments, or developing recommendations.
- Selection of participants—selection included different methods (such as use of a computer-generated lists, random selection, advertisements, online bulletin boards, “civic lottery”, direct approach of individuals with experience) and different sources (such as “white pages”, listings, marketing databases, respondents to surveys, lecture attendees, referrals from current members).
- Number of members—size ranged between eight and 57 members. A higher number of participants was included in committees (citizens’ panel and citizens’ council) that aimed to ensure a larger representation and stratification of various groups of participants.
- Meetings structure—in many cases the meetings were run on weekend days; their duration ranged from 2 hours to all day long for 1 day or multiple days at a time.
- Membership and lifetime of committees—tenure ranged from 6 days before the committee was disassembled to a maximum of 3 years membership, with the possibility to renew participation in some cases.
- Accountability and reporting—reports were directed to the sponsored agencies in various forms based on the structure and tasks of the committee, and consisted of minutes and reports after each meeting or at the end of the project. In some cases reports were also shared with public via the Internet.
- Training—this was an important activity in all committees and included provision of orientation and an overview of the sponsoring agency, provision of a guide/manual to emphasize tasks and activities, training sessions, mentoring, professional advice, workshops, and/or team-building exercises.

Evaluation of the committees involved surveys of participants and independent reviews. A number of best practices were identified and lessons learned.

- The committees should consist of a balanced and representative group of members selected to reflect the scope, functions, and purpose of the committee, outlined in the terms of reference established prior to members' commencing their work in the committee.
- Engagement of the public in committees for deliberations should include careful selection of the appropriate number and types of people, providing them with essential information and clear goals and objectives, and eliciting their values and expectations.
- Practices at sponsoring agencies that successfully involve public advisory committees vary in many specific ways. Successful involvement of committees relies on practices that suit the organizations' needs and context.
- The sponsoring agency should pay careful attention to the details of the committee's operations and organization. Processes should be transparent, tailored to circumstances, should give priority to participants' discussions, and should be reviewed for improvement.
- Committee meetings are good forums in which to exchange ideas and opinions and develop suggestions or recommendations. In the included examples, even if participants had different opinions at the start of activities in a committee, they could achieve common ground during discussions and deliberations. If time between the meetings is increased, participants may find it difficult to interact with each other. Usually committee members become more comfortable with each other and their roles after being involved in about three meetings.
- Creating "point persons" within the sponsoring agency increases communication and the link between the committee and the sponsoring agency and helps answer questions and set guidelines and goals in the committee, keeping the committee on track.
- The sponsoring agency should provide feedback to committee members about what happens to their recommendations, or whether their recommendations were not feasible, with explanations as to why or why not.
- Having an executive or a representative of the sponsoring agency attend committee meetings increases the level of involvement by the governing agency. Committee members could be invited to attend board meetings of the sponsoring agency, where they can contribute their suggestions; this increases the impact of the consultation and the satisfaction of participants who, as a result, perceive greater value in their role, input, and contributions to the sponsoring agency.
- Training and education opportunities should be provided, as well as recognition for public participation in some form of acknowledgement. Financial incentives, respect, and staff support ensure committee members' satisfaction and continuing engagement.

## **Strengths and limitations**

- The review had a very narrow focus, aiming to identify committees very similar to the IHE Layperson Committee. As anticipated, not many examples were located after screening the results from a comprehensive literature search. Some of the reasons may include the differences in structures and processes, the complexity of the area of study, the number of terms/synonyms used in the publications, variations in definitions, the large span of

publications, different uses of concepts, access to publication, and time restrictions. The definition of lay participation is particularly problematic, as it could refer to different overlapping groups of people, public citizens, patients, service users, and/or members from various organizations. To overcome these limits, the inclusion criteria were detailed a priori (see Appendix A).

- The information about the committees included in the review is not detailed in all publications in terms of describing committee structures, processes, and evaluation of the effectiveness and outputs/outcomes of those committees. The majority of information comes from reports, studies, and presentations sourced in the grey literature. Some of the committees completed their mandate and are not currently active/existent, while information about new, active committees may not be available in the databases and public domain, or the sparse information available did not qualify them for inclusion. Due to time constraints, no attempts were made to contact the sponsored agencies for more details.
- None of the selected publications included terms of references for the committees, which makes it difficult to determine an accurate level of participation and involvement of the committee members in the activities of the various committees.
- Only full text, English articles were included. One reviewer screened the abstracts of published studies, applied the pre-determined inclusion criteria in selecting the studies, and did the data extraction. A quality assessment of the publications was not conducted.

A “good” committee sets clear and obtainable goals, has a chairperson who keeps the group on task, and includes committed, diverse members that act as a cohesive group, as well as maintains a good working relationship with the sponsoring agency and receives formal and informal feedback regarding their guidance and recommendations.

Currently, interest is growing in ongoing advice and deliberative types of public engagement. Formal evaluation of public engagement efforts is not common, and the way in which public views might be integrated with other decision inputs is vague.

Each engagement model presents its own characteristic strengths and shortcomings for public engagement. Identifying the most effective way to engage the public within a given context remains a complex endeavour. Healthcare managers and decision-makers can improve their public engagement strategies based on their needs and objectives.

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## APPENDIX A: METHODOLOGY

### Search strategy

One IHE Research Librarian (DC) conducted a search of electronic databases to retrieve articles published between April 1998 and April 2013. The search was developed and carried out prior to the study selection process. The reference lists of retrieved articles were also searched for potential studies that may have been missed in the database search. Grey literature was identified through an Internet search using Google<sup>®</sup> as well as by searching the websites of other HTA agencies and Canadian and international organizations.

**Table A.1: Search strategy**

Database	Edition or date searched	Search Terms ††
MEDLINE (includes in-process and other non-indexed citations) OVID Licensed Resource	1998 to April 15, 2013	<ol style="list-style-type: none"> <li>1. ((lay* or consumer* or public or citizen* or community) adj2 (board*or body or bodies or committee* or panel* or jury or juries or council* or group*)).ti.</li> <li>2. exp Consumer Participation/</li> <li>3. exp Public Opinion/</li> <li>4. 2 or 3</li> <li>5. Advisory Committees/</li> <li>6. 4 and 5</li> <li>7. Community-Institutional Relations/</li> <li>8. 5 and 7</li> <li>9. 1 or 6 or 8</li> <li>10. limit 9 to (english language and yr="1998 -Current")</li> </ol> <p><b>584 results</b></p>
Embase	1998 to April 15, 2013	<b>666 results</b>
ABI Inform	1998 to April 15, 2013	ti((lay* OR consumer* OR public OR citizen* OR community) NEAR/2 (board* OR body OR bodies OR committee* OR panel* OR jury OR juries OR council* OR group*)) OR su.Exact("consumer participation" OR "consumer relations" OR "public opinion") AND su(("advisory committees" OR "panels")) <p><b>293 results</b></p>
CINAHL	1998 to April 16, 2013	S1 OR S6 Limiters – English Language; Published Date from: 19980101–20131231 Search modes – Find all my search terms Interface – EBSCOhost Search Screen – Advanced Search Database – CINAHL Plus with Full Text <p><b>623 results</b></p> S7 S1 OR S6 Search modes – Find all my search terms Interface – EBSCOhost Search Screen – Advanced Search Database – CINAHL Plus with Full Text <p><b>832 results</b></p>

*Continued on next page*

CINAHL (cont'd)		<p>S6 S4 AND S5 Search modes – Find all my search terms Interface – EBSCOhost Search Screen – Advanced Search Database – CINAHL Plus with Full Text <b>103 results</b></p> <p>S5 S2 OR S3 Search modes – Find all my search terms Interface – EBSCOhost Search Screen – Advanced Search Database – CINAHL Plus with Full Text <b>30,187 results</b></p> <p>S4 (MH "Committees") Search modes – Find all my search terms Interface – EBSCOhost Search Screen – Advanced Search Database – CINAHL Plus with Full Text <b>5,057 results</b></p> <p>S3 (MH "Public Opinion") OR (MH "Public Relations") OR (MH "Community-Institutional Relations") OR (MH "Guest Relations") OR (MH "Vendor Relations") Search modes – Find all my search terms Interface – EBSCOhost Search Screen – Advanced Search Database – CINAHL Plus with Full Text <b>14,552 results</b></p> <p>S2 (MH "Consumer Participation") OR (MH "Consumer Attitudes") OR (MH "Consumers") Search modes – Find all my search terms Interface – EBSCOhost Search Screen – Advanced Search Database – CINAHL Plus with Full Text <b>16,154 results</b></p> <p>S1 TI ((lay* or consumer* or public or citizen* or community) N2 (board* or body or bodies or committee* or panel* or jury or juries or council* or group*)) Search modes – Find all my search terms Interface – EBSCOhost Search Screen – Advanced Search Database – CINAHL Plus with Full Text <b>736 results</b></p>
PAIS	1998 to April 16, 2013	<p>ti((lay* OR consumer* OR public OR citizen* OR community) NEAR/2 (board* OR body OR bodies OR committee* OR panel* OR jury OR juries OR council* OR group*)) <b>70 results</b></p>
Web of Science	1998 to April 16, 2013	<p>ti((lay* OR consumer* OR public OR citizen* OR community) NEAR/2 (board* OR body OR bodies OR committee* OR panel* OR jury OR juries OR council* OR group*)) <b>1562 results</b></p>
CRD	April 17, 2013	<p>((board* OR body OR bodies OR committee* OR panel* OR jury OR juries OR council* OR group*)):TI AND ((lay* OR consumer* OR public OR citizen* OR community)):TI IN DARE, NHSEED, HTA FROM 1998 TO 2013 <b>17 results</b></p>

Google	May, 2013	<p>((lay* or consumer* or public or citizen* or community) adj2 (board* or body or bodies or committee* or panel* or jury or juries or council* or group*)).ti.</p> <ul style="list-style-type: none"> <li>• Lay advisory or consumer advisory or public advisory or citizen advisory or community advisory</li> <li>• Lay committee or consumer committee or public committee or citizen committee or community committee</li> <li>• Lay panel or consumer panel or public panel or citizen panel or community panel</li> <li>• Lay jury or consumer jury or public jury or citizen jury or community jury</li> <li>• Lay council or consumer council or public council or citizen council or community council</li> </ul>
Canadian Foundation for Health Care Improvement (CFHI)	April 16, 2013	<p>Lay or public or community or citizen or consumer or advisory or committee</p> <p><b>6 relevant results</b></p>
Health Council Canada	April 17, 2013	<p>Lay advisory; Consumer advisory; Public advisory; Citizen advisory; Lay committee; Consumer committee; Public committee; Citizen committee; Community committee; Lay panel; Consumer panel; Public panel; Citizen panel; Community panel; Lay jury; Consumer jury; Public jury; Citizen jury; Community jury; Lay council; Consumer council; Public council; Citizen council; Community council</p> <p><b>0 results</b></p>
International Association for Public Participation	April 17, 2013	<p>Browsed website.</p> <p><b>0 results</b></p>
National Institute for Health and Clinical Excellence	April 17, 2013	<p>"lay advisory" OR "consumer advisory" OR "public advisory" OR "citizen advisory" OR "lay committee" OR "consumer committee" OR "public committee" OR "citizen committee" OR "community committee" OR "lay panel" OR "consumer panel" OR "public panel" OR "citizen panel" OR "community panel" OR "lay jury" OR "consumer jury" OR "public jury" OR "citizen jury" OR "community jury" OR "lay council" OR "consumer council" OR "public council" OR "citizen council" OR "community council"</p> <p><b>17 results</b></p>
World Health Organization (WHO)	April 17, 2013	<p>"lay advisory" OR "consumer advisory" OR "public advisory" OR "citizen advisory" OR "lay committee" OR "consumer committee" OR "public committee" OR "citizen committee" OR "community committee" OR "lay panel" OR "consumer panel" OR "public panel" OR "citizen panel" OR "community panel" OR "lay jury" OR "consumer jury" OR "public jury" OR "citizen jury" OR "community jury" OR "lay council" OR "consumer council" OR "public council" OR "citizen council" OR "community council"</p> <p><b>0 results</b></p>
Dissertations & Theses	April 17, 2013	<p>ti(((lay* OR consumer* OR public OR citizen* OR community) NEAR/2 (board* OR body OR bodies OR committee* OR panel* OR jury OR juries OR council* OR group*) ) )</p> <p><b>10 relevant results</b></p>
Canadian Evaluation Society Grey Literature Database	April 17, 2013	<p>Browsed: Community participation; Data collection; Decision-making; Partnership; Public relations; Research methods; Stakeholder involvement</p>

		<b>3 results</b>
Consumers' Association of Canada	April 17, 2013	Lay advisory; Consumer advisory; Public advisory; Citizen advisory; Lay committee; Consumer committee; Public committee; Citizen committee; Community committee; Lay panel; Consumer panel; Public panel; Citizen panel; Community panel; Lay jury; Consumer jury; Public jury; Citizen jury; Community jury; Lay council; Consumer council; Public council; Citizen council; Community council <b>0 results</b>
Public Policy Forum	April, 17 2013	Browsed Results <b>2 results</b>
Campbell Library	April 17, 2013	lay advisory OR consumer advisory OR public advisory OR citizen advisory OR lay committee OR consumer committee OR public committee OR citizen committee OR community committee OR lay panel OR consumer panel OR public panel OR citizen panel OR community panel OR lay jury OR consumer jury OR public jury OR citizen jury OR community jury OR lay council OR consumer council OR public council OR citizen council OR community council <b>11 results</b>
NEOS Library Consortium Catalogue	April 17, 2013	Limited all searches to title, and did first 120 results. 'lay\$ advisory' OR 'consumer\$ advisory' OR 'public\$ advisory' OR 'citizen\$ advisory' OR 'community advisory' <b>418 results</b> 'lay\$ committee\$' OR 'consumer\$ committee\$' OR 'public\$ committee\$' OR 'citizen\$ committee\$' OR 'community committee\$' <b>3594 results</b> lay panel\$' OR 'consumer\$ panel\$' OR 'public\$ panel\$' OR 'citizen\$ panel\$' OR 'community panel\$' <b>182 results</b> 'lay jury' OR 'consumer\$ jury' OR 'public\$ jury' OR 'citizen\$ jury' OR 'community jury' <b>104 results</b> lay council\$' OR 'consumer\$ council\$' OR 'public\$ council\$' OR 'citizen\$ council\$' OR 'community council\$' <b>2373 results</b>
CADTH	April 24, 2013	Lay or public or community or citizen or consumer or advisory or committee <b>0 results</b>
KUUC	April 24, 2013	Lay or public or community or citizen or consumer or advisory or committee <b>2 results</b>
ICES	April 24, 2013	Browsed list <b>2 results</b>
Health Canada Public Involvement program		Browsed site <b>3 results</b>
Canadian Policy		Browsed list of publications

Research Network (CPRN)		15 results
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**Note:**

††, \*, # and ? are truncation characters that retrieve all possible suffix variations of the root word; for example, surg\* retrieves surgery, surgical, surgeon, etc.

**Search Strategy:**

# Searches Results

**Literature selection**

One reviewer screened titles and abstracts, retrieved relevant articles, and determined eligibility of key reports/publications according to the inclusion and exclusion criteria outlined below.

***Inclusion criteria***

- **Public participation committees**

Public means citizens other than those affiliated with government and healthcare providers, employees of pharmaceutical and device companies, employees of disease-focused groups and elected officials. The following are considered for inclusion:

- engagement examples that fit the general structure of a citizens’ council, lay committee, community advisory committee, etc., that function at various levels—national, provincial, regional, local
- committees that are representative of citizens from their communities
- committees established by the same sponsoring organization/agency, functioning over various durations of activity and covering various topics
- various levels of participation ranging from information to consultation (deliberative processes), and various levels of participation in the decision-making process
- topics: healthcare field (various topics, not linked only to specific disease areas); health technology assessment; other non-health fields (such as justice, education, industry)

- **Literature search**

Original primary and secondary/review studies; studies published in peer review journals and grey literature publications supplemented by review of the reference lists/bibliographies of retrieved articles and publications referenced by participants in the project:

- content providing substantial information about roles, purpose, structure, processes, and outcomes; examples of model frameworks; terms of reference documents that outline processes for selection, accountability, evaluation/assessment of their effectiveness
- years of publication from April 1998 to April 2013
- articles published in English
- focusing on countries with developed market economies, since the processes in countries with transitional or developing economies were likely to be too different from those of Canada to be relevant (countries deemed to have developed economies, as defined by the United Nations, were Australia, Canada, Japan, New Zealand, the United States, and European countries (except for those with transitional economies)<sup>24</sup>

- databases searched being MEDLINE, OVID, Embase, ABI Inform, CINAHL, PAIS, Web of Science, and CRD

### ***Exclusion criteria***

Studies were excluded if they meet any of the following criteria:

- **Public participation committees**
  - non-deliberative public engagement groups (for example, focus groups)
  - lay committees/advisory groups of patients
  - lay committees/advisory groups of special population groups
  - lay committees involved in designing or providing feedback, or in participating in activities connected with primary research
  - mixed lay committees that include members of the sponsoring organization (to ensure a power balance between lay people and other stakeholders)
  - lay persons or consumer members/participants on boards and committees of sponsoring organizations (shared decision-making through adding lay members to decision-making committees, which only engages a few lay people at any one time and in which citizens are subject to power imbalances)
  - partnerships between lay/community boards and multiple institutions or research organizations or associations
  - committees whose meetings are open to the general public as observers or participants (that is, members of the public can attend during the deliberative meetings and be involved in the process)
  - committees/panels/juries formed at events such as conferences or symposiums; Internet panels that discuss one or multiple topics and dissolve after one meeting
- **Study type**
  - cross-sectional surveys that evaluate multiple groups, or participants in multiple committees from various organizations that provide aggregate results
  - theoretical and conceptual publications and background papers that focus on general concepts (such as lay committees, citizens' juries, or advisory committees); these publications are used to inform the background and discussion sections of the review
  - conference abstracts, commentaries, letters

### **Quality assessment**

No quality assessment was conducted of the included publications, mainly due to their design.

### **Data extraction**

One reviewer extracted data according to a predetermined data extraction form. Extracted information included data about:

- structure: type of committee, setting (national, regional, provincial, local), terms of reference, objectives and roles, membership and committee composition, mechanism of selection/appointment, lifetime/terms/tenure of members, reporting and accountability,

type and frequency of meetings, and remuneration of members and reimbursement of expenses

- elements of the process: level of involvement (IAP2: inform, consult, involve, collaborate, empower); activities; support from the sponsored organization; training
- outputs/outcomes, evaluation, lessons learned
- sponsoring organization, country, year of development of committee, field (healthcare, HTA, non-healthcare)

### **Data analysis**

Data from the included publications was summarized narratively. Information was presented in tabular form for comparison.

## APPENDIX B: EXCLUDED STUDIES

A total of 1748 studies were excluded that, on the basis of the abstracts, clearly did not meet the inclusion criteria. Copies of the full text of 76 potentially eligible publications were retrieved. Closer examination of the studies revealed that 71 of them did not meet the inclusion criteria specified by the protocol; those studies were excluded. Publications were excluded for 11 primary reasons.

### 1. Committees/advisory groups of patients (n=1)

Rhodes P, et al. A service users' research advisory group from the perspectives of both service users and researchers. *Health & Social Care in the Community* 2002;10(5):402-9.

### 2. Committees/advisory groups of special population groups (n=12)

Ahmed SM, et al. Community engagement in research: Frameworks for education and peer review. *American Journal of Public Health* 2010;100(8):1380-87.

Hunt LM, et al. Understanding self-evaluations of effectiveness by forestry advisory committee members: A case of Ontario's Local Citizens Committee members. *Journal of Environmental Management* 2007;83(1):105-14.

Chene R, et al. Mental health research in primary care: Mandates from a community advisory board. *Annals of Family Medicine* 2005;3(1):70-2.

Stenger DP. The role of lay review committees in diabetes research. *Diabetes/Metabolism Research and Reviews* 2003;19(4):271-9.

Bryan V, et al. Reflections on citizen-state child welfare partnerships: Listening to citizen review panel volunteers and agency liaisons. *Children and Youth Services Review* 2011;33(5):612-21.

Bryan V, et al. Key features of effective citizen-state child welfare partnerships: Findings from a national study of citizen review panels. *Children and Youth Services Review* 2010;32(4):595-603.

Bryan V, et al. Civic engagement or token participation? Perceived impact of the citizen review panel initiative. *Children and Youth Services Review* 2007;29(10):1286-1300.

Jones BL. Effectiveness of citizen review panels. *Children and Youth Services Review* 2004;26(12):1117-27.

Grisham JL. NIH seeks more public input: Newly established Council of Public Representatives will advise agency on priority setting, other issues. *Chemical & Engineering News* 1999;77(20):37-8.

National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC). HTA Advisory Panels Role. Public members: Role description, terms and conditions and person specification. Available: [www.hta.ac.uk/public/advisory\\_panels\\_role.pdf](http://www.hta.ac.uk/public/advisory_panels_role.pdf), 2011.

Nipissing Forest. Local Citizens Committee Handbook. A guide for public participants in the forest management planning process. Northwatch Forest Project. Available: [www.web.net/nwatch/fmp/LCC\\_handbook/NipissingForestLCC\\_Handbook.pdf](http://www.web.net/nwatch/fmp/LCC_handbook/NipissingForestLCC_Handbook.pdf), 2007.

Victorian Integrated Cancer Services. Consumer Participation Network. Consumer Participation Toolkit. Available: [www.gha.net.au/Uploadlibrary/410266204VICConsumerParticipationToolkitFINAL.pdf](http://www.gha.net.au/Uploadlibrary/410266204VICConsumerParticipationToolkitFINAL.pdf), 2012.

**3. Committees of lay people or members of the general public involved in designing or providing feedback, or in participating in activities connected with primary research (n=5)**

Terry SF, et al. Community engagement about genetic variation research. *Population Health Management* 2012;15(2):78-89.

James S, et al. Community ACTION boards: An innovative model for effective community-academic research partnerships. *Progress in Community Health Partnerships* 2011;5(4):388-404.

Thompson B, et al. A small grants program to involve communities in research. *Journal of Community Health* 2010;3:294-301.

White-Cooper S, et al. Community engagement in Prevention Research: The Centers for Disease Control and Prevention's Prevention Research Centers' National Community Committee. *Progress in Community Health Partnerships: Research, Education, and Action* 2009;1:73-81.

National Institute for Health Research. Being a consumer panel member. What you need to know. Available: [www.northumberlandlink.org.uk/wp-content/uploads/2012/11/Consumer-Panel-Member-Information-v2.pdf](http://www.northumberlandlink.org.uk/wp-content/uploads/2012/11/Consumer-Panel-Member-Information-v2.pdf), 2013.

**4. Mixed committees of lay people or members of the general public that include members of the sponsoring organization, ensuring a power balance between the lay people and other stakeholders (n=3)**

Weaver P. Involving consumers on boards. *Issue Brief (Center for Medicare Education)* 2002;3(8):1-4.

Periera G, et al. Use of citizen panels to enhance community involvement in environmental public health actions at ATSDR. *Environmental Epidemiology and Toxicology* 2000;2-3:74-8.

Transit Cooperative Research Program. Effective use of citizen advisory committees for transit planning and operations. A synthesis of transit practice. TCRP Synthesis 85. Available: [http://onlinepubs.trb.org/onlinepubs/tcrp/tcrp\\_syn\\_85.pdf](http://onlinepubs.trb.org/onlinepubs/tcrp/tcrp_syn_85.pdf), 2012.

**5. Partnerships between committees of lay people or members of the general public and multiple institutions or research organizations or associations (n=2)**

Kreis J, et al. 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.

Canterbury District Health Board. Consumer Council Terms of Reference, August 2012. Available: [www.bqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/Canterbury-DHB-Consumer-Council-ToR-August-2012.pdf](http://www.bqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/Canterbury-DHB-Consumer-Council-ToR-August-2012.pdf), 2012.

**6. Committees of lay people or members of the general public whose meetings are open to**

**the general public as observers or participants (that is, members of the public can attend during the meetings and be involved in the process) (n=5)**

Davies C, et al. Opening the Box. Evaluating the Citizens Council of NICE. Report prepared for the National Co-ordinating Centre for Research Methodology, NHS Research and Development Programme March 2005. Available: [www.hta.ac.uk/nihrmethodology/reports/1566.pdf](http://www.hta.ac.uk/nihrmethodology/reports/1566.pdf), 2005.

Public Priorities for Ontario's Health System. A report of the Citizens' Reference Panel on Ontario Health Services. Available: [www.pwc.com/ca/en/healthcare/publications/Citizens-reference-panel-report-2011-06-en.pdf](http://www.pwc.com/ca/en/healthcare/publications/Citizens-reference-panel-report-2011-06-en.pdf), 2011.

Ontario Citizens' Council. Terms of Reference, July 2010. Available: [www.health.gov.on.ca/en/public/programs/drugs/councils/docs/terms\\_reference.pdf](http://www.health.gov.on.ca/en/public/programs/drugs/councils/docs/terms_reference.pdf), 2010

Santos SL, et al. Evaluating citizen advisory boards: The importance of theory and participant-based criteria and practical implications. *Risk Analysis* 2003;23(2):269-79.

Barham L. Public and patient involvement at the UK National Institute for Health and Clinical Excellence. *The Patient: Patient-Centered Outcomes Research* 2011;4(1):1-10.

**7. Committees/panels/juries formed at events such as conferences, symposiums; Internet panels that discuss one or multiple topics and dissolve after one meeting (n=4)**

Woodward V. Community engagement with the state: A case study of the Plymouth Hoe Citizens Jury. *Community Development Journal* 2000;35(3):233.

Shaw L, et al. A community panel on occupations to consider economic opportunities outside major urban centres: Occupations in Thunder Bay, Canada. *Journal of Occupational Science* 2009;16(1):12-17.

Menon D, et al. Engaging the public in priority-setting for health technology assessment: Findings from a citizens' jury. *Health Expectations* 2008;11(3):282-93.

Kenyon W, et al. Citizens' juries: An aid to environmental valuation? *Environment and Planning C: Government and Policy* 2001;19(4):557-66.

**8. Cross-sectional surveys that evaluate multiple groups or participants in multiple committees from various organizations and report aggregate information (n=5)**

Dougherty GW, et al. Appointed public volunteer boards: Exploring the basics of citizen participation through boards and commissions. *American Review of Public Administration* 2011;41(5):519.

Thompson B, et al. Factors related to participatory employee advisory boards in small, blue-collar worksites. *American Journal of Health Promotion* 2005;19(6):430-7.

Chessie K. Health system regionalization in Canada's provincial and territorial health systems: Do citizen governance boards represent, engage, and empower? *International Journal of Health Services* 2009;39(4):705-24.

Rissel C, et al. Participation and success among Sydney community action groups. *Australian Journal of Primary Health* 2001;1:61-4.

Tewdwr-Jones M. Rural government and community participation: The planning role of community councils. *Journal of Rural Studies* 1998;14(1):51-62.

**9. Theoretical and conceptual publications and background papers that focus on general concepts (such as lay committee, citizens' jury, advisory committee, etc.). These publications are used to inform the background and discussion sections of the review. (n=22)**

Fattal et al. Health technology assessment use and dissemination by patient and consumer groups: Why and how? *International Journal of Technology Assessment in Health Care* 2008;24(4):473-80.

Kenyon W. A critical review of citizens' juries: How useful are they in facilitating public participation in the EU Water Framework Directive? *Journal of Environmental Planning and Management* 2005;48(3):431-43.

Callahan K. The utilization and effectiveness of citizen advisory committees in the budget process of local governments. *Journal of Public Budgeting, Accounting & Financial Management* 2002;14(2):295-319.

Venuta R, et al. Involving citizens and patients in health research. *Journal of Ambulatory Care Management* 2010;33(3):215-22.

Sykes M. User involvement in clinical governance. *Quality in Primary Care* 2003;11(1):13-18.

Shin Y et al. What makes a group of good citizens? The role of perceived group-level fit and critical psychological states in organizational teams. *Journal of Occupational & Organizational Psychology* 2010;83(Pt 2):531-52.

Smith G, et al. The theory and practice of citizens' juries. *Policy and Politics* 1999;27(3):295-308.

Gilbert D. Primary care groups. Lay involvement in primary care. *NT Learning Curve* 1999;3(3):14-5.

Newman SD et al. Community advisory boards in community-based participatory research: A synthesis of best processes. *Preventing Chronic Disease* 2011;8(3):A70.

Mack L. Community advisory committees: Drivers of consumer, carer, and community participation in Victoria's public health services. *Journal of Ambulatory Care Management* 2010;3:198-204.

Bruni RA, et al. Public engagement in setting priorities in health care. *CMAJ* 2008;1:15-8.

Iredale R, et al. From passive subject to active agent: The potential of Citizens' Juries for nursing research. *Nurse Education Today* 2007;7:788-95.

Ruelas E. Citizens' quality councils: An innovative mechanism for monitoring and providing social endorsement of healthcare providers' performance? *Healthcare Papers* 2006;6(3):33-7.

Strauss RP, et al. The role of community advisory boards: Involving communities in the informed consent process. *American Journal of Public Health* 2001;12:1938-43.

Brown MB. Survey article: Citizen panels and the concept of representation. *Journal of Political*

*Philosophy* 2006;14(2):203-25.

Moore EA. A typology of collaborative watershed groups: Citizen-based, agency-based, and mixed partnerships. *Society & Natural Resources* 2003;16(5):451-60.

Carr DS, et al. An evaluation of three democratic, community-based approaches to citizen participation: Surveys, conversations with community groups, and community dinners. *Society & Natural Resources* 2001;14(2):107-26.

Licket B, et al. Elements of a lay theory of groups: Types of groups, relational styles, and the perception of group entitativity. *Personality and Social Psychology Review* 2001;5(2):129-40.

Smith G, et al. Citizens' juries and deliberative democracy. *Political Studies* 2001;48(1):51-65.

Australian Government, et al. A model framework for consumer and community participation in Health and Medical research. December 2004. Available: [www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/r33.pdf](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/r33.pdf), 2005.

Abelson J, et al. CIHR's citizen engagement in health casebook. Case 12, Consulting Ontario citizens to inform the evaluation of health technologies: The Citizens' Reference Panel on Health Technologies. Available: [www.cihr.ca/e/45358.html#a16](http://www.cihr.ca/e/45358.html#a16), 2012.

Hailey D, 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. Abstracts conferences, commentaries, letters (n=11)

Waters E, et al. Evidence synthesis, upstream determinants and health inequalities: The role of a proposed new Cochrane Public Health Review Group. *European Journal of Public Health* 2008;18(3):221-3.

Weeks S. Citizens' juries on NHS just another political exercise. *Nursing Standard* 2007;22(3):33.

McKee M. Citizens' juries: more questions than answers? *Journal of Epidemiology & Community Health* 2010;64(9):750-1.

Williamson J, et al. *Engaging consumers: A paediatric oncology model in practice*. Pediatric Blood and Cancer. Conference: 43rd Congress of the International Society of Paediatric Oncology, SIOP 2011 Auckland New Zealand. Conference publication 758, 2011.

Seidenfeld JD, et al. *More effectively engaging consumers in comparative effectiveness research*. Value in Health Conference: 15th Annual International Meeting of the International Society for Pharmacoeconomics and Outcomes Research, ISPOR 2010, Atlanta (GA), United States. Conference publication A81: 2010.

Friedland C. Where were the lay council members? *Pharmaceutical Journal* 2007;7474:438-9.

Swankin D. Consumer advisory committees. *Healthplan* 2003;3:19-22.

Wiley D.L. Managing online forums: Everything you need to know to create and run successfully community discussion boards. *Online* 2008;32(5):63.

Wild A. Speaking for patients and carers—Health consumer groups and the policy process.

*Sociology of Health & Illness* 2006;28(7):995-6.

Fry AM, et al. Justifying the development of a lay panel to produce utilities for use in health technology assessments (HTAS): Review of current issues, and views of technology appraisal committee members. *Value in Health* 2003;6(3):305.

Chaston JE. Advisory appointments committee lay members. *British Dental Journal* 1998;184(12):579.

#### **11. Study unavailable (n=1)**

Williams H. CHC redundancies are a waste of money and talent... Community Health Councils. *Nursing Times* 2002;98(45):15.

## APPENDIX C: CHARACTERISTICS OF STUDIES

Table C.1: Committees, structures, processes, and outcomes

Committee, organization, settings, level of involvement, ToR	Membership	Processes, meetings	Evaluation, lessons learned
<p><b>Citizens' Panel</b><sup>5-7</sup> City of Edmonton, Canada</p> <p><u>Setting:</u> Local</p> <p><u>Healthcare field:</u> No; Other: budget priorities (Pilot project, Panel 2009), energy and climate change (Panel 2012)</p> <p><u>HTA field:</u> No</p> <p><u>Level of involvement:</u> Collaborate (wide spectrum—consultation to active participation)</p> <p><u>Terms of reference:</u> NR</p>	<p><u>Composition:</u> about 60 members (57 members, Panel 2009).</p> <p><u>Selection process:</u> Recruitment over a 2-week period. Two-thirds of panelists (about 35) were contacted by the use of a computer-generated list of names and addresses selected randomly from Edmonton's 411 ("white pages") listings. One-third of panelists (about 17) were recruited through outreach at inner-city agencies and through advertisements in community newspapers and on online bulletin boards. Prospective panelists qualified for appointment if they were (a) willing and able to participate in discussions about budget priorities at the City of Edmonton; and (b) available to attend at least five of the six sessions on the planned dates. Full functional literacy was not required. Demographic targets: resident less than 3 years, women, aboriginal, disabled, visible minority, each of six wards.</p> <p><u>Lifetime:</u> Six days (Saturdays); Writing Committee: to meet about four times; also to participate at the meetings of the panel.</p>	<p><u>Meetings:</u> Six full-day sessions (Saturdays).</p> <p><u>Accountability:</u> Develop recommendations and final report to Edmonton City Council. Final report developed by a Writing Committee made up of six to eight volunteers from the Citizens' Panel. At the end of each session, an overview of the discussion was published on the website.</p> <p><u>Support/training:</u> Handbook that summarizes the process, expert facilitators, project staff, and researchers; presenters and resource people to provide information and respond to questions. A video version of the handbook, a primary discussion resource for the early stage of the Citizen Panel, was also produced.</p> <p>Panelists were not required to read materials in advance of sessions, although they could do so if they wished.</p> <p><u>Reimbursement:</u> Panelists who attended and participated in at least five of the six sessions were eligible to receive an honorarium of 500.</p>	<p><u>Evaluation:</u> Through its design and management, the Citizens' Panel pilot project encouraged informed, values-based discussion by citizens through providing broad-based direction to City Council, which can then be used to support, inform, correct, or shape policy-making decisions. Reflections from the panel members were collected at the final session.</p> <p><u>Lessons learned:</u> NR</p>
<p><b>Melbourne Health</b></p>	<p><u>Composition:</u> Eight to 12 volunteer</p>	<p><u>Meetings:</u> At least bimonthly, minimum</p>	<p><u>Evaluation:</u> Biennial review includes</p>

<p><b>Community Advisory Committee (CAC)</b><sup>8,9</sup>          Victorian Government Department of Human Services, Australia  <u>Setting:</u> local  <u>Healthcare field:</u> Yes  <u>HTA field:</u> No  <u>Level of involvement:</u> Consult  <u>Terms of reference:</u> Yes, mentioned in publications; guidelines available</p>	<p>members appointed as individuals, not as a representative of any organization, preferably having some connections to established formal or informal community or consumer networks. At least one but not more than two members of the board are appointed in the CAC.  <u>Selection process:</u> Criteria: not a registered provider, nor currently employed or engaged in the provision of health services; preferably connected to formal or informal community or consumer networks, or having capabilities to develop such links. Source: recommendation of individuals from peak bodies, direct approaching of individuals with experience as consumers, carers, or community members, open advertisements.  <u>Lifetime:</u> Initial appointments for 2 or 3 years, with opportunity for reappointment.</p>	<p>of six meetings per year, for two or three hours each meeting. The CEO or an alternative executive identified by the public health service board is in attendance at each meeting, either as a member or as a resource to the committee. Melbourne committee members are involved in other working groups, quality committees, planning groups.  <u>Accountability:</u> To the public health service board; provide minutes of the meetings. Develop an annual work plan.  <u>Support/training:</u> Receives support from the management team; in-house, formal orientation and training, appropriate professional advice, mentoring, attend relevant training and workshops.  <u>Reimbursement:</u> Costs of participation such as travel, accommodation.</p>	<p>discussion about:</p> <ul style="list-style-type: none"> <li>• achievement of major goals and objectives of the work plan in the time frames</li> <li>• whether the advice of the committee has been sought by the board</li> <li>• whether the board has benefited from the advice</li> <li>• whether the committee made recommendations and whether they have been considered and responded to</li> <li>• whether the recommendations resulted in changes in practice in the public health service</li> </ul> <p>In 2008 an independent evaluation of CACs (using a self-evaluation tool for health services and consultations with board members, CAC members, and executive management from 14 metropolitan and five rural services) concluded that CACs had contributed significantly to progressing the role and profile of community participation among health service boards and their senior executives; had been a catalyst for community participation, had contributed to a cultural change within health services.  <u>Lessons learned:</u> Members' participation in other committees and projects has increased the scope of consumer and community involvement across the organization and enabled CAC members to "get to know" their health service. Clear communication pathways with the board and other committees have been crucial. The key lesson was the need for the CAC agenda to be driven by consumers on the basis of their perspectives and experience, and for a health service to put its own perceptions to one side and really listen to what consumers have to say.</p>
<p><b>Citizens' Reference</b></p>	<p><u>Composition:</u> 14 members</p>	<p><u>Meetings:</u> Planned to meet two or</p>	<p><u>Evaluation:</u> No policy impacts were expected,</p>

<p><b>Panel on Health Technologies (CCRPHT), Ontario</b><sup>10-12</sup></p> <p>Centre for Health Economics and Policy Analysis at McMaster University, Canada</p> <p><u>Setting:</u> Provincial</p> <p><u>Healthcare field:</u> Yes</p> <p><u>HTA field:</u> Yes</p> <p><u>Level of involvement:</u> Consult</p> <p><u>Terms of reference:</u> NR</p>	<p><u>Selection process:</u> Members were randomly selected using a "civic lottery" from a representative group selected by geographic region and stratified by gender and age, with one participant coming from each of Ontario's 14 Local Health Integration Network regions. Members were recruited by an advisory firm (that is, MASS LBP).</p> <p><u>Lifetime:</u> Five 1-day meetings were held between February 2009 and June 2010.</p>	<p>three times per year. Alternance of senior MAS/OHTAC officials at the meetings and open invitation for panel members to attend an OHTAC meeting. Relevant documents (background material, including research summary, media articles, workbook with topic summaries, set of discussion questions) were circulated one week prior to each meeting.</p> <p><u>Accountability:</u> Thematic summaries of panel discussions were prepared after each meeting and shared with OHTAC members, in either report or presentation format, for discussion at monthly OHTAC meetings.</p> <p><u>Support/training:</u> NR</p> <p><u>Reimbursement:</u> An honorarium (CAD65) sent after attending each meeting covered travel expenses associated with meeting attendance.</p>	<p>but the panel provided MAS and OHTAC with new insights into social values and ethics data. Inputs were explicitly used in OHTAC deliberations for the technologies reviewed.</p> <p>Most panel participants felt their input was valued by OHTAC. Others considered that it had a minimal influence but felt it was a crucial step toward increasing the awareness of MAS and OHTAC.</p> <p>CIHR assessed the panel. The following strengths were identified:</p> <ul style="list-style-type: none"> <li>• Input was integrated from a wide range of perspectives (citizen included) to contribute to provincial policy making.</li> <li>• The panel met its objective to provide citizen input on societal and ethical issues.</li> <li>• Facilitation of meetings kept the group on track and encouraged participation from all members.</li> <li>• Use of small groups provided a platform for all members' input.</li> <li>• An arm's length relationship existed between CRPHT and MAS/OHTAC.</li> <li>• Sponsor's attendance at CRPHT meetings re-affirmed the roles and contributions of panel members.</li> <li>• Awareness was raised of the importance of incorporating public input into the HTA process.</li> <li>• Created a model for public involvement in HTA that can be improved upon in the future.</li> </ul> <p>Challenges were:</p> <ul style="list-style-type: none"> <li>• Informational requirements: "going into it cold," and the large quantity of information to take in during the session.</li> </ul>
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			<ul style="list-style-type: none"> <li>• Discussions "meandered" or were "monopolized" at times.</li> <li>• It was challenging to feel part of the panel again at each meeting, given the time between meetings.</li> <li>• The size and representativeness of the panel posed a challenge.</li> <li>• Role confusion was a challenge.</li> <li>• Communication between the citizen's panel and the sponsor was a challenge. The higher education and income levels present in panel members may have determined the selection of values that may not have been representative of minority groups or the general population but rather of citizens who may be more resourceful or who experience fewer challenges in accessing health care.</li> </ul> <p><u>Lessons learned:</u> A carefully designed citizens' reference panel with a clear purpose and coordinated linkages to an expert advisory body can usefully inform health technology advisory decisions.</p> <p>Suggestions included: Increase the frequency of meetings, and consider alternative and additional communication vehicles; ensure adequate attendance at each meeting and expand the size and reach of the panel; improve the clarity of roles and activities for panel members; clarify and strengthen the supporting infrastructure of the panel and the interface between the panel and the sponsoring organizations.</p>
<p><b>Toronto Health Policy Citizen's Council</b><sup>13</sup> University of Toronto, Priority Setting Research</p>	<p><u>Composition:</u> 26 members (24 after the fourth meeting). <u>Selection process:</u> Volunteers, none of whom are involved in healthcare-related</p>	<p><u>Meetings:</u> Held over the two weekend days. Various health policy topics were discussed (such as funding technology, public reporting by hospitals, wait times in emergency</p>	<p><u>Evaluation:</u> The deliberative process of the Citizen's Council was effective; it helped citizens clarify their positions on different health policy topics. It was apparent that citizens were satisfied with the Citizen's</p>

<p>Group, Canada  <u>Setting:</u> Provincial  <u>Healthcare field:</u> Yes  <u>HTA field:</u> No  <u>Level of involvement:</u> Consult  <u>Terms of reference:</u> NR</p>	<p>occupations, representative of Toronto's diverse population. Selected randomly (random digit dial) by an independent company to approximate the age, gender, educational level, socio-economic status, ethnic background and health status distribution of the citizens of Ontario. Inclusion criteria included: citizens of Ontario, 18 years or older, eligible to vote. Exclusion criteria included: healthcare professionals, employees of healthcare professionals, employees or directors of pharmaceutical companies, individuals owning significant equity in pharmaceutical companies, members or employees of political action groups (for example, patient advocacy groups), members of provincial parliament and other elected officials, employees of the Ministry of Health and Long-Term Care, and individuals affiliated with marketing, advertising, public media, or public relations companies.  <u>Lifetime:</u> Two-year commitment; seven meetings were held between 2008 and 2010.</p>	<p>rooms, and patient satisfaction; some topics were chosen in consultation with the citizens. Meetings were closed to the public, though backgrounders, agendas, and reports were posted to the Council's website, and reports were disseminated to appropriate people.  <u>Accountability:</u> University of Toronto, Priority Setting Research Group; Council's report after each meeting, including participants' opinions, formulation of policy-type recommendations and conclusions. Detailed analysis of why Council members responded the way they did. First draft prepared by facilitator with member input before submission.  <u>Support/training:</u> Team-building exercises at the onset of Council formation, at Meeting 1 and Council meetings, included presentations on opposing viewpoints of the issue at hand by experts in the field, small group deliberative sessions, and plenary "toward consensus" sessions, if consensus was possible (consensus was not required). Expert witnesses were in attendance, background information was distributed.  <u>Reimbursement:</u> Flat per diem remuneration of CAD200 following full participation at each meeting.</p>	<p>Council model being used to elicit the public's values. Citizens were generally positive about the Council process, and they enjoyed it, as indicated by the results of the satisfaction survey. Their top two reasons for continuing to participate in the Council were: 1) learning about health care, and 2) the possibility of making a difference to Ontario health policy.  <u>Lessons learned:</u> Variation of opinion was ensured by selection. The dimension of the group facilitated deliberations. In public engagement, involving participants in all aspects of the process is important—participants feel respected knowing their views will be heard—but for public engagement to have capacity to make an impact, it is also important that topics are timely and questions are conducive to deliberation, which the research team ensured. Participants could identify areas of interest and appropriate policy outcomes. Public engagement is a good way of educating citizens about health policy issues.</p>
<p><b>Consumer Advisory Group</b><sup>14</sup>          UK HealthCare, USA</p>	<p><u>Composition:</u> 30 members (current and past patients and members of the community who use other medical organizations). Chaired by Senior</p>	<p><u>Meetings:</u> Bimonthly, with a degree of flexibility by using subgroups for meetings. Meet as needed, averaging one 2-hour meeting every 2 months.</p>	<p><u>Evaluation:</u> NR  <u>Lessons learned:</u> For various advisory groups—get buy-in and approval from management; it is important while recruiting, at</p>

<p><u>Setting:</u> local <u>Healthcare field:</u> Yes <u>HTA field:</u> No <u>Level of involvement:</u> Consult <u>Terms of reference:</u> NR</p>	<p>Manager of Marketing Research. <u>Selection process:</u> Recruited from UK HealthCare's marketing database, which consists of callers to the organization's consumer call center. Other sources: respondents to patient satisfaction surveys, health lecture attendees, referrals from current members. Currently, recruiting efforts are underway to ensure panelist representation in key interest groups. <u>Lifetime:</u> No commitment.</p>	<p><u>Accountability:</u> NR; manager marketing research. <u>Support/training:</u> Orientation; short overview of the agency marketing plan and current goals. <u>Reimbursement:</u> UK HealthCare merchandise; dinner; \$10 gift card</p>	<p>the first meeting, and periodically thereafter, to remind the group that they are an advisory group and that not all recommendations can be used. Provide an opportunity to freshen the group and bring in an individual representing a different segment. It usually takes at least three meetings before members of a group begins to become comfortable with each other and with their roles. Recommendations from advisory committees provide valuable input for senior management and a level of comfort that key participant groups have brought in. Having advisory committees lets the public and community leaders know that the organization is including community input into its efforts. It is also an avenue to make sure marketing is included at the organization's decision-making committees.</p>
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## **APPENDIX D: CASE STUDY: CITIZENS' REFERENCE PANEL ON HEALTH TECHNOLOGIES**

The information presented here is taken entirely, without any content modification from CIHR's Citizen Engagement in Health Casebook, 2012; available at:  
[www.cihr.ca/e/45358.html#a16](http://www.cihr.ca/e/45358.html#a16)

*CIHR's Citizen Engagement in Health Casebook*

## Consulting Ontario Citizens to Inform the Evaluation of Health Technologies: The Citizens' Reference Panel on Health Technologies

Health Quality Ontario (HQO)

Julia Abelson, Ph. D, McMaster University, F. Wagner, MHSc, University of Toronto, L. Levin, MD, Ministry of Health and Long-Term Care, Head, Medical Advisory Secretariat, Y. Bombard, PhD, Yale University and Memorial Sloan Kettering Cancer Center, F-P. Gauvin, PhD, National Collaborating Centre for Healthy Public Policy, D. Simeonov, MSc, Institute for Clinical Evaluative Sciences, S. Boesveld, MSc, Doctoral student, McMaster University

### *Introduction*

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In December 2008, a 14-member Citizens' Reference Panel on Health Technologies (CRPHT) was established to inform the work of the Medical Advisory Secretariat (MAS) and the Ontario Health Technology Advisory Committee (OHTAC), which produces evidence-based recommendations regarding the use of health technologies throughout Ontario's health system. One of the panel's specific goals was to elicit the societal and ethical values that should guide OHTAC in developing its recommendations. The creation of the CRPHT represents an early experimentation with a deliberative engagement method in order to incorporate public values and citizen perspectives into the expert-driven health technology assessment processes.

### *Methods*

#### **Participant recruitment**

A civic lottery methodology was used to recruit the panel.<sup>1</sup> Thirty-five hundred Ontario residents were mailed an invitation letter, information sheet and postage-paid response form. From this sample, 163 expressions of interest in panel membership were received, from which 14 panel members—selected by geographic region and stratified by gender and age, with one participant coming from each of Ontario's 14 Local Health Integration Network regions—were selected blindly from the respondent pool. All travel expenses associated with meeting attendance were covered and each panel member received a \$65 honorarium after attending each meeting.

#### **Deliberative discussions**

The 14-member panel was convened for five one-day meetings at McMaster University in Hamilton, Ontario, between February 2009 and May 2010. At each meeting, panel members participated in structured dialogues covering two broad topic areas:

- 1) the core values that should guide the evaluation of health technologies—when and by whom should this be done?; and

<sup>1</sup> Dowlen, O. Sorted: *Civic Lotteries and the Future of Public Participation* (Toronto: MASS LBP, 2006).

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- 2) reviews of selected health technologies (e.g., screening for colorectal and breast cancer, serological testing for celiac disease, and personalized medicine) to provide ethics and social values input to OHTAC deliberations.

The technologies selected for discussion at each meeting were jointly agreed upon by the research team, Medical Advisory Secretariat staff and OHTAC members.

Background material about each deliberation topic—including research summary and media articles, a workbook with topic summaries, and a set of discussion questions—was circulated one week before each meeting. Meetings began with an introduction to each topic, a brief summary presentation by the meeting facilitator or invited guest expert, and a question and answer session. Following the presentation, large and small groups held either externally- or self-facilitated discussions of questions that had been circulated prior to the meeting. Representatives from MAS and OHTAC attended two of the five meetings to describe the MAS-OHTAC process, to explain the rationale for the creation of the Citizens' Panel, and to answer questions from panel members.

Each of the five CRPHT meetings generated two types of outputs to inform MAS-OHTAC deliberations regarding the evaluation of selected technologies:

1. Qualitative reflections on a set of pre-circulated questions designed to elicit societal and ethical values related to the technology under review.
2. Pre- and post-meeting survey results of panel member rankings of the societal and ethical values central to the technology under review.

Examples of the "moral" questions reflected on by panel members for each technology included (but were not restricted to) considering how (or does) the technology:

- demonstrate respect for religious, social or cultural convictions?
- affect the distribution of health care?
- challenge patient autonomy?
- ensure that human dignity is respected?<sup>2</sup>

Despite slight variances across technologies, "universal access," "choice," and "quality care" were identified as core values that should be considered in both the evaluation of health technologies and the ensuing recommendations.<sup>3</sup>

A thematic summary of panel discussions was prepared in either report or presentation format following each panel meeting. It was then shared with OHTAC members for discussion at monthly OHTAC meetings.

<sup>2</sup> The list of moral questions for health technology assessment was adapted from Hofmann, B., "Toward a Procedure for Integrating Moral Issues in Health Technology Assessment," *International Journal of Technology Assessment in Health Care* 21.3 (2005): 312-318.

<sup>3</sup> Bombard, Y., Abelson, J., Simeonov, D., Gauvin, F.P. "Eliciting Ethical and Social Values in Health Technology Assessment: A Participatory Approach," *Social Science and Medicine* 73.1 (2011): 135-144.

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Several specific suggestions were made to improve the panel's structure, processes and impact:

**1. Increase the frequency of meetings, and consider alternative (and additional) communication vehicles.**

A shorter gap between meetings (no more than 2 months) was recommended to make it easier for panel members to re-immense themselves in the material and to improve how the CRPHT's functioned. Face-to-face meetings could continue to be used as the dominant interaction medium, but additional media such as the internet, teleconferences and video conferencing also should be explored as a way of complementing face-to-face meetings

**2. Ensure adequate attendance at each meeting, and expand the size and reach of the panel.**

Panel members expressed concerns about ensuring both a critical mass of participants and balanced representation across age and gender (minimum) at each meeting. Ultimately, this yielded several suggestions:

- Alternates for each of the 14 panel members should be selected, or the panel's size should be expanded.
- The work and reach of the panel should be complemented by surveys, mini-panels or focus groups on selected topics.

**3. Improve the clarity of roles and activities for CRPHT.**

A clearly articulated purpose for these types of panels is essential, and it needs to be re-affirmed and revised periodically. This ensures that the panel reflects the thoughts of panel members and sponsors about how best to use it, but it also clarifies the panel's role relative to the sponsors, ensuring that it contributes meaningfully to their deliberations.

**4. Clarify and strengthen the supporting infrastructure of CRPHT and the interface between CRPHT and sponsoring organizations.**

An adequate infrastructure for the panel was viewed as critical to sustaining it over time. More specifically, a number of roles need to be formalized and nurtured to establish an effective and efficient interface, including:

- content expertise to inform the preparation of materials for CRPHT meetings and relevant technology-specific discussions; and
- a strong liaison function to ensure that potential topics for CRPHT meetings are identified in a timely manner and that input from the citizens' panel is effectively integrated into MAS and OHTAC deliberations.

This report has been produced in response to a request from Alberta Health (AH). The objective was to perform a review of practices of engaging committees composed of lay people or members of the general public at international, national, provincial, and regional levels.



Institute of Health Economics

1200 – 10405 Jasper Avenue

Edmonton AB Canada T5J 3N4

Tel. 780.448.4881 Fax. 780.448.0018

[info@ihe.ca](mailto:info@ihe.ca)

[www.ihe.ca](http://www.ihe.ca)

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