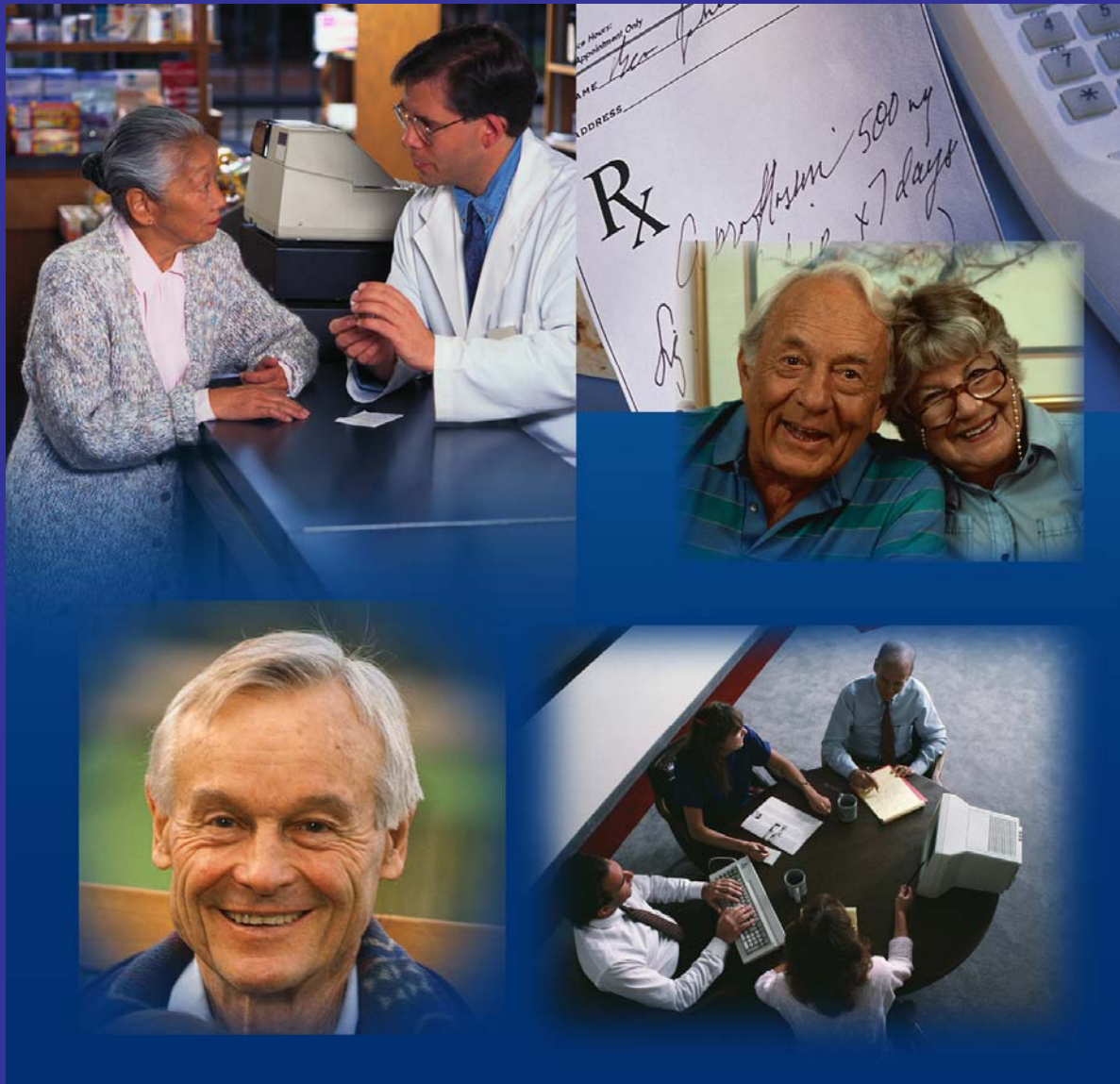


Recommendations for Establishing a Citizens' Council to Guide Drug Policy in Ontario



The University of Toronto Priority Setting
in Health Care Research Group

November 2006

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Report by The University of Toronto Priority Setting in Health Care Research Group

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The Institute for Clinical Evaluative Sciences

The Institute for Clinical Evaluative Sciences (ICES) is an independent, non-profit organization that uses population-based health information to produce knowledge on a broad range of health care issues. Its unbiased evidence provides measures of health system performance, a clearer understanding of the shifting health care needs of Ontarians, and a stimulus for discussion of practical solutions to optimize scarce resources.

ICES knowledge is highly regarded in Canada and abroad and is widely used by governments, hospitals, planners and practitioners, to make decisions about care delivery and to develop policy. ICES research findings are profiled in the media to bring health-related problems and potential solutions to the public's attention. (www.ices.on.ca)

The Institute for Work & Health

The Institute for Work & Health (IWH) is an independent, not-for-profit organization whose mission is to conduct and share research with workers, labour, employers, clinicians and policy-makers to promote, protect and improve the health of working people. The Institute has been providing research and evidence-based practical tools for clinicians, policy-makers, employees and managers since 1990.

The Institute maintains a strong research focus on factors that contribute to work-related soft-tissue illness, injury and disability. This breadth of research aims to inform both primary prevention efforts—programs, policies and initiatives to prevent work-related injury, and secondary prevention efforts—treatment and management programs to reduce disability and recurrence of work-related injury. In addition, IWH scientists examine the broader population-level work-health issues. (www.iwh.on.ca)

The Department of Medicine of The University of Toronto

The Department of Medicine of The University of Toronto is one of the oldest and largest in North America, dating back to the establishment of the founding of the School of Medicine in 1843. A major milestone in the Department's history was the establishment of the Sir John and Lady Eaton Professorship of Medicine in 1919, the first full-time Chair in Clinical Medicine in what was then the British Empire. Today the Department houses over 400 full-time faculty members who are distributed among several teaching hospitals and the University campus, 17 Divisions, and 400 postgraduate trainees and fellows in Core Internal Medicine, and in the medical specialties and subspecialties. Members of the Department supervise over 130 graduate students through the Institute of Medical Science, the Program in Clinical Epidemiology and Health Care Research, and through basic science departments to which several members of the Department are cross-appointed. The Department plays a major role in the undergraduate MD program, and supports an extensive program of continuing education. (www.deptmedicine.utoronto.ca)

The University of Toronto Joint Centre for Bioethics

Formed in 1995, The University of Toronto Joint Centre for Bioethics (JCB) is a partnership between The University of Toronto and affiliated health care organizations. The JCB studies important ethical, health-related topics through research and clinical activities. The JCB is a network of over 180 multidisciplinary professionals seeking to improve health care standards at both national and international levels. At the JCB, theory is put into practice. Its mission is to provide leadership in bioethics research, education and clinical activities. (www.utoronto.ca/jcb)

Cancer Care Ontario

Cancer Care Ontario is an umbrella organization that steers and coordinates Ontario's cancer services and prevention efforts so that fewer people get cancer, and patients receive the highest possible quality of care. As the provincial government's chief cancer advisor, Cancer Care Ontario directs over \$500-million in public funding for cancer prevention, detection and care. The agency also operates screening and prevention programs; collects, monitors and reports information about cancer system performance; develops evidence-based standards and guidelines; and works with regional providers to plan and improve services for patients. (www.cancercare.on.ca)

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Executive Summary

The Ontario legislature recently passed Bill 102, the *Transparent Drug System for Patients Act*, which mandates the establishment of a Citizens' Council. The intent of the Council is to help guide drug policy in Ontario. Specifically, the legislation states that the Citizens' Council is to advise the executive officer, who oversees the decisions for inclusion or removal of drugs from the formulary. The bill also states that "the Minister shall establish a Citizens' Council whose duty shall be to ensure the involvement of patients in the development of pharmaceutical and health policy". Many decisions regarding drug listing and reimbursement are value-laden, and a Citizens' Council is one method of ensuring that the public has input into the social aspects of health policies and priority-setting. In some countries, citizens' councils are used to advise decision-makers about the value judgments that underpin how priorities are set by health policy makers.

In this report, we describe theoretical and practical issues related to establishing a citizens' council, present approaches used in other jurisdictions and recommend preferred options for the Citizens' Council proposed in the *Transparent Drug System for Patients Act*.

Examples of citizens' councils included in this report are:

- ***National Institute for Health and Clinical Excellence, England and Wales***
- ***Department of Planning, New South Wales, Australia***
- ***Health Products and Food Branch Public Advisory Committee, Health Canada***
- ***Institute for Public Policy Research, United Kingdom***
- ***Research Institute for Citizen Participation and Planning Procedures, Germany***
- ***Jefferson Center for New Democratic Processes, USA***
- ***The Citizens' Assembly on Electoral Reform, British Columbia, Canada***

These seven were chosen partly because they are prominent examples of public engagement that fit the general structure of a citizens' council, and partly because they provide a substantial amount of information about the processes and outcomes, and can give clues about the likely paths to success or failure. A further example of public involvement that is particularly relevant to drug policy decision-making, the Oregon-led Drug Effectiveness Review Project, is described in the Introduction.

In the Executive Summary, we summarize our recommendations for Ontario's Citizens' Council, and describe the "lessons learned" from citizens' council experiences from around the world. Further detail and supporting rationale for the recommendations can be found in the main body of the report.

Description and Purpose of the Citizens' Council

Citizens' councils are typically established by governing bodies to determine societal values surrounding a variety of complex issues. We believe that the stated goal of the Ontario government in forming the Citizens' Council, to "give the public an opportunity to guide public drug policy", succinctly states what the purpose of the Council should be (See section 2.9).

Membership Eligibility

We recommend that stakeholder representatives be prohibited from joining the Council because they often have a predetermined position on the issues at hand, and since their voices are already being heard through other means. The following list is not intended to be exhaustive, but offers examples of the kinds of individuals who should be excluded from membership on the Citizens' Council.

- Health care professionals and all employees of health care providers
- Employees of associations representing health care professionals
- Employees or directors of pharmaceutical companies
- Individuals owning significant equity in pharmaceutical companies
- Employees, board members or other decision-makers of patient advocacy groups
- Members or employees of political action groups
- Members of Provincial Parliament and other elected officials
- Employees of the Ontario Ministry of Health and Long-Term Care

Should the scope of the Council be expanded at a future date, we suggest that similar bars should be placed on membership for people with evident conflicts of interest (for example, if the Council were to consider issues concerning medical devices, then people employed by or with interests in the devices industry ought to be excluded). Aside from these criteria, we would suggest that anyone eligible to vote (i.e., anyone 18 years of age or older in possession of Canadian citizenship) should be considered to be a member of "the public" for the purposes of the Council (See section 3.11).

Methods of Recruitment and Selection

We believe that more useful information related to values and societal opinion will be obtained through deliberative discussions held among "ordinary citizens" (as opposed to "expert members" of the public), and therefore recommend that this be an explicit goal for Ontario's Citizens' Council. We also recommend that members be selected to approximate the age, gender, socioeconomic, ethnic, and health status distributions of the Ontario population.

Finally, we recommend that the external agency commissioned to recruit members be given instructions to recruit a group who are not only collectively representative of Ontario's population as described above, but who individually possess personal attributes that are likely to result in them being effective participants in a deliberative process. An important step in the recruiting process ought to be a personal interview with a short list of candidates using pre-arranged criteria (See section 4.9).

Number of Members

We recommend that between 15 and 20 individuals be appointed to the Council (See section 5.8). We recommend that the Council start with 15 members and increase its numbers to 20 individuals if needed.

Remuneration

We tentatively recommend a flat per diem in the range \$150-\$200 per day plus reimbursement for expenses, including transportation, meals, accommodation and child care. Special expenses necessarily incurred by disabled members should be reimbursed, and there should be further individualized planning or help for individuals with disabilities as may be required for their attendance (See section 6.8).

Duration of Membership

We recommend a term of service of three years, with one-third of the members retiring each year. Terms of the initial Council members could be randomly set at two, three and four years to allow for staggered retirement. The terms should begin at the first meeting rather than when Council members are appointed (See section 7.8).

Conflicts of Interest

We recommend that Council members be required to declare interests that conflict with the proceedings of council meetings. Members are prohibited from having any relationship with pharmaceutical companies and must disclose any contact with them. Potential conflicts of interest should be assessed by the Council chair and the arm's length agency that facilitates Council meetings (see section 8.1).

Training and Orientation of Members

We recommend a one to two day orientation for new members, both initially and as each subsequent group of Citizens' Council members is appointed. During this orientation, councillors should be oriented to content issues (e.g., the health system, the Ontario Drug Benefit Program) as well as process issues (e.g., how to communicate one's views effectively in a group, how to question a witness). A manual should be developed for new members that would brief them on expected behaviour, terms of reference, the conduct of meetings, the history of past meetings and their consequences, and other such matters so that they can be brought "up to speed" as rapidly as possible (See section 9.9).

Organizer of Meetings

We strongly recommend that the Ministry hire an independent organization to facilitate meetings of the Council. Possible organizations include Canadian Policy Research Networks, the University of Toronto Joint Centre for Bioethics, EKOS Research Associates or any other organization with expertise in the area. The facilitator should be advised by a standing Advisory Council comprising Ministry staff, members of the Committee to Evaluate Drugs and

Cancer Care Ontario, as well as independent experts in pharmaceutical policy and/or public engagement in health care. The Advisory Council could help with the selection of expert witnesses, agenda setting, etc. For the Council's chair, we recommend an individual with a commitment to public life and a reputation for being impartial, committed and neutral rather than political. This person should be free of all conflicts of interest preferably in the past and present. The Advisory Council could put forward a short list of names, from which the Minister could choose the Council's chair (See section 10.9).

Questions for the Council to Debate

The clarity and relevance of the questions to be put to the Council are critical to its success. Most commonly, it has been the commissioning body in conjunction with stakeholders that is responsible for this task. One way of making sure that the questions put to the Council are phrased at the right level of specificity is by providing members with a context for the decisions that might be informed by their answer and the reasons why decision-makers need an answer from the Council. With an ongoing Council, members may also engage in a dialogue with the Advisory Committee regarding potential key questions. A dialogue will provide Council members with an opportunity to express their concerns and reactions to potential questions and to ask for clarifications before questions are finalized. The Advisory Committee can use these reactions to alter the questions as needed. We therefore recommend that the questions to be discussed by the Citizens' Council be decided by the Advisory Committee, after consultation with stakeholders and Council members (See section 11.9).

Content of Meetings

We recommend that each meeting start with a session reviewing the brief, easily understandable background material that has been provided to Council members in advance of Council meetings.

To promote deliberation, we recommend the use of frequent small group sessions during Council meetings, with frequent use of witnesses and expert presenters. Witnesses and experts will be required to disclose any conflicts of interest prior to addressing the Council. Guidelines for witness presentation should include a time limit for presentations, submission of paper copies of the presentation and information about the focus of the presentation. By whatever means are practical, we recommend that Council members be able to help choose witnesses and expert presenters (See section 12.19).

Meeting Outcomes

We recommend that the contents of each meeting be summarized in a written report. The production of this report should be a collaborative endeavour where the facilitator prepares the first draft and Council members are invited to submit editorial changes. The report should include a detailed analysis of why members felt the way they did, and how their views changed as a result of what they heard and discussed at the meeting. Ideally, summaries of the presentations from expert witnesses, including question-and-answer sessions, should be included as appendices. We recommend that the content of the final report (including any dissenting comments) be required to have the approval of a supermajority of Council members (e.g., 80%). We also recommend that the Advisory Council and the Ministry, in conjunction with the Citizens' Council itself, design a plan for promoting the Council to the public and disseminating its reports. Although we recommend that meetings be closed to the public (see below), backgrounders, agendas and meeting reports should be made available on the Ministry website and the work of the Citizens' Council should be publicized. As one of the goals of the Citizens' Council is to increase public engagement beyond that of the Council itself, promoting and publicizing the work of the Council will likely be beneficial and will lead to a wider public understanding of the complexities involved in making decisions relating to drug policy (See section 13.10).

Meeting Frequency and Duration

We recommend that the Council meet three to four times per year initially, for two days, and that this frequency and meeting duration be reassessed after one year (See section 14.9).

Meeting Location

To promote regional representation and also to ensure that the perspectives of Ontarians from around the Province are being considered, we recommend that the Council meet at various locations throughout Ontario. During the first year of the Council's activity, we recommend that one to two meetings be held outside Toronto. We recommend that meetings be closed to the public due to logistical concerns and the potential for council deliberations to be

muted as a result. Members of the Council should be physically present at meetings, rather than phoning in to meetings, as a part of their commitment to the Council (See section 15.8).

Assessment and Evaluation

We recommend an external review of the Ontario Citizens' Council's work after one year of deliberations, with periodic subsequent reviews. Reviewers should be independent of the Ministry, the external agencies hired for recruitment and/or facilitation, the Committee to Evaluate Drugs, Cancer Care Ontario and the Advisory Council (See section 16.9).

Lessons Learned from Citizens' Council Experiences

Drawing on various experiences of citizens' councils around the world, some "take home messages" are as follows^{1,2}:

- *Arm's length from decision-makers.* The council should be at "arm's length" from the official decision-making authorities to ensure its independence and to give it credibility.
- *Local ownership.* The issue being discussed must be of importance to the participants, their community and stakeholders. Topics that are far removed from the current situation in the community will lead to a fruitless council session.
- *Choice of subject.* Issues appropriate for citizens' councils are relevant, action-based questions that community groups have helped to frame.
- *Participants should be motivated.* The questions that members are asked to address ought to be focused and the reason for their being asked should be made clear.
- *The commitment of policy makers must be established from the beginning.* If local agencies do not "buy in" to the process from early on, they are much less likely to take the outcomes of public participation seriously.
- *Organizing a citizens' council demands a great deal of organizational capacity.* This form of deliberation can be extremely time consuming and expensive. A high level of commitment from commissioning bodies is essential.
- *The process must be open to wider public scrutiny.* For citizens' councils to encourage a public dialogue, there must be an opportunity for wider scrutiny of the process, the findings and the decision-makers' responses. Media coverage is one way of encouraging the wider involvement of the community and of holding decision-makers accountable for any commitments they make.
- *Participants should be enthusiastic and committed.* In most citizens' councils, being invited to have a say is highly valued by the participants, who generally enjoy the debate and take their responsibilities extremely seriously.
- *Good quality chairing.* The skills of the chair are critical in reassuring members about the authenticity of the process, ensuring that each member participates, that no single voice dominates and that the deliberation remains focused.
- *Clear timelines.* The timelines for decisions, calling of witnesses and the entire process from start to finish should be clear.
- *Appropriate support.* The technical and administrative support for the council should be well-founded and command the trust of the council members.
- *Evidence presentation.* The kind of evidence to be brought before the council and its manner of presentation (e.g., presentations by and examination of expert witnesses) should be clearly discussed and well-organized.

- *Use of in camera sessions.* When indicated, *in camera* sessions encourage free expression of opinion. Otherwise, councils should be as open and transparent as possible (for example, public sharing of agendas, data, interim conclusions, minutes, etc.).
- *Time for reflection.* There should be sufficient time available for members to study, discuss and reflect before, during and after council meetings.
- *Reduce barriers to participation.* Barriers to representative participation should be minimized by such means as the provision of child care, reasonable compensation, and reimbursement of travel and accommodation expenses.
- *Members' mutual respect.* The selection process, while seeking a balance of ethnic, regional and other demographic characteristics, should also ensure that the interpersonal "chemistry" is likely to work well and that members will show respect for one another.

1. Introduction

- 1.1. Public participation in health policy decision-making has become increasingly attractive to democratic governments in Western Europe and North America. To ensure that health policy decisions are consistent with the values of Canadian citizens, decision-makers in our country are currently actively examining different ways of involving the public in the decision-making process.
- 1.2. The organization and delivery of health services is a complex responsibility that depends on the collaboration of many stakeholders, including individual citizens. For every question, the “right” answer can depend on local considerations, resources, external comparisons and temporal factors—all of which are grounded in values. In any pluralistic democracy, different people will emphasize different values and these different views often conflict—many possible answers can be viewed as “right”, and almost any decision can be argued with. Therefore, it is important that decision-makers follow fair decision-making processes—processes that establish legitimacy in the eyes of both the public and professionals.³
- 1.3. In Canada’s publicly funded health system, resources are limited and must inevitably be rationed. In the case of public resources, decisions regarding their rationing should reflect values held by the general public and even involve the public directly in the processes of priority setting and decision-making.⁴ The primary goal of public participation in health policy making is to ensure that those decisions reflect the needs, values, culture and attitudes of patients (for whom the system exists) and citizens (who provide the resources for the system). It is well established that policy makers and health care professionals cannot represent the values of patients or lay citizens in policy making—direct public involvement is necessary.⁵ As a secondary goal, public participation can lead to better understanding, trust and wider popular support for decisions taken by government and, ultimately, an enhanced empowerment of citizens.⁶
- 1.4. Despite these laudable objectives, numerous challenges to public involvement have emerged. Time constraints, lack of broad representation among public participants and difficulties in reaching marginalized populations have been cited as key challenges.⁷ Additionally, a lack of resources, poor communication, differing definitions of participation, and incongruence between the stated purpose and real-world practice have hindered previous efforts to improve participation,⁶ and undoubtedly led to some cynicism regarding the true purpose of public engagement exercises.
- 1.5. One of the first steps in a public participation process is to identify the main purpose of the exercise. According to Health Canada’s “public involvement framework”, there are five levels of involvement, each with criteria to guide the planning process (Health Canada Corporate Consultation Secretariat, Health Policy and Communications Branch, 2000). The five levels are described in Exhibit 1.1.

Exhibit 1.1 Health Canada’s Five Levels of Public Involvement

Level	Description	When to Use	Examples
1	Inform or educate: Distribution of information to help the public understand the issues, the process, the options and the solutions.	A decision has already been made; there is no opportunity to influence the final outcome; the issue is relatively simple.	Conducting public awareness campaigns, web postings of public advisories or other information, etc.
2	Gather information: Collecting the public’s concerns and perspectives.	Primarily to listen and gather information; policy decisions are still being shaped; no firm commitment to do anything with the views collected.	Surveys, focus groups, discussion documents for feedback (mail-out or web posting), etc.

3	Discuss: Two-way information exchange where the public discusses the policy or issue. Discussion among and with different stakeholders is encouraged.	Individuals or groups will likely be affected by the outcome; the final outcome can be influenced; input may shape policy/program decisions.	Public or town hall meetings, bilateral meetings, etc.
4	Engage: Thorough and in-depth deliberation about the policy or issues. Different perspectives are shared and parties can influence each other. Underlying values and principles are highlighted.	There is a need for citizen dialogue regarding complex, value-laden issues; there is a capacity for citizens to shape decisions that affect them.	Citizens' juries or panels, deliberative discourse, study circles, advisory committees, etc.
5	Partner: Parties share responsibility for implementing aspects of policy or program decisions. Often involves joint decision-making.	Citizens and groups agree to develop their own solutions; governing organizations assume the role of enabler; it is agreed that solutions generated by citizens will be adopted and implemented.	Public or patient representation on decision-making committees.

- 1.6. A more general approach to classifying methods of public engagement distinguishes between deliberative and non-deliberative processes. Non-deliberative methods of public engagement are consultative—in other words, public input is sought, but not necessarily challenged or modified in response to opposing considerations. The non-deliberative approach has been referred to aptly as a “Sounding Board Model” of participation, where the governing body wants to understand the implications of a decision before the decision is taken.⁷ In the Health Canada continuum, consultation refers to Level 2 and 3 of public engagement, and includes methods such as surveys, focus groups, public hearings and open houses.
- 1.7. In contrast, deliberation is commonly understood to mean a weighing of evidence, a consideration of the reasons for and against some course of action, or a balancing of different considerations (ibid). Deliberative models of participation systematically educate participants about the issue in question as it is being discussed. Exhibit 1.2 describes five attributes of deliberative dialogue according to Abelson et al.

Exhibit 1.2—The Five Attributes of Deliberative Dialogue⁹

1. The formation of a representative group (12-20 members) of citizens.
2. Holding one or many face-to-face meetings.
3. Gathering and dissemination of background information about the issue under discussion.
4. Participation of key witnesses or experts to inform the discussion and answer questions.
5. The preparation of a detailed report of recommendations or proposals based on the group's deliberation.

- 1.8. Public deliberation therefore ideally envisages an environment where individuals with different backgrounds and experiences can exchange thoughts about an issue, reflect on the differences which emerge between participants, argue about what constitutes the best course of action, and ultimately offer recommendations to the decision-making body or the public. Such deliberation is informed by a balanced range of information about relevant facts and values and, unlike mere consultation, might even give rise to changes of minds and changes of values on the part of the participants.
- 1.9. Three advantages have been asserted for public deliberation. First, public deliberation leads to *better quality decisions* by bringing diverse voices into the dialogue about a complex issue and thereby eliciting additional information, albeit not usually of a scientific kind, with a bearing on the issue in question.¹⁰ Furthermore, the additional information provided for consideration enhances the potential for new implications to emerge. The second claim is that participation secures *citizen advantage*: the idea that citizens become better informed, more civic-minded and active long after the deliberative process has ended. The third claim is that of *enhanced legitimacy/social solidarity*. According to this argument, the openness and inclusiveness of deliberative processes combined with the known participation of “ordinary” citizens promotes greater approval of controversial decisions and generates greater social cohesion in the community overall. Thus Mendelberg¹¹ wrote: “...deliberation is expected to lead to empathy with the other and a broadened sense of people’s own interests through an egalitarian, open-minded and reciprocal process of reasoned argumentation. Following from this result are other benefits: citizens are more enlightened about their own, and others, needs and experiences, can better resolve conflict, are more engaged in politics, place their faith in the basic tenets of democracy, perceive their political system as legitimate, and lead a healthier civic life” (pp 153-4).
- 1.10. This is not to say that deliberative processes are the only useful form of public participation. Oregon, for example, has used various forms of public participation in making decisions about state drug policy. The Oregon experience includes the Drug Effectiveness Review Project (DERP) and the Oregon Health Resources Commission, two organizations that interact with each other and the public.
- 1.11. DERP “is a collaboration of public and private organizations, including 15 states, that have joined together to provide systematic evidence-based reviews of the comparative effectiveness and safety of drugs in many widely used drug classes and to apply the findings to inform public policy and related activities.” The systematic reviews are used by the participating organizations to inform drug funding decisions. Draft reports are posted for public review and are revised as required before being published on the DERP website. In Oregon, systematic reviews are delivered to the Oregon Health Resources Commission (HRC). The HRC meets ten times per year and advises the Department of Human Services on the drugs within chosen drug categories for inclusion on the Medicaid formulary. Members of the HRC and its subcommittees include physicians, pharmacists, nurse practitioners, other health care professionals and consumers. “Lessons learned” from public involvement in Oregon’s initiative to create a fair and efficient system for drug plan decision-making are described below in Exhibit 1.3; these lessons can and should be used to inform the establishment of Ontario’s Citizens’ Council.

Exhibit 1.3—Lessons Learned from Oregon

Transparency—The Drug Effectiveness Review Project (DERP) collaboration posts all its information on a public website, including information about the Project and reports of drug class reviews. Much of this information would otherwise be unavailable to the public. Meetings of the Oregon Health Resources Commission (HRC) are open to the public, and agendas are posted several days before meetings. Although publication of the agenda can occasionally be problematic (e.g., when changes to the agenda are desirable), posting the agenda adds credibility to the process.¹² Meeting minutes are posted on the website and audiotapes of the meetings are available upon request. In addition, all emails between HRC members are posted online and paper copies are available at meetings.

Public Involvement—DERP shares important draft documents, including those for key questions and reports, and welcomes comments from the public via their website. The decision-making process for individual drugs involves the public by including consumers on the HRC and its subcommittees. Experience has shown that with detailed training and sufficient time spent on the issues, “lay members” of the HRC are able to meaningfully participate alongside physicians and pharmacists.¹² In addition, interested citizens are allowed to testify at HRC meetings, either in person or in writing, after disclosing potential conflicts of interest to the HRC.

Independence—Skepticism about the trustworthiness of government drug purchasers like Medicaid is common in Oregon and has been partially neutralized by having independent agencies organize the processes by which drug funding decisions are made.¹² Both the DERP collaboration and HRC meetings are organized by groups independent of government and the pharmaceutical industry, minimizing both real and perceived bias. The university-based Centre for Evidence-based Policy, which organizes the DERP collaboration, is a non-governmental agency unaffiliated with Oregon’s Medicaid agency. Further credibility is added by having an independent group of researchers conduct the systematic reviews. Independence from the pharmaceutical industry is also enhanced by requiring HRC members (and individuals testifying at HRC meetings) to declare potential conflicts of interest, including gifts or honoraria from pharmaceutical companies.

- 1.12. Recent attempts to increase public participation in Canada have taken the form of public opinion polls, a nation-wide citizens’ dialogue that explored Canadians’ values and their preferred choices by asking citizens to reflect on four scenarios for reforming the health care system,¹³ and adding patient representation to decision-making boards. In Ontario, significant steps have been taken to improve public participation. A citizens’ assembly on electoral reform will begin examining Ontario’s electoral system in November 2006. More recently, the Ontario legislature passed Bill 102, the *Transparent Drug System for Patients Act*, which mandates the establishment of a Citizens’ Council. The Council will ideally provide Ontarians with an opportunity to shape drug policy. Specifically, the legislation states that the Citizens’ Council is to advise the executive officer, who oversees the decisions for inclusion or removal of drugs from the formulary. The bill also states that “the Minister shall establish a Citizens’ Council whose duty shall be to ensure the involvement of patients in the development of pharmaceutical and health policy”.
- 1.13. In this report, we describe theoretical and practical issues related to establishing a citizens’ council, present approaches used in other jurisdictions and make recommendations concerning the Citizens’ Council proposed in the *Transparent Drug System for Patients Act*.
- 1.14. The terminology in the public participation field is evolving and can be confusing. First, the same phrase is sometimes used to refer to different concepts or organizational structures. Second, different phrases are sometimes used to refer to bodies or processes that are virtually identical. Nevertheless, a general glossary of terminology is helpful; details from such a glossary prepared by Abelson et al¹⁴ are presented in Exhibit 1.4. In this report we use the term “citizens’ council” to refer to any one of the bodies described in Exhibit 1.4.

Exhibit 1.4—Citizens’ Council Variations¹⁴

The term “citizens’ council” is used to refer to any one of the bodies described below.

Citizens’ juries usually consist of 12-20 randomly selected citizens who broadly represent their community’s demographics. Juries meet over several days to deliberate on a single policy question. The group is informed about the issue through written information and oral information by witnesses. Witnesses are cross-examined or questioned. The jury then discusses the matter as a group and reaches a decision with a vote.

Citizens' panels are generally the same size as citizens' juries but meet regularly (e.g., three times per year) and deliberate on more than one issue. Panels often act as "sounding boards" for the governing authority.

Planning cells consist of approximately 25 participants and have a similar form and function as a citizens' jury. Groups are commissioned by governing authorities to help with decision-making. Discussion and deliberation of policy issues result in a report that is presented to the sponsor, the media and any other interested group. The sponsoring authority agrees to take decisions into consideration.

Consensus conferences are used to put issues of a scientific and/or technical nature to a group of citizens with various backgrounds. Conferences often have two stages: the first consisting of private discussions, meetings with experts and working toward consensus, and the second involving the public presentation of main observations and conclusions.

Deliberative polling involves larger numbers than citizens' juries and builds on the opinion poll by adding deliberative dialogue. The goal of deliberative polling is to measure what public opinion would be if it were better informed and engaged. An example is the *AmericaSpeaks'* 21st Century Town Meeting, which creates engaging, meaningful opportunities for citizens to participate in public decision-making by taking opinion polls throughout the deliberation process.

Public advisory committees provide a mechanism for longer-term involvement of citizens in policy-making processes. Committee members build their knowledge and understanding of the organizing body and the issues it faces, and thus can provide informed advice from a citizen's perspective.

- 1.15. A common thread of deliberation exists within these variations of citizen engagement. Citizens' councils, and variations thereof, have not normally been given the power to make decisions. Rather, they usually explore issues and make recommendations. Citizens' councils can therefore be regarded as a complement to representative democracy. The face-to-face nature of debates is seen as a way of drawing people into the political process and enabling them to think not as isolated, anonymous individuals, but as citizens working together via dialogue for the "common good".¹⁵
- 1.16. Historically, citizens' councils have played a crucial role in the education sector and in environmental planning, with less focus on the health sector. Nevertheless, newer councils have begun looking at health issues and many lessons can be learned from these councils as well as more established, non-health-related citizens' councils.
- 1.17. The citizens' councils described in this report are:
 - **National Institute for Health and Clinical Excellence, England and Wales**
 - **Department of Planning, New South Wales, Australia**
 - **Health Products and Food Branch Public Advisory Committee, Health Canada**
 - **Institute for Public Policy Research, United Kingdom**
 - **Research Institute for Citizen Participation and Planning Procedures, Germany**
 - **Jefferson Center for New Democratic Processes, USA**
 - **The Citizens' Assembly on Electoral Reform, British Columbia, Canada**
- 1.18. These seven examples were chosen partly because they are prominent examples of public engagement that fit the general structure of a citizens' council, and partly because they provide a substantial amount of information about processes and outcomes. Using these seven examples can give clues about the likely paths to success or failure for the Ontario Citizens' Council.
- 1.19. Lessons learned from the evaluation of these and other citizens' councils are summarized in this report. The National Institute for Health and Clinical Excellence has developed attributes of deliberative dialogue that are common features among the seven examples used in this report. These commonalities are listed in Exhibit 1.5.

Exhibit 1.5—Commonalities between two or more citizens' councils

- ✓ Fair selection, giving equal opportunity for all who have a stake in the outcome to participate.
- ✓ A degree of independence from the sponsor agency with respect to devising mechanisms to ensure a balance in setting the questions to be addressed by the council, preparing the evidence and calling witnesses.
- ✓ Freedom of participants to challenge/change the process, to query the question set, revise/devise procedures, call for replacement of facilitators.
- ✓ A pre-set “contract” regarding how the results will be treated by sponsors.
- ✓ Openness to media and public scrutiny, often with the opportunity for non-council members of the public to attend deliberative sessions. Similarly, the media is often provided with the opportunity to observe and/or interview participants, sponsors, facilitators and witnesses.
- ✓ Routine debriefing, providing the opportunity for participants to discuss their experience in ways that are passed on to sponsors.
- ✓ Proportionality, expending a level of time and financial resources that will be seen as adequate for the context and the question being addressed.

2. Description and Purpose of a Citizens' Council

- 2.1. Citizens' councils are typically established by governing bodies as an effective approach to determining societal values surrounding a variety of complex issues. Although the councils described in this document explore a wide range of issues, from health care to urban development to politics, their general structure and function are similar.
- 2.2. **National Institute for Health and Clinical Excellence, England and Wales (www.nice.org.uk).** The National Institute for Health and Clinical Excellence (NICE) is a "Special Health Authority" within the National Health Service (NHS). The NICE Citizens' Council, inaugurated in 2002, calls upon citizens for ongoing advice on the set of social value judgments that colour health decision-making. NICE is advised by a Citizens' Council Steering Committee consisting of the Chair and Vice-Chair of the Board, a Project Manager and one other non-executive board member, together with Executive Directors (for planning, corporate development, communications and clinical affairs).⁷ The role of NICE's Citizens' Council is to provide its views and opinions on focused issues of social value, creating a backdrop against which NICE and the independent committees that advise it can develop recommendations about the cost-effective use of health technologies and issue authoritative clinical guidelines (NICE press release, August 19, 2002). NICE uses reports from the Council to develop documents on the scientific and social value judgments that will inform the work of the independent groups who develop guidance for the NHS.¹⁶ NICE also reviews the methodology used to develop its guidance and the work of the Council has informed these reviews. Specific roles of the Citizens' Council include keeping NICE in touch with public opinion, providing views on issues that may challenge independent groups that advise NICE, providing perspective on technical issues and providing non-technical, common sense advice.
- 2.3. **Department of Urban Affairs and Planning, New South Wales, Australia (www.duap.nsw.gov.au).** The New South Wales Department of Urban Affairs and Planning created a guide to using citizens' juries based on their experiences looking at various community attitudes towards development and new technology. Recently, juries in Australia have begun examining health issues. Two citizen jury sessions were held in 2000 and 2001 to explore community values about priority setting in health care. While little information has been published about these councils, their general structure and process follow the guidance of the New South Wales Department of Urban Affairs and Planning.¹⁷ Citizens' juries in New South Wales "provide a forum in which the panel can consider how best to deal with an issue of public importance". Juries are organized in consultation with an advisory committee (and at times with an additional stakeholder reference group) from the Department of Urban Affairs and Planning. Recommendations are compiled in a detailed report that is distributed to the public and stakeholders, and is used to inform decision-making processes. Juries are set up by a Citizens' Jury Advisory Committee and a Project Manager.¹⁸
- 2.4. **Health Products and Food Branch Public Advisory Committee, Health Canada (www.hc-sc.gc.ca/a-hc-asc/branch-dirgen/hpfb-dgpsa/ocpi-bpcp/pac-ccp/index_e.html).** The Health Products and Food Branch (HPFB) of Health Canada is responsible for the management of the health-related risks and benefits of health products and food. In 2000, the Office of Consumer and Public Involvement (OCAPI) was established to help the HPFB provide Canadians with opportunities to become meaningfully involved in the Branch's decision-making processes regarding priorities, policies and programs. The Public Advisory Committee (PAC) is made up of individuals drawn from the public who provide advice from the individual consumer perspective, not as representatives of particular groups. The mandate of the PAC is to:
- Provide the Assistant Deputy Minister and the Branch Executive Committee with advice from the consumer/public perspective on issues and initiatives as requested by the Branch;
 - Provide guidance to OCAPI and HPFB relating to planning and management of consumer/public involvement activities; and,
 - Provide advice on how to increase the effectiveness of OCAPI and HPFB communications and information dissemination to consumers/the public.

- 2.5. ***Institute for Public Policy Research, United Kingdom (www.ippr.org.uk)***. In 1996, the Institute for Public Policy Research (IPPR) partnered with several health authorities to pilot five citizens' juries on matters of health care policy, including health care rationing. The pilot series was initiated by the desire to build a habit of active citizenship in the United Kingdom, and to develop competent decision-making in the public interest. The citizens' jury experiment was designed to address some of the perceived weaknesses of other public involvement techniques, while demonstrating that innovation is possible in engagement strategies (Lenaghan, 1999).
- 2.6. ***Research Institute for Citizen Participation and Planning Procedures, Germany***. The Research Institute for Citizen Participation and Planning Procedures is commissioned by government bodies in Germany to organize "planning cells", the earliest variation of the citizens' jury. Developed by Professor Peter Dienel, planning cells were established as small groups, randomly selected, to exclude the bias of organized interests. Cells have concentrated predominantly on architectural, planning and environmental issues at the local level.¹⁵ As the organizer of these planning cells, the Research Institute is responsible for briefing the jury, selecting witnesses, organizing presentation of information, moderating the proceedings and reporting on the findings to the sponsoring organization.
- 2.7. ***Jefferson Center for New Democratic Processes, USA (www.jefferson-center.org)***. The Jefferson Center is a non-profit, independent organization that develops citizens' juries across America. Juries aim at bringing some of the benefits of small group, face-to-face decision-making to large scale democracies. Areas of policy covered include health care, agriculture, planning and social policy. The role of the Jefferson Center as organizer of juries is similar to that of the German Research Institute, in terms of planning and reporting of information.
- 2.8. ***Citizens' Assembly on Electoral Reform, British Columbia, Canada (www.citizensassembly.bc.ca/public)***. The Citizens' Assembly on Electoral Reform was established in 2003 to assess different models for electing members of the Legislative Assembly and to recommend whether the current system for provincial elections should be retained or whether a new model should be adopted. For 11 months the Assembly studied voting systems, conducted public hearings, listened to expert witnesses, and deliberated on what kind of an electoral system would best reflect the values, hopes and desires of the Province's populations. The Assembly eventually recommended an electoral system based on the "single-transferable vote".
- 2.9. ***Discussion and Recommendations for the Ontario Citizens' Council***. Most jurisdictions that have established citizens' councils have found them to be useful. Citizens' councils provide a unique forum for members of the public to educate themselves about an issue, deliberate about decisions and their ramifications, and then provide input back to decision-making bodies. The information that can be obtained from a well-functioning citizens' council is extremely difficult to obtain through other means. Citizens' councils, when used appropriately, also have the advantage of adding legitimacy to government decisions. We believe that the stated goal of the Ontario government in forming the Citizens' Council, to "give the public an opportunity to guide public drug policy", succinctly states what the purpose of the Council should be.

3. Membership Eligibility

- 3.1. Although all citizens' councils strive to increase "public" participation in decision-making processes, the definitions of what exactly constitutes the "public" can differ. One useful definition of "public" in health care decision-making is "the general group of individuals who, though interested in health and health services, do not choose to have the same level of involvement in healthcare [*I have left "healthcare" here as one word, b/c it is part of a quotation and cannot be edited/changed; however, elsewhere I have made it two words as per ICES style*]decision-making as clients, patients, residents, consumers, their families, advocates, etc."¹⁹ Although patients are not entirely free to choose their level of involvement with the health care system, this definition separates engaged citizens from others who, by choice (and sometimes due to financial or political interests), have taken an interest in health care decision-making.
- 3.2. Public engagement strategies often distinguish between the organized and non-organized public. The organized public involves participants who represent organized public groups. In the seven examples of citizens' councils described in this document (and in citizens' councils in general), participants are drawn from the non-organized public, and are generally not affiliated with, or accountable to, any other organization. Members are expected to bring a citizen's perspective to the issues, unfettered by organizational positions.
- 3.3. When the word "citizen" is used to describe the public, it often (but not always) indicates that people are being asked to participate as individuals. They do not speak for a group or constituency and are not mandated to vote in particular ways. Rather, they are being asked to express their own views and perspectives on an issue. In the parlance of political science, the role of members is "Burkean": "...it ought to be the happiness and glory of a representative to live in the strictest union, the closest correspondence and the most unreserved communication with his constituents. Their wishes ought to have great weight with him; their opinion, high respect; their business, unremitting attention...But his unbiased opinion, his mature judgment, his enlightened conscience he ought not to sacrifice to you, to any man, or to any set of men living. Your representative owes you, not his industry only, but his judgment; and he betrays, instead of serving you, if he sacrifices it to your opinion... [A]uthoritative instructions; mandates issued, which the member is bound blindly and implicitly to obey, to vote, and to argue for, though contrary to the clearest conviction of his judgment and conscience, these are things utterly unknown to the laws of this land and which arise from a fundamental mistake of the whole order and tenor of our constitution." (Burke's *Speech to the Electors of Bristol*, 1774). The examples described below generally adopt this definition.
- 3.4. **National Institute for Health and Clinical Excellence, England & Wales.** Citizens' council members are to reflect the society from which they are drawn. Members are expected to be new to the issues and to be independent of supply or provider interests. Members cannot include health professionals, employees of the NHS or health care supply industries or people involved in patient groups. Thus, the public in this case is not exactly a microcosm of society; rather, it is a combination of all those that NICE has not yet consulted via its formal processes when developing clinical guidelines or appraising technologies.
- 3.5. **Department of Urban Affairs and Planning, New South Wales, Australia.** Citizens' juries are open to all those who are interested, except individuals with any significant involvement in the issue under discussion.
- 3.6. **Health Products and Food Branch Public Advisory Committee, Health Canada.** "Public" refers to all the individuals or groups who may be interested in or affected by the decision-making body. This may include consumers, patients, professionals, industry, academia and the groups representing them.

- 3.7. ***Institute for Public Policy Research (IPPR), United Kingdom.*** The IPPR views the “public” as citizens with a broad and long-term interest in the health service, as voters, taxpayers and members of the community. Their interest lies not only in what happens to themselves, but also to their families, neighbours and fellow citizens, both now and in the future. This view is contrasted with one that defines the public as service users, with an immediate and personal interest in the particular service being discussed. The IPPR uses the former definition of the public, indicating that jurors simply speak for themselves and do not have a vested interest in the issue.
- 3.8. ***Research Institute for Citizen Participation and Planning Procedures, Germany.*** Planning cells are open to all those over 18 years of age who are interested in the issue at hand, except members of Parliament and government, and those who do not have the right to vote, such as prisoners. Earlier exclusions, such as having an age cutoff of 68 years and only including German citizens, have been abandoned.
- 3.9. ***Jefferson Center for New Democratic Processes, USA.*** Citizens’ juries are open to all those over the age of 18 who are willing to participate.
- 3.10. ***The Citizens’ Assembly on Electoral Reform, British Columbia.*** The Citizens’ Assembly was open to interested British Columbians over the age of 18, except the following persons: members of Parliament, local government, the Legislature or Executive Council; election candidates and their representatives; current officers or representatives of registered provincial parties; and chiefs under the *Indian Act*.
- 3.11. ***Discussion and Recommendations for the Ontario Citizens’ Council.*** Many stakeholders have a clear interest in the issue of pharmaceutical formulary and funding decisions in Ontario. Known stakeholders include, among others, pharmacists, prescribing health care professionals as well as their professional associations, pharmaceutical companies (either research-based or generic), patient advocacy groups, as well as political action groups that support either increased public or private funding in health care. Including representatives from these groups would likely have several negative effects on the Council. Stakeholder representatives would by definition have difficulty in playing the “Burkean” role outlined above, having previously “staked out” a position on the issue at hand and being mandated by their constituents. Input from stakeholders is more readily acquired through direct contact with their organizations and through established channels of communication. Moreover, commercial and professional stakeholders generally possess the resources and means to ensure that their views come to the attention of decision-makers and they therefore do not need a citizens’ council to do so. Including stakeholder representatives might make it harder for the Council’s chair to ensure a balance in participation and “voice”. For these reasons, we recommend that stakeholder representatives be prohibited from joining the Council. The following list is not intended as exhaustive, but offers examples of the kinds of individuals who should be excluded from membership on the Citizens’ Council.
- Health care professionals and all employees of health care providers
 - Employees of associations representing health care professionals
 - Employees or directors of pharmaceutical companies
 - Individuals owning significant equity in pharmaceutical companies
 - Employees, board members or other decision-makers of patient advocacy groups
 - Members or employees of political action groups
 - Members of Provincial Parliament and other elected officials
 - Employees of the Ontario Ministry of Health and Long-Term Care

Should the scope of the Council be expanded at a future date, we suggest that similar bars be placed on membership for people with evident conflicts of interest (for example, if the Council were to consider issues concerning medical devices, then people employed by or with interests in the devices industry ought to be excluded).

- 3.12. Aside from these criteria, we would suggest that anyone eligible to vote (i.e., anyone 18 years of age or older in possession of Canadian citizenship) should be considered to be a member of “the public” for the purposes of the Citizens' Council.

4. Methods of Recruitment and Selection

- 4.1. Recruiting members of a citizens' council may require the help of an external organization, may be active (mail-outs, telephone recruitment) or passive/reactive (newspaper advertisements), and may or may not provide detail about the specific issues to be faced by the council. These and other factors can markedly affect the quality and quantity of responses garnered by the recruitment process, and are described below in more detail.
- 4.2. **National Institute for Health and Clinical Excellence, England and Wales.** Recruitment and facilitation of meetings is the responsibility of an external organization, Vision 21. Vision 21 is a small company with a strong record for facilitating citizens' juries in the United Kingdom. Member recruitment is organized by Vision 21 in partnership with Nexus, an independent communications agency commissioned by NICE. All media communication is handled by Nexus. The first step of the initial recruitment process was ensuring that the public was aware of the newly established Citizens' Council. Advertisements were placed in regional and national media, including eight national and 70 local newspapers. To access traditionally underrepresented groups, Vision 21 used their own grassroots database, contacted the ethnic minority press and mounted an email campaign. Nexus drafted press releases while NICE executives did radio and television interviews. In-house analysis suggested that radio and television appearances were most effective. In total, almost 4,500 application forms were received for the 30 available seats on the Council. For the initial selection of members, NICE used data from the Office of National Statistics to build a picture of the population of England and Wales. Using this information, Vision 21 created a shortlist of 350 applicants. Application forms were then carefully screened, removing any individuals who did not meet pre-defined eligibility criteria. Finally, the applicant list was narrowed further to ensure an appropriate mix of ethnic, geographic and socioeconomic background. Telephone interviews were conducted with the remaining 200 candidates. Finally, using those left in the pool, Vision 21 selected a group reflective of the general population with a good range of experience and attitudes. Others were held in reserve as replacements. From a statistical standpoint, NICE's Citizens' Council approximates the population reasonably well in its mix of gender, social class, ethnicity, age, geography and disability. The final list for the first group of members included 15 men and 15 women, with an age range of 18-76. A broad spectrum of working backgrounds was reflected, from housewife to electrician, from retired civil servant to retail clerk, from builder to pilot.
- 4.3. **Department of Urban Affairs and Planning, New South Wales, Australia.** Recruitment for citizens' juries was done by advertising in popular newspapers, mail-outs using the electoral roll or telephone listings, or randomized phone dialing (see Exhibit 4.1). No specific information was offered about the issue to be discussed, simply an invitation to participate in an innovative consultation method that had the potential to influence government policy. Respondents were asked to give brief details about themselves, including sex, age, area of residence, educational qualifications, occupation, ethnic origin and household structure. The Department of Planning aimed to produce citizens' juries that represented a broad cross section of the general population. However, the Department did not insist on an exact match for demographic criteria. From the pool of respondents expressing interest in any given jury, a final panel of 12-20 jurors was obtained through a two-stage process. First, the pool was divided into groups according to sex and education level. Second, predetermined quotas for each education category (basic/skilled/degree) were filled by random selection, approximating the proportions in the population. The potential panel of jurors generated by this round of selection was then checked against the remaining characteristics in the following order: age, area of residence, household structure, ethnicity and employment to ensure a reasonable match between the jury and the New South Wales population.

Exhibit 4.1—Sample Jury Invitation letter

Dear Sir/Madam,

RE: Invitation to participate in a Citizens' Jury

Would you like to play an important role in influencing government policy? If so, the Institute for Sustainable Futures (ISF), an independent research institute at the University of Technology, Sydney would like to hear from you.

I am writing to ask if you would like to be considered as a member of a **Citizens' Jury**. You are one of only a limited number of people - less than 1% of the NSW population - whose name has been randomly selected to be invited to take part.

A **Citizens' Jury** is an event at which a panel of citizens from NSW is given the opportunity to discuss and debate an issue of concern to the people of NSW, and to present their views and recommendations to the government. Unlike juries in the legal system, Citizens' Juries make policy recommendations rather than final decisions. The aim is to gauge the opinions of a cross-section of the general public. Although this is an unusual event in Australia, Citizens' Juries are well established in Europe and in the US, where they form an important part of the policy-making process.

The Citizens' Jury will be held in Sydney from **Friday to Sunday, 9–11 February 2001**, with a welcome/introductory dinner on the evening of **Thursday 8 February**. ISF will cover all travel, accommodation, refreshments and meal expenses for the jury members, as well as a reasonable allowance for time. If you have any special needs relating to accommodation, travel, health or child care we will make every effort to meet them.

Please complete the enclosed form as fully as possible and send it to us indicating whether or not you, or another adult member of your household, are able to attend. Replies should be posted in the pre-paid envelope by **1 December** (no stamp is required). Even if you feel unable to take part, the information you supply will assist with our research. All information will remain **confidential** and will not be passed onto any other organisations. If you indicate that you wish to be included, we will add your name to a list from which the final panel of around 16 people will be further randomly selected. Successful volunteers will be notified by phone by 15 December 2000, at which time background information on the discussion topic will be sent to you.

Although it involves a considerable time commitment, *this is a unique opportunity to take part in an important event for NSW that promises to be both interesting and rewarding*. Please do not feel that you need to be an expert in a particular area; we are interested in the views of all members of the public and would value your input. I very much hope you are able to help us.

Whether you would like to participate or not we would be grateful if you could post the form to ISF by **1 December**. If you have any questions, please do not hesitate to contact either Carolyn Hendriks or Jane Palmer at ISF on *FREE CALL 1800 220 200*. We look forward to hearing from you.

Yours sincerely
Carolyn Hendriks
Citizens' Jury Project Co-ordinator

- 4.4. **Health Products and Food Branch Public Advisory Committee, Health Canada.** The initial membership of the Public Advisory Committee (PAC) was selected by the Assistant Deputy Minister, in consultation with senior management of the Branch and with members of the PAC Working Group. After screening approximately 150 potential candidates, committee members were selected to achieve balance in terms of regional diversity, age, gender, education, occupation, disability, culture, ethnicity and language. Health Canada did not however aim to create a microcosm of the public; most PAC members would be considered "policy experts" rather than lay citizens.

- 4.5. ***Institute for Public Policy Research, United Kingdom.*** For the five pilot juries, IPPR commissioned Opinion Leader Research, an independent market research company, to recruit the members of the jury. Two methods were used. The first was door-to-door recruitment to obtain a jury that matched relevant demographic profiles. In the second method, 2,000 randomly selected residents received a letter, and 16 people were selected from the positive responses to match the profile of the area. Opinion Leader Research used census and other demographic data to obtain a profile of the relevant area (e.g., the boundaries of a local or health authority). Selection was matched to the following criteria: social class, age, gender, ethnicity and housing tenure (apartment, government housing, etc.). A breakdown of the demographics of each jury is not available. However, juries were intended to be statistically representative of the communities from which they were created.
- 4.6. ***Research Institute for Citizen Participation and Planning Procedures, Germany.*** Jurors were selected at random from the electoral register without any affirmative action to include particular groups, and therefore were usually reasonably balanced in terms of age and occupation. Despite the random selection procedures used, planning cells are surprisingly representative of their geographic areas with respect to age and occupation.
- 4.7. ***Jefferson Center for New Democratic Processes, USA.*** The method used to recruit jurors has changed with experience. Early fears that there would be insufficient interest meant that telephone surveys were supplemented by local recruitment meetings. The idea was to guarantee that jurors were sufficiently interested in the issue to want to participate. With more experience came the realization that people were, on the whole, enthusiastic to participate in citizens' juries. Telephone surveys alone are now used to select jurors. Independent companies specializing in telephone surveys carry out the task. Typically, 100 randomly selected people are called to form a jury pool. The day after the initial phone call, a packet of materials is sent to all those who indicated interest in participating in the jury. The packet contains a letter explaining the project, a fact sheet on the project and a form to be filled out for demographic information. The Jefferson Center sets quotas for age, gender, race, geographic location and education, which must be achieved when selecting the final jury. Census material from the appropriate geographic area is used to determine what percentage of the jurors should fill these categories. In addition, one more variable that reflects the general attitude towards the issue is used. Attitudes are measured by opinion polls and jurors are selected to statistically represent the views of the country or region as a whole. A breakdown of the demographics of each jury is not available. However, juries are intended to be statistically representative of the regions from which they were created.
- 4.8. ***The Citizens' Assembly on Electoral Reform, British Columbia (BC).*** The first step of the recruitment process was to update the provincial voters list and to introduce the Citizens' Assembly on Electoral Reform to British Columbians. A media campaign and household mail-outs informed citizens to register or update their address or other information. Next, Elections BC drew a randomized list of 200 names for each of British Columbia's 79 electoral districts. The names were grouped by age (18-24, 25-39, 40-55, 56-70, 71+) and gender to produce a list representative of the provincial population. The 15,800 people on this list were sent a letter introducing the Assembly and providing a brief outline of its agenda. An external contractor was hired to mail the letters on a weekly basis over a period of seven weeks. This schedule coincided with selection meetings (see below). The letters invited recipients to register their interest in attending a selection meeting given by Assembly staff in various communities in the province. The responses from the initial letters were logged by electoral district, age cohort and gender. In those electoral districts that received fewer interested responses, Elections BC produced a second mail-out to 200 randomly selected names. The initial letter, mailed to 200 randomly selected citizens in each electoral district, asked recipients if they wanted to participate in the Assembly process and if they were interested in attending a selection meeting. Of the citizens expressing interest in attending the selection meeting, 10 female and 10 male respondents per electoral district were randomly sent invitations to attend a selection meeting. Following the selection meeting, these individuals were again asked to confirm their willingness to commit to the project and accept the responsibilities of membership. Assembly members were then chosen by lot from this group of attendees. Two members (one male and one

female) were drawn from each of the selection meetings held in the 79 electoral districts of British Columbia for a total of 158 Assembly members. The Citizens' Assembly was broadly representative of the adult population of British Columbia, especially with respect to age, gender and geographical distribution.

- 4.9. **Discussion and Recommendations for the Ontario Citizens' Council.** There are several issues related to recruitment that need to be considered carefully. First is the issue of whether the Ministry itself recruits members of the Citizens' Council or whether it commissions an external agency to do this work. Potential advantages of doing recruitment internally are cost savings and an ability to control the process. Potential disadvantages are that it would be difficult to rebut any suspicion of bias, patronage or "meddling" in the selection of individuals, as well as having little experience in recruiting from underrepresented groups. External agencies may also have more experience and skill at identifying the subtler elements of suitability for membership of a body like the Ontario Citizens' Council. For these reasons, but especially to avoid the appearance of bias or that the members were "stooges", we recommend that the Ontario government commission an external agency to recruit members for the Citizens' Council.
- 4.10. A second issue concerns the level of detail to give, when recruiting, to interested members of the public about the specific mandate and purview of the Citizens' Council. If, for example, the purpose of the Citizens' Council were to be made clear in radio and newspaper advertisements, it is quite likely that the applicant pool would be biased towards those individuals with a vested (or personal) interest in the drug reimbursement process (e.g., members of the public with higher-than-average drug costs). On the other hand, if the purpose of the Citizens' Council is not made clear until after individuals have already joined, there is a risk of recruiting individuals with no interest at all in pharmaceutical formulary decisions. We therefore recommend that initial advertisements state only that the Ontario Ministry of Health and Long-Term Care is looking for members of the public who are willing to be involved in ongoing discussions about governmental policy as it affects the health of Ontarians. We recommend that these initial advertisements not specify that the specific focus of the Citizens' Council will be on pharmaceutical issues. We also recommend that the further particulars provided to applicants give examples of the kind of issues that might be referred (without commitment) to a future Council, and these examples include some pharmaceutical issues but are not exclusively made up of such examples.
- 4.11. A third issue is whether initial recruitment should be passive (e.g., dependent on advertisements) or active (e.g., using techniques such as phone solicitation, mail-outs to randomly selected individuals, door-to-door consultation, etc.). An advantage of passive recruiting would be that participants are more likely to be interested in public deliberation. An advantage of active recruitment is that the Council is more likely to be representative of the public at large. NICE has succeeded with a primarily passive strategy, and we recommend that the Ministry use similar advertisements in widely available media (mainstream and community-based newspapers, television and radio programs, etc.) for its initial recruitment.
- 4.12. The process by which Council members are selected will be among its most important features. One choice that the Ministry will have to make is to decide between selecting "expert members" of the public (e.g., in a manner similar to the Health Protection and Food Branch Public Advisory Committee) or "ordinary citizens" (e.g., in a manner similar to NICE's Citizens Council). We believe that more useful information related to values and societal opinion will be obtained through deliberative discussions held among "ordinary citizens", and therefore recommend that this be an explicit goal for Ontario's Citizens' Council.
- 4.13. We also believe that values and societal opinion can be adequately assessed only if the Council is broadly representative of the Ontario population. For this reason, we recommend that members be selected to approximate the age, gender, socioeconomic, ethnic, and health status distributions of the Ontario population. Because individuals from certain groups (e.g., individuals with low socioeconomic status, certain minority groups, the elderly, the chronically ill, etc.) are probably less likely to volunteer for a body like the Citizens' Council, the Ministry will have to ensure that extra effort is expended to ensure that these groups have adequate representation on the Council.

- 4.14. We recommend that the external agency commissioned to recruit members be given instructions to recruit a group who are not only collectively representative of Ontario's population as described above, but who individually possess personal attributes that are likely to result in them being effective participants in a deliberative process. An important step in the recruiting process ought to be a personal interview with a short list of candidates using pre-arranged criteria. The criteria to be used in moving from the initial list of applicants to successive shorter lists and to the final complement of members ought to be negotiated with an experienced and reputable Canadian agency.

5. Number of Members

- 5.1. **National Institute for Health and Clinical Excellence, England and Wales.** The council contains 30 members.
- 5.2. **Department of Urban Affairs and Planning, New South Wales, Australia.** Juries consist of 12-20 members.
- 5.3. **Health Products and Food Branch Public Advisory Committee, Health Canada.** The Public Advisory Committee may consist of up to 20 members at any one time. In 2004, there were 17 members.
- 5.4. **Institute for Public Policy Research, United Kingdom.** Juries consisted of 16 members.
- 5.5. **Research Institute for Citizen Participation and Planning Procedures, Germany.** Planning cells usually consist of 25 members.
- 5.6. **Jefferson Center for New Democratic Processes, USA.** Juries have 12-18 members.
- 5.7. **The Citizens' Assembly for Electoral Reform, British Columbia, Canada.** 160 people (158 from the initial selection round and two members of aboriginal descent) were selected to participate.
- 5.8. **Discussion and Recommendations for the Ontario Citizens' Council.** In determining the size of the Citizens' Council, a balance needs to be struck between more accurate representation of Ontario's diverse population (a goal which favours a large council) and ensuring the council does not become too large to preclude effective deliberation. Given the experience of others as described above, we recommend that between 15 and 20 individuals be appointed to the Council. We recommend the Council start with 15 members and increase its numbers to 20 individuals if needed.

6. Remuneration

- 6.1. **National Institute for Health and Clinical Excellence, England and Wales.** Members are paid £150 per day. Travel costs and accommodation are covered. Child care support and special help for particular disabilities are provided.
- 6.2. **Department of Urban Affairs and Planning, New South Wales, Australia.** Jury members are paid \$200 for the three to four day jury period. Transportation, accommodation and meals are provided.
- 6.3. **Health Products and Food Branch Public Advisory Committee, Health Canada.** Members are entitled to reimbursement of expenses incurred in relation to their attendance at committee meetings in accordance with the Government of Canada's policy (i.e., travel and accommodation expenses). Members are not remunerated for the time they spend on committee work.
- 6.4. **Institute for Public Policy Research, United Kingdom.** In IPPR's pilot series, citizens were paid £50 per day.
- 6.5. **Research Institute for Citizen Participation and Planning Procedures, Germany.** Each planning cell participant is given a fixed payment as well as compensation for lost wages. Employers are also given compensation payments to fend off opposition to jurors being absent from work. Child care support is also provided.
- 6.6. **Jefferson Center for New Democratic Processes, USA.** Jurors are paid \$75-100 per day plus expenses (travel, accommodation, etc.).
- 6.7. **The Citizens' Assembly on Electoral Reform, British Columbia.** Members received an honorarium of \$150 per meeting day. As well, the cost of travel, food and accommodation for Citizens' Assembly work were covered. In addition, arrangements were made for those with special needs, such as people with child care responsibilities or those requiring physical assistance.
- 6.8. **Discussion and Recommendations for the Ontario Citizens' Council.** Some form of remuneration will clearly be necessary to enable the participation of socioeconomically disadvantaged individuals. Perhaps more important than compensation however are issues like child care support and help for individuals with disabilities. We tentatively recommend a flat per diem in the range \$150-200 per day plus reimbursement for expenses, including transportation, meals, accommodation and child care. Special expenses necessarily incurred by disabled members should be reimbursed and there should be further individualized planning or help for individuals with disabilities as may be required for their attendance. We recommend that further consultation be undertaken concerning the level of remuneration and that this, too, be a matter to be discussed with the arm's length agency used for facilitation and the Advisory Council.

7. Duration of Membership

- 7.1. **National Institute for Health and Clinical Excellence, England and Wales.** Members are appointed for a minimum of three meetings. At the end of the third meeting, ten members (one-third) are randomly withdrawn or “retired” from the Council. The “retirement policy” was implemented to answer the question of how to involve ordinary people on an ongoing basis without capturing them and removing their “ordinariness”.
- 7.2. **Department of Urban Affairs and Planning, New South Wales, Australia.** Citizens’ juries are not ongoing, so membership lasts only for one session.
- 7.3. **Health Products and Food Branch Public Advisory Committee, Health Canada.** Members are appointed for a term of two to three years, which may be extended for an additional term to a maximum period of six consecutive years.
- 7.4. **Institute for Public Policy Research, United Kingdom.** Citizens’ juries were not ongoing, thus membership only lasted for one session.
- 7.5. **Research Institute for Citizen Participation and Planning Procedures, Germany.** Planning cells are generally not ongoing, thus membership only lasts for one session.
- 7.6. **Jefferson Center for New Democratic Processes, USA.** Citizens’ juries are not ongoing. Membership lasts for one session.
- 7.7. **The Citizens’ Assembly on Electoral Reform, British Columbia.** Members were expected to serve on the Assembly for the full 11 months of the project.
- 7.8. **Discussion and Recommendations for the Ontario Citizens’ Council.** The challenge in setting the term length for members of Ontario’s Citizens’ Council is that too short a term would mean too high a proportion of time would be spent on training, and there would be too little time for members to get to know one another well enough to work effectively together. Whereas too long a term would remove the members’ “ordinariness” and result, eventually, in a Council of “insiders”. As a compromise, we recommend a maximum term of three years, with one-third of members retiring each year. Term lengths of the initial Council members could be set at two, three and four years to allow for staggered retirement. The terms should begin at the first meeting rather than when Council members are appointed.

8. Conflicts of Interest

- 8.1. Although not well-described in the literature, interests that conflict with the proceedings of council meetings are expected to be declared by participants. An example of a potential conflict of interest to be declared would be any health problems the council members or their immediate families have. Also, members are prohibited from having any relationship with pharmaceutical companies and must disclose any contact with them. Before appointment, council members should submit conflict of interest declarations regarding any circumstance that may place, or be seen to place, the member in real, apparent or potential conflict of interest. Once proceedings have begun, members should be expected to frequently review their disclosure and declare any changes that may be necessary should their personal situations change or where the matters before the council may affect the interest of a member. Potential conflicts of interest should be assessed by the arm's length agency. If a conflict does indeed exist, the organizing body can decide to exclude the member from the proceedings, in whole or in part, permit their continuing presence but without voice, or other such conventions as may seem appropriate to the chair and organizing agency under the circumstances at the time.

9. Council Member Training and Orientation

- 9.1. Member orientation can take the form of an informal gathering (introductions at dinner) or can be a highly structured process involving intense learning. Both approaches are commonly described in the literature and are important ways of easing participant anxiety over the proceedings of the upcoming meetings. Member training also allows participants to get to know each other and develop a level of comfort and trust with one another. Further, training sessions are a means of disseminating the terms of reference and ground rules of the council, and of briefing members on the context and background of the “content areas” they will be considering.
- 9.2. **National Institute for Health and Clinical Excellence, England and Wales.** New members of the Citizens Council are invited to an “induction weekend” organized by Vision 21 prior to their first Council meeting. The weekend consists of group work, practising debating policies and priorities, and discussing how to question witnesses. For group work, members are initially divided into predefined groups and are later given the opportunity to choose their own groups. This allows members to intermingle as much as possible. Considerable time is spent explaining media behaviour, as council meetings are to be videotaped and publicized. Vision 21 also notes which participants speak less frequently, and offers them more support before their first Citizens Council meeting.
- 9.3. **Department of Urban Affairs and Planning, New South Wales, Australia.** Members are invited to a welcome dinner the evening before the jury deliberation begins. Following introductions, jury members are provided with a detailed outline of the citizens’ jury process.
- 9.4. **Health Products and Food Branch Public Advisory Committee, Health Canada.** Work is taking place regarding how an effective ongoing orientation/training program might be implemented.
- 9.5. **Institute for Public Policy Research, United Kingdom.** Orientation occurred on the first day of the jury session and introduced jury members to the citizens’ jury model of deliberation.
- 9.6. **Research Institute for Citizen Participation and Planning Procedures, Germany.** No information available.
- 9.7. **Jefferson Center for New Democratic Processes, USA.** Jurors are oriented to the jury process on the morning of the first day, and are also provided with the opportunity to introduce themselves to one another. Center staff then review the background of the citizens’ jury process, explain the details of the current project, and distribute guidelines and rules of procedure. A values exercise is also conducted on the introductory morning. Jurors are presented with a fictitious issue to be discussed, with the purpose of encouraging jurors to think in terms of the “common good” rather than private interests.
- 9.8. **The Citizens’ Assembly on Electoral Reform, British Columbia.** Assembly staff made a significant effort to educate Assembly members on the electoral system of British Columbia and other electoral systems used elsewhere (known as the Learning Phase). Over six weekends, Assembly staff introduced members to the deliberative process, explained the electoral system in BC and elsewhere, and provided criteria for assessment and evaluation of various voting systems.
- 9.9. **Discussion and Recommendations for the Ontario Citizens’ Council.** The amount and intensity of training and orientation of council members depends on many factors, including the amount of technical knowledge needed to tackle the issues in question. We recommend a one to two day orientation for new members, both initially and as each subsequent group of Council members is appointed. During this orientation, members could be oriented to content issues (e.g., the health system, the Ontario Drug Benefit Program, etc.) as well as process issues (e.g., how to communicate one’s views effectively in a group, how to question a witness, etc.). A manual should be developed for new members that would brief them on expected behaviour, terms of reference, the conduct of meetings, the history of past meetings and their consequences, and other such matters so that they can be brought “up to speed” as rapidly as possible.

10. Organizer of Meetings

- 10.1. Council meetings are often organized by the sponsoring authority in conjunction with an external organization in order to ensure a fair process, as a guarantee of impartiality and because the external organization has expertise in establishing councils. Stakeholders, and sometimes members of council themselves, also give input into the meeting agendas.
- 10.2. **National Institute for Health and Clinical Excellence, England and Wales.** Vision 21 facilitates council meetings. The meeting design and agenda is a joint effort between Vision 21, the Citizens' Council Steering Committee and the Citizens' Council project manager, a NICE employee. As previously mentioned, the Citizens' Council Steering Committee consists of the chair and vice-chair of the board, a project manager and one other non-executive board member, together with executive directors (for planning, corporate development, communications and clinical).
- 10.3. **Department of Urban Affairs and Planning, New South Wales, Australia.** Citizens' Jury meetings are arranged by a project manager, meeting facilitator and/or chair and an advisory committee. The project manager is an independent consultant who assumes overall responsibility for organizing the jury; he or she encourages the appropriate stakeholders to participate in the project, selects the jury, identifies presenters, provides background information and support to all participants, determines the key question to be put to the jury, addresses issues arising during the process, and provides reports and evaluations of the process. The project manager often has a team of support staff coordinating various aspects of the process. The advisory committee is composed of individuals with various backgrounds who are knowledgeable on the topic and may include stakeholders in the issue. No more than 10 people sit on the Advisory Committee; its role is to provide advice concerning the terms of reference, agenda, selection of expert witnesses, etc. The advisory committee is supposed to help the project staff avoid bias and help to ensure independence and credibility. The meeting facilitator is an independent and neutral individual who manages the group dynamics and supports the jury. The meeting chair, who is also independent, manages expert presentations and discussion sessions. The chair is responsible for timekeeping and ensuring that presenters remain focused on key issues. The role of the chair is sometimes combined with the role of the facilitator.
- 10.4. **Health Products and Food Branch Public Advisory Committee, Health Canada.** Public Advisory Committee members and Branch staff are canvassed for agenda items at least six weeks in advance of regularly scheduled meetings. The agenda is developed by the chair, in collaboration with Health Canada staff. Meetings are facilitated by an independent facilitator, who works with Health Canada staff prior to each PAC meeting to clarify expectations and suggest processes that will help the panel to provide focused, useful input.
- 10.5. **Institute for Public Policy Research, United Kingdom.** An advisory board, made up of key stakeholders on a given topic, is created to oversee the development of meeting agendas and the selection of witnesses. The board's role is to ensure that all viewpoints are given a fair hearing. To secure the independence of the jury process, an external professional organization is commissioned to develop and oversee guidelines, and a team of two moderators runs the meeting itself.
- 10.6. **Research Institute for Citizen Participation and Planning Procedures, Germany.** The Research Institute, in conjunction with government sponsors, sets the meeting agenda. Staff at the Institute research the subject at hand, prepare written background information, brief jurors and witnesses about procedures, and make sure that all parties have received the necessary material. A project manager is appointed from the Institute staff and is responsible for each project. Roles of the project manager include designing the project, planning the sequence of events, deciding what information should be used and how it should be presented, and maintaining contact with the sponsor, experts, the press and public institutions. Another manager is responsible for inviting and securing the participation of all those involved in the project. For the deliberation session, two to three moderators are used. Moderators do not instruct jurors or lead them in any way. Their purpose is solely to

facilitate discussions. They are also responsible for keeping time, and making sure that all viewpoints receive equal time and consideration. Moderators are required to have specific knowledge of the topic in question.

- 10.7. **Jefferson Center for New Democratic Processes, USA.** Each jury has a project manager who oversees the entire project, assisted by project staff. Project managers and staff are independent from the sponsor of the citizens' jury project and are generally employees of the Jefferson Center. In addition, the Center establishes an Advisory Committee consisting of individuals knowledgeable about the issues at hand. Their role is to ensure that project staff are aware of and understand the different perspectives and the relevant issues to ensure that an appropriate issue, agenda and witness list can be developed. A working group is also appointed to work closely with the sponsor. The function of the group is to ensure that the project plan fulfills the needs and aims of the sponsor. Essentially, the working group is the "middle man" between the sponsor and the project staff. An "oversight committee" at the Jefferson Center monitors the entire process and ensures that it is not manipulated by any group or individual. One or two moderators are used at each session. The moderator acts as a recorder of the jurors' views; he or she asks each juror in turn to explain their position on a particular point and summarizes it so all jurors are aware of each other's opinions.
- 10.8. **The Citizens' Assembly on Electoral Reform, British Columbia.** Gordon Gibson, a prominent British Columbian with extensive experience in the areas of politics, public policy, federalism, governance and aboriginal relations, was appointed to make "recommendations for the appointment, size, composition and administrative structure of the Citizens' Assembly." The Special Committee on the Citizens' Assembly on Electoral Reform (a special committee of the Legislature) was established to review the appointment of the Assembly chair and senior staff appointments, and to receive interim reports from the chair on the progress of the Assembly's work. The government nominated the Assembly chair (Jack Blaney, a retired university president), who worked in conjunction with the Special Committee to discuss senior staffing appointment criteria. The chair was also responsible for providing overall leadership and direction for all phases of the Assembly; maintaining contact with Assembly members, the Special Committee, government, media, the public and other jurisdictions; developing policies and procedures for the operation of the Assembly; and, chairing all meetings of the Assembly. A chief research officer, confirmed by the Special Committee, was appointed to plan and implement the Learning Phase of the Assembly's work, while an associate research officer prepared, developed and presented learning materials during this phase. Thirteen facilitators, graduate students from the University of British Columbia and Simon Fraser University, were recruited to ensure all members were fully involved in the discussions groups, to record discussions and summarize group conclusions, and to provide additional background information where necessary.
- 10.9. **Discussion and Recommendations for the Ontario Citizens' Council.** We strongly recommend that the Ministry hire an independent organization to facilitate meetings of the Citizens' Council. Possible organizations include Canadian Policy Research Networks (CPRN), the University of Toronto Joint Centre for Bioethics (JCB), EKOS Research Associates, or any other organization with expertise in the area of meeting-facilitation and/or policy research. CPRN aims to "create knowledge and lead public dialogue and debate on social and economic issues important to the well-being of Canadians", and has significant experience in holding roundtables, workshops and similar meetings. The JCB studies important ethical and health-related topics and represents the largest multidisciplinary group of bioethicists in Canada. EKOS specializes in public opinion research, communications advice, program evaluation and human resources research. Hiring an external organization will undoubtedly require additional expense but it is crucial if both members and the wider public are to view the Council as having a credible and independent voice. In addition, an external organizer can possess special expertise in meeting facilitation and evaluation. For these reasons, the facilitator should be advised by a standing Advisory Council comprising Ministry staff and members of the Committee to Evaluate Drugs and Cancer Care Ontario, as well as independent experts in pharmaceutical policy and/or public engagement in health care. The Advisory Council could help with the selection of expert witnesses, agenda setting, etc. For the council chair, we recommend an individual with a commitment to public life with a reputation for being impartial, committed and neutral rather than political. This person should be free of all conflicts of interest,

preferably in the past and at present. The Advisory Council could put forward a short list of names for the Minister to choose from for the final selection of the Council chair.

11. Questions for the Council to Debate

- 11.1. The clarity and relevance of the questions put to the citizens' council are critical to its success. Most commonly, it is the commissioning body in conjunction with stakeholders who are responsible for this task. The following section gives insight into who will identify key questions and how they will do so.
- 11.2. **National Institute for Health and Clinical Excellence, England and Wales.** The topic to be debated at each Council meeting is set by the Institute, with significant input coming from the Citizens' Council Steering Committee and the Appraisals and Guidelines Committees. NICE hosts in-house topic-setting workshops (attended by NICE board members, senior staff, members of advisory committees, Vision 21 directors, etc.) and examines past Citizens' Council reports for emerging themes to be further explored. A topic can on occasion be considered by the Council for two or more meetings if it is sufficiently complex and important, or if initial discussions reveal a wider agenda than can be embraced at the initial meeting.
- 11.3. **Department of Urban Affairs and Planning, New South Wales, Australia.** The "charge" set to the panel takes the form of a question or series of questions that jury members attempt to answer. Often the question is offered by a governing body and is developed in conjunction with the advisory committee and must be accepted by stakeholders. Key questions usually concern controversial issues, legislation or decisions that need guidance through societal values and opinions.
- 11.4. **Health Products and Food Branch Public Advisory Committee, Health Canada.** Key questions can be submitted by PAC members or the HPFB. The Assistant Deputy Minister and Branch Executive Committee make the final decision about topics. To date, the PAC has advised HPFB on integrated planning, strategic directions and discussed policy consequences of various possible decisions.
- 11.5. **Institute for Public Policy Research, United Kingdom.** The commissioning body (e.g., local health authority) of each jury selects the topic to be addressed. Questions chosen for consideration are complex, "live topics" of interest to the health authority.
- 11.6. **Research Institute for Citizen Participation and Planning Procedures, Germany.** Government bodies are encouraged to submit proposals for possible key issues to the Research Institute. Institute staff decide on the question in conjunction with the sponsoring government organization. Although key questions currently reflect the interests of existing political institutions, the Research Institute is considering developing a process through which individual citizens can bring new issues forward. Generally, policy dilemmas where solutions have been difficult to find are chosen as issues for deliberation.
- 11.7. **Jefferson Center for New Democratic Processes, USA.** Project staff usually draft a preliminary charge or key question after consultation with the sponsors. The draft is then revised and refined after further consultation with sponsors, partners and advisory committee members. The sponsoring organization seeks the advice of a citizens' jury when they are faced with a dilemma requiring public guidance.
- 11.8. **The Citizens' Assembly on Electoral Reform, British Columbia.** The question of examining the current electoral system and possible alternatives to it was asked by the provincial government of British Columbia.
- 11.9. **Discussion and Recommendations for the Ontario Citizens' Council.** Deciding what questions a citizens' council will address is obviously an important consideration. When the question presented to a citizens' council is too broad (e.g., when NICE asked its Citizens' Council to recommend what should be taken "into account when making decisions about clinical need"), council members may feel that there is no overall direction to their deliberation. Conversely, posing too narrow a question leads to an overly restricted discussion, with council members feeling they are unable to explore

issues of equal or greater importance. One way of making sure that the questions put to the Council are phrased at the right level of specificity is by providing members with a context for the decisions that might be informed by their answer, and the reasons why decision-makers need an answer from the Council. With an ongoing Council, members may also engage in a dialogue with the Advisory Committee regarding potential key questions. A dialogue will provide Council members with an opportunity to express their concerns and reactions to the question, and also ask for clarifications. We therefore recommend that the questions to be discussed by the Citizens' Council be decided by the Advisory Committee after consultation with stakeholders and the Citizens' Council.

12. Content of Meetings

- 12.1. The following section describes the basic proceedings of a typical citizens' council meeting. In general, meetings consist of presentations by various stakeholders, question and answer sessions, small and large group discussion, and review sessions.
- 12.2. **National Institute for Health and Clinical Excellence, England and Wales.** Citizens' Council meetings consist of witness presentations, questions to witnesses, small group work and review sessions. The amount of time spent on each varies with each meeting. During coffee and lunch breaks, members interact informally and reflect upon the issues. A "logic observer" (a.k.a., "living dictionary") is on hand to answer any questions about the health system. Witnesses present various perspectives on the topic in question. External speakers, apart from witnesses, explain the background to the question in consideration. In general, witnesses speak for 20-40 minutes either in lecture style or interactively, using an overhead projector or PowerPoint display and sometimes using video presentations. Witnesses may conduct case study exercises with Council members to explore, for example, the differences between value-based and evidence-based issues. For example, to answer the question "What should NICE take into account when making decisions about clinical need?", one witness explored the case history of a real patient and the various aspects of her illness, including features of the disease, impact on quality of life, treatment costs, etc. Feedback from Council members indicates that lay witnesses (such as patients) are most effective and that expert witnesses often mistakenly assume the audience is at a postgraduate or undergraduate level. Since Council members will often have little background knowledge on the issues, a basic level of presentation is preferred. In addition, witnesses who are very clearly positioned, pro or con, on the dilemma in question are better understood by council members and their points of view (as well as their biases) are easily seen. After listening to witnesses, members can question them. Question and answer sessions normally last 30 minutes and are chaired by Vision 21.
- 12.3. Small group sessions are used for members to work on tasks such as formulating questions to witnesses, developing role-plays and working through case studies aimed at helping them to focus on the topic. In one role-play, members were asked to distribute a grant allocation from a local health board that had money to spend on new treatments. Groups took turns preparing arguments for why they were the ones to be awarded the money while the rest of the council acted as a decision-making subcommittee. Small groups vary in size and composition, ranging from groups of two or three individuals to larger groups of 10 to 15. Activities in twos and threes include working on a particular part of the question or topic, reviewing previous sessions and coming to some conclusions about their recommendations for the report. Members can also nominate their own topic to be discussed during small group sessions if they feel that a relevant aspect of the issue has been omitted.
- 12.4. Deliberative facilitation is a key aspect of meetings, particularly in review sessions. The facilitator challenges the Council to identify and focus on key issues and differences in opinion, pulling these out wherever possible. At strategic points in the meeting (typically at the end of each day) and after a period of small group work, the Council as a whole can review progress. Sessions may focus on evaluating and recording evidence presented by witnesses and fleshing out recommendations for the final report.
- 12.5. A significant portion of the first few Citizens' Council meetings was spent discussing the *process* of the meetings, such as the organization of the meetings by Vision 21, discussion about the task itself and how best to organize things—talk that often occurred when the members were struggling with their task, trying to work out what they should be doing or were unhappy about procedures. Input from members often shape how tasks are structured and carried out. For example, the first few meetings were overloaded with witness presentations (e.g., the first meeting had 10 presentations), leaving jurors overwhelmed with information. Complaints were fed back to the organizers and future meetings contained fewer witness presentations and more opportunity for interactive learning via role-plays, group work, case studies, etc.

- 12.6. Following evaluation of the first few Council meetings, evaluators determined the criteria listed in Exhibit 12.1 for what does and does not work for the NICE Citizens' Council.

Exhibit 12.1. What works and what does not work in the NICE Citizens' Council process

What works	What does not work
<ul style="list-style-type: none"> • Yes/no concrete dilemma 	<ul style="list-style-type: none"> • Convoluted question with different facets and qualifications
<ul style="list-style-type: none"> • Personal engagement and individual stake in the discussion 	<ul style="list-style-type: none"> • Climate of disengaged and abstract general debate
<ul style="list-style-type: none"> • Clarity of the aims for the event and good mesh between aims and activity design 	<ul style="list-style-type: none"> • Confusion over aims
<ul style="list-style-type: none"> • Careful application of the Citizens' Council format. Testing whether its elements are appropriate for the goals of the deliberative assembly desired. 	<ul style="list-style-type: none"> • Loose usage of the Citizens' Council format (witnesses and witness questioning)
<ul style="list-style-type: none"> • Size designed for deliberation rather than population representativeness 	<ul style="list-style-type: none"> • Larger size
<ul style="list-style-type: none"> • Deliberative AND inclusive facilitation practices. Inclusive facilitation alone does not allow for argument and challenging of opinions. 	<ul style="list-style-type: none"> • Entirely inclusive facilitation, where everyone receives an equal opportunity to speak
<ul style="list-style-type: none"> • Interactive witness sessions 	<ul style="list-style-type: none"> • Witness lectures with no question-and-answer sessions
<ul style="list-style-type: none"> • Clearly positioned witnesses with the information being balanced overall 	<ul style="list-style-type: none"> • Witnesses adding too much complex detail at points where the basic dilemma is not clear
<ul style="list-style-type: none"> • Good mix of plenary and small group work to encourage inclusive practice across gender, age, ethnicity and disability 	<ul style="list-style-type: none"> • Small group work sessions insufficiently facilitated to enable members to contribute effectively to the meeting
<ul style="list-style-type: none"> • Activity-led review sessions 	<ul style="list-style-type: none"> • Review sessions that simply reiterate main points
<ul style="list-style-type: none"> • Involvement of the parent organization and clarity over the role of the Council in relation to the parent organization 	<ul style="list-style-type: none"> • "Watchdog" mentality and suspicion of the parent organization if acting as an advisory group
<ul style="list-style-type: none"> • A mesh between report style and procedures to reach recommendations (e.g., if the report is to reflect individual views, polling of councillors is a good practice) 	<ul style="list-style-type: none"> • Recommendations emerging from uncoordinated reviewing of evidence
<ul style="list-style-type: none"> • Clarity and transparency about the kind of report wanted 	<ul style="list-style-type: none"> • Confusion over the type of report required

- 12.7. **Department of Urban Affairs and Planning, New South Wales, Australia.** The panel's task is to present the views and recommendations of informed members of the public on the issue in question. Any one citizens' jury may include the following components: discussion of background material, witness presentation, small or large group deliberation, brainstorming and preparation of reports. An independent consultant familiar with the content and key arguments surrounding the issue is available for questioning to assist the jury in understanding the views of different stakeholders. Written information is provided as impartial background material and is usually compiled by the project manager with input from various stakeholders. In some cases, provision of material is outsourced to independent journalists or writers. Background information should define the issue, outline the "charge" and terms of reference, and provide information such as criteria for assessing options or models presented by witnesses and details on where to seek further information. Key arguments "for" and "against" the issue in question are also presented in the document.
- 12.8. Witnesses and experts give a brief presentation representing a variety of opinions and perspectives and answer questions from the jury after. Individuals knowledgeable about the issue serve as experts who provide in-depth information about various aspects of the issue. Emphasis is placed on the interactions between jury members and witnesses and their questioning of the arguments. Witnesses may be called again by the panel at a later stage of the session to clarify any issues. Presenters provide a brief written summary of their presentation for the benefit of the jury.
- 12.9. **Health Products and Food Branch Public Advisory Committee, Health Canada.** Meetings are rooted in dialogue-based processes that generate discussion. Discussions are open, acknowledging the emotional and cultural components of issues, while bringing underlying assumptions to the surface and stimulating creative thinking. At the discretion of the PAC and with the approval of the chair, interested parties may be invited to make representations to the PAC in writing or in person. The Assistant Deputy Minister may, in consultation with the chair, grant observer status to selected individuals including Branch staff who would benefit from the deliberations of the Committee. Generally, meetings consist of presentations by key stakeholders, questions to presenters, discussion and deliberations about key issues, and sometimes field trips to laboratories to improve knowledge on the issue being discussed. PAC members are provided with comprehensive binders of information at least two weeks prior to each meeting. Key feedback for the topics explored in the previous PAC meeting is delivered by a representative from the Office of Consumer and Public Involvement.
- 12.10. **Institute for Public Policy Research, United Kingdom.** In order to help juries understand and answer the question put before them, they are briefed about the background to the question through written information and oral evidence from witnesses. Witness presentation often consists of a case study to provide a concrete example of the issue in question. Jurors scrutinize the information, cross-examine witnesses and discuss the different components of the question in small groups and plenary sessions. The jury's verdict need not be unanimous, nor is it binding.
- 12.11. **Research Institute for Citizen Participation and Planning Procedures, Germany.** The general format of planning cells is as follows: presentations by witnesses from both sides, cross-examination of witnesses by jurors, deliberation among jurors (in small groups as well as all together), recall of witnesses if necessary, and coming to a decision or making recommendations about the issue. Witnesses are initially selected by Institute staff in consultation with the contracting government body, but jurors may also select witnesses if they feel they need another expert to testify. Witnesses present oral information supplemented by written information prepared by the Institute. No background information is provided in advance of the sessions. "Specialists" are also present at meetings to answer questions about the issue being discussed and to expand on their own practical experiences of how policy decisions are made. Planning cells are sometimes divided into five groups of five members each. Generally, each group of five is given a presentation by a different witness. The results of each discussion are then presented to the entire planning cell. Since it is problematic to present summarized arguments to the group, more and more experts present to the entire group of 25. Toward the end of the session, each juror comments on his or her own position on the subject

while the rest of the group can query each other's views. Majority decisions are used in the final report, and votes given to different positions are recorded as well.

- 12.12. **Jefferson Center for New Democratic Processes, USA.** Over the days of the jury session, jurors learn about the issue, the underlying topics and the different perspectives from experts and witness presentations. When a highly political issue is addressed with clearly opposing sides, advocates for each "side" (usually members of the Advisory Committee) select their own witnesses to present and argue for their point of view. When the issue is not highly political, advocates are not used and jurors are assisted instead by experts carefully chosen by the Jefferson Center. When a number of different perspectives exist on an issue, a panel can be used for presentations and questioning. Sometimes the Jefferson staff compiles a list of potential witnesses representing different perspectives and gives this list to jurors in case they would like to call another witness at any point during the jury session. Following presentations and questioning, juries discuss and deliberate in both small and large groups to come up with final recommendations. On the last day of the session, the conclusions reached by the jury are presented in a report to the media and the public.
- 12.13. **The Citizens' Assembly on Electoral Reform, British Columbia.** There were three phases to the Citizens' Assembly. After the "Learning Phase" (described above in section 9.8), public hearings were held throughout the Province for members to hear what their fellow citizens had to say about electoral reform. During the third, deliberative phase, the Assembly attempted to reach a consensus and make a recommendation about what type of electoral system British Columbia should adopt.
- 12.14. The model for the deliberation phase used by the Assembly was similar to that of the "Learning Phase", with lecture-style presentations being delivered in plenary sessions followed by small group discussions of 10-15 people. This method of deliberation proved to be effective according to Assembly members and evaluators.
- 12.15. A workshop on dialogue and decision-making was held by Assembly staff, in consultation with the research staff, as well as with three consultants who were experts in dialogue and decision-making processes. The attendees elaborated working principles useful to the deliberative process, recommending that the Assembly start from a clear statement of their values. They accepted the premise that "nothing is decided until everything is decided", which would allow all members to stay engaged in a sustained, step-by-step decision-making exercise.
- 12.16. The deliberation phase occurred over six weekend sessions. Session one summarized the information and viewpoints collected at the public hearings, and reviewed the key aspects of different electoral systems, including the basic values reflected by each system. Session two was designed to help members resolve differences, reach consensus and continue working together. This session was run by an external consultant with considerable experience in group dynamics. Sessions three and four were devoted to narrowing down acceptable alternatives to the Province's current system and voting on the final recommendations for the Province. Members were to determine which system best corresponded to their values, the needs of the Province and the institutional imperatives of the wider constitutional and parliamentary system. Sessions five and six were set aside to discuss the content and design of the final report.
- 12.17. A particularly interesting aspect of the process by which the Citizens' Assembly did its work was the online Discussion Forum. The forum was a member-only section of the Assembly website allowing members to "talk" or "listen". Questions posted on the forum were often brought forward to the weekend sessions or were forwarded to the Assembly's research staff.
- 12.18. The plenary sessions were videotaped by staff from the Centre for Dialogue in Vancouver, where weekend sessions were held. The videotapes were broadcast over the provincial legislature's television service and were also webcast. Judging by the download activity on the site, the webcasts were widely circulated. The public was allowed to attend plenary discussions, but only as observers.

- 12.19. **Discussion and Recommendations for the Ontario Citizens' Council.** Determining how meetings are to be conducted will be crucial in ensuring that the Citizens' Council is equipped to make a valuable contribution to public policy. Ideas that work in other jurisdictions for other questions may need to be modified for the purposes of deliberating over drug policy in Ontario. One question that must be addressed is whether or not written information should be provided in advance. Given the complexity of pharmaceutical decision-making, we support providing Council members with brief, easily understandable written documentation in advance of Council meetings. This documentation should be concise, adequately supported by graphic elements, and should be written so that it can be easily understood without special technical knowledge. To ensure that all Council members have had an opportunity to digest this information prior to deliberation, we recommend that each meeting start with a session reviewing the background material.
- 12.20. Experience with citizens' councils in other jurisdictions has shown that deliberation is more easily achieved in small group settings. To promote deliberation, we recommend the use of frequent small group sessions (with activities such as role-plays) during Council meetings. Experience has also shown that members may be excessively deferential to witnesses and experts, probably because they appear to be powerful and are often highly articulate. A brief presentation from a witness, followed by small group sessions where Council members can discuss what questions they would like to propose to the witness and why, might help with the process of deliberation and with overcoming the natural authority of the witness. Witnesses and experts will be required to disclose any conflicts of interest prior to addressing the Council. Guidelines for witness presentation should include a time limit for presentations, submission of paper copies of the presentation and information about the focus of the presentation.
- 12.21. Council members should also have some say in the selection of witnesses. In advance of meetings, it may be feasible to use e-mail or other communication modalities to share with Council members the list of proposed witnesses. Council members could provide suggestions for the kinds of witnesses they would like to see added to the list. Similarly, during a meeting it may become apparent that a particular perspective would be helpful. Council members should be able to ask that a witness with that perspective be called. Logistically, however, it may be difficult to procure such a witness on extremely short notice. This is why deliberation may need to extend beyond one session. By whatever means are practical, however, we recommend that Council members be able to help choose witnesses and expert presenters.

13. Meeting Outcomes

- 13.1. This section details the methods by which council recommendations are compiled and publicized. Specific information regarding the impact of each council on their respective governing bodies is described in section 16, Assessment and Evaluation.
- 13.2. **National Institute for Health and Clinical Excellence, England and Wales.** At the end of each three-day Citizens' Council meeting, a formal report is drafted by Vision 21. The aim of the report is to capture the "patchwork" of social values present within the council, paint a clear picture of minority views and describe how members change their opinions as deliberation continues. Council members spend a significant portion of meetings working on recommendations and drawing out the reasons behind members' decisions. Individual writing tasks and small group work helps make this task more manageable for facilitators. Small groups report their recommendations in a final plenary session, while individual writing tasks enable facilitators to systematically incorporate individual views into the report. Vision 21 rapidly completes the draft report in the days immediately following the Council meeting. The draft is circulated to Council members, who can suggest editorial changes prior to approving the report. Once finalized, reports are distributed to NICE and are posted for the public on the NICE website.
- 13.3. **Department of Urban Affairs and Planning, New South Wales, Australia.** Following final deliberations, the jury releases its findings and recommendations in a public forum. The jurors develop and write the recommendations and present the report to the decision-making body. The project managers follow up with the jury, keeping them informed of the outcomes of their recommendations while accurately representing jury findings to governments. The project managers also ensure that recommendations are given the agreed-upon publicity by the sponsors. A public explanation of what will happen as a result of the jury is also given.
- 13.4. **Health Products and Food Branch Public Advisory Committee, Health Canada.** The PAC chair prepares minutes of the meeting, which aim to effectively summarize the proceedings and to reflect advice offered. Comments from individual members are unattributed unless the member indicates he or she wishes to be noted by name in the minutes. HPFB staff distribute the minutes to PAC members, and after approval by the chair and the Assistant Deputy Minister, they are posted on the Health Canada website.
- 13.5. In addition, the PAC secretariat prepares a report after each meeting summarizing the feedback from the committee and program staff. The executive secretary presents this information to the HPFB Executive Committee. Suggestions from PAC members and Branch staff regarding future topics for deliberation are also presented. For example, at a meeting looking at antimicrobial resistance, PAC members highlighted other health-related issues taking place in their regions such as internet pharmacies and the recent agreement of Central Canadian broadcasters to advocate for the ban on direct-to-consumer prescription drug advertising to be lifted.
- 13.6. **Institute for Public Policy Research, United Kingdom.** The full deliberations of each jury are transcribed and drafted into a report. The report is agreed to by all jurors before being published and submitted to the commissioning authority. Following distribution of the report, the commissioning body is expected to publicize the jury and its findings, to respond within a set time and either follow its recommendations or explain publicly why it did not.
- 13.7. **Research Institute for Citizen Participation and Planning Procedures, Germany.** Reports are written by staff of the Research Institute. Reported recommendations must be traceable, meaning that all results are cross-checked with documentation from the deliberation process. All questionnaires, photographs and descriptions used during the proceedings must be included in the report. All those involved in the session receive a copy of the report that they can question for inconsistencies. In Germany, the sponsor is obliged to publicize the results, in official publications, and in local and national media.

- 13.8. **Jefferson Center for New Democratic Processes, USA.** On the afternoon of the final day, the jury presents its findings and recommendations in a public forum. An initial report is issued at this time. The language of the recommendations is developed and approved by the jurors. A final report of the project is completed within three weeks of the hearings. All recommendations included in the report are approved by the jurors in advance. The final report also includes additional information about the project. All final reports are made available to the public.
- 13.9. **The Citizens' Assembly on Electoral Reform, British Columbia.** The final report was drafted by Assembly staff and approved by Assembly members. The recommendations of the Assembly were communicated to the wider public via the Citizens' Assembly website and the media.
- 13.10. **Discussion and Recommendations for the Ontario Citizens' Council.** For some citizens' councils, members themselves write reports summarizing their discussions and presenting their recommendations. For others, drafts of the report are prepared by the facilitator. For the Ontario Citizens' Council, we recommend a collaborative approach where the facilitator prepares the first draft and Council members are invited to submit editorial changes. The report should include a detailed analysis of why members felt the way they did and how their views changed as a result of what they heard and discussed at the meeting. Ideally, summaries of the presentations from expert witnesses should be included as appendices. An example of an effective report is the report from NICE's Citizens' Council's deliberation on "the rule of rescue" (available at <http://www.nice.org.uk/page.aspx?o=332563>). Although we would not expect all Council members to agree on the actual recommendations themselves, the vast majority should be able to agree that the content of the report accurately reflects the content of the meeting. We therefore recommend that the content of the final report, including any notes of dissent from the majority view, be required to have the approval of a supermajority of Council members (e.g., 80%). Furthermore, we recommend that the Advisory Council and the Ministry, in conjunction with the Citizens' Council itself, design a plan for promoting the Council to the public and disseminating its reports. The Citizens' Council itself, for example, may wish to decide how it interacts with the media (e.g., through the facilitator, Ministry Staff, or by appointing a small number of spokespeople at each meeting). Although we believe that richer deliberation will occur if meetings are closed to the public (and to the media), we recommend that meetings be publicized and that agendas, backgrounders and meeting reports be made publicly available on the Ministry website. As one of the goals of the Citizens' Council is to increase public engagement beyond that of the Council itself, promoting and publicizing the work of the Council will likely be beneficial and will lead to a wider public understanding of the complexities involved in making decisions relating to drug policy.

14. Meeting Frequency and Duration

- 14.1. Each of the organizations we evaluated has a different frequency and duration of meetings:
- 14.2. **National Institute for Health and Clinical Excellence, England and Wales.** Council meets two to three times a year, in public, for three days (Friday, Saturday and Sunday) on each occasion.
- 14.3. **Department of Urban Affairs and Planning, New South Wales, Australia.** Jury sessions are held on an “as needed” basis and take place over three to four full days on each occasion.
- 14.4. **Health Products and Food Branch Public Advisory Committee, Health Canada.** Meetings occur three times per year for a two-day period (Saturday and Sunday).
- 14.5. **Institute for Public Policy Research , United Kingdom.** Jury sessions were non-continuous and took place over four days on each occasion.
- 14.6. **Research Institute for Citizen Participation and Planning Procedures, Germany.** Planning cells are held on an “as needed” basis for a one-week period.
- 14.7. **Jefferson Center for New Democratic Processes, USA.** Juries are held “as needed” for a period of four to six days.
- 14.8. **The Citizens' Assembly on Electoral Reform, British Columbia.** The “Learning Phase” took place on six alternating weekends beginning in October 2003. Following the “Learning Phase”, assembly members served on the various public hearing panels for two months. They then met again for the “Deliberation Phase”, which took place again on six alternating weekends.
- 14.9. **Discussion and Recommendations for the Ontario Citizens' Council.** Citizens' councils in other jurisdictions meet anywhere from once to several times per year, depending on the issue being discussed and the nature of the council. For citizens' councils to be able to offer meaningful, ongoing input on complex health-related issues, they likely need to be able to meet several times per year. We recommend that the Ontario Citizens' Council meet three to four times per year initially, and that this frequency be reassessed after one year.

15. Meeting Location

- 15.1. **National Institute of Clinical Excellence, England and Wales.** Meetings are held in hotels in different locations across England and Wales.
- 15.2. **Department of Planning, New South Wales, Australia.** Meetings are held in a central location in Sydney.
- 15.3. **Health Products and Food Branch Public Advisory Committee, Health Canada.** At least one meeting a year is held outside of Ottawa, to accommodate the various regional backgrounds of PAC members.
- 15.4. **Institute for Public Policy Research, United Kingdom.** Juries are held in central locations in the respective health authority districts.
- 15.5. **Research Institute for Citizen Participation and Planning Procedures, Germany.** No information provided.
- 15.6. **Jefferson Center for New Democratic Processes, USA.** Juries are held in a central location in the respective regional districts.
- 15.7. **The Citizens' Assembly on Electoral Reform, British Columbia.** The "Learning and Deliberation Phases" were held at Simon Fraser University's Centre for Dialogue in downtown Vancouver. Public hearings were held in central locations in each electoral district.
- 15.8. **Discussion and Recommendations for the Ontario Citizens' Council.** To promote regional representation and also to ensure that the perspectives of Ontarians from around the Province are being considered, we recommend that the Citizens' Council meet at various locations around Ontario. For the first year, we recommend that one or two meetings be held outside Toronto. The long-term goal should be to hold meetings in as wide a variety of locations as possible. We recommend that meetings be closed to the public due to logistical concerns and the potential for Council deliberations to be muted as a result. Members of the council should be physically present at meetings, rather than phoning in to meetings, as a part of their commitment to the Council.

16. Assessment and Evaluation

- 16.1. The value of citizens' councils depends upon the method of citizen selection, the adequacy of the exploration, the competence of the citizens, and the avoidance of bias among other factors.¹⁵ How well the report summarizing the deliberation is constructed and disseminated also reflects the value and success of the council. While there is no shortage of articles describing the advantages and disadvantages of different types of public involvement in rationing decisions, much of this literature focuses on the processes concerned, rather than the outcomes of the exercise.²⁰ The organizations included in this report employed similar methods of evaluation for their efforts, but interpretation of the evaluation is markedly different. One common, yet limited measure of success is participant reactions to the process of deliberation. Enthusiastic and committed participants are considered one measure of success.
- 16.2. **National Institute for Health and Clinical Excellence, England and Wales.** NICE has adopted a reflective developmental strategy that extends to its Citizens' Council. Structures and processes are under constant review, documents are always "living documents", and guidance is open to appeal and eventual review. Specific evaluation of the Citizens' Council was undertaken in 2003 after three full Council meetings were completed. The study was an independent evaluation, commissioned by NICE in association with the National Coordinating Centre for Research Methodology, of the NHS Research and Development Program. The evaluation team used expertise from a number of social science disciplines including social psychology, sociology, organization studies and health policy to develop a qualitative and ethnographic research design. The study offered a meaningful account of the changing thinking of NICE and the NHS as it initially shaped the initiative, before-and-after analysis of the perceptions of the Council members and a description of Council activity based on close observation of the proceedings of the first three Council meetings. Although there were clearly "growing pains", the evaluators concluded that "given an appropriately concrete question, facilitation which balances the requirements of inclusivity and deliberation, and a properly supported expertise space, ordinary members of the public can contribute to a national level debate", and that "[deliberation] is an option that delivers something different, for example, from a public opinion survey, an advisory group or a stakeholder dialogue."
- 16.3. **Department of Urban Affairs and Planning, New South Wales, Australia.** With the consent of jury members, every meeting of a citizens' jury is attended by an evaluator. The evaluator does not participate in the jury proceedings in any way. Evaluations use both qualitative and quantitative methodologies that include pre-and-post jury questionnaires to assess attitude change, as well as semi-structured interviews with jury members, facilitators and organizers. The results of any independent evaluation are included in the final report. Evaluators have generally concluded that through the citizens' jury process, the community can give meaningful advice on broad issues underlying health resource allocation. Due to the apparent success of these juries, more Divisions of General Practice have sought the community view using a similar process 17.
- 16.4. **Health Products and Food Branch Public Advisory Committee, Health Canada.** At the end of each meeting, PAC members fill out evaluation forms indicating the extent to which the objectives and expected results of the session were clear, the briefing notes and documentation were useful and the deliberative processes enabled them to express their views. They evaluate the Branch in terms of their explanation of how PAC input will be used and their commitment to ensuring that PAC advice would be used. The HPFB personnel who have consulted PAC also complete evaluation forms after the meetings. They clarify the messages they heard from PAC, the extent to which this feedback meets their objectives, what was innovative about PAC's recommendations, and how they intend to use the feedback. They also indicate whether they would consult PAC again in the future. The Assistant Deputy Minister, the Branch Executive Committee and PAC will review the Committee annually to ensure that the Committee continues to meet ongoing needs. Success of PAC meetings is determined by the impact the meetings' conclusions have on the HPFB decision-making processes. Branch policy-making has been enriched by PAC input in a number of ways. A few examples listed in the Public Advisory Committee's 2004 Annual Report include:

- Regarding the issue of antimicrobial resistance, PAC has provided concrete advice on how to communicate to Canadians those actions that Health Canada is taking, and what Canadians can do to increase their awareness of antimicrobial resistance and reduce its spread.
 - The draft “Health Canada Framework on Biotechnology” has been revised to reflect suggestions from PAC. Based on PAC's advice, there are plans underway to create a short, public-oriented communications document to highlight Health Canada's role and the key challenges on the topic of animal livestock cloning for food use. The Food Directorate also plans to explore the possibility of using a “Canadian Biotechnology Advisory Committee (CBAC) Genetically Modified Food and Feed Dialogue Tool” to allow for ethical issues to be examined more thoroughly. This is because the PAC emphasized the importance of further review of the ethical issues surrounding this technology.
 - PAC's advice on various issues has been presented at Health Canada workshops, helping to increase internal awareness of public opinions. For example, the Committee's advice on plant molecular farming (PMF) was presented at Health Canada's policy-making workshop on PMF held in October 2004.
 - The PAC's input on the definitions of transparency and openness helped to shape and ultimately define the terms and principles for the Branch.
- 16.5. ***Institute for Public Policy Research, United Kingdom.*** Jurors' views on both the process itself and the issues to be addressed were obtained using a combination of quantitative and qualitative methods. Key questions asked in assessing the success of the pilot series were: “Have juries altered the policy, behaviour or perception of a commissioning body?” and, “Have they changed the views of the jurors taking part?” The evaluators concluded that the jury process had worked well according to juror and stakeholder reactions and that, in many instances, it had affected local policy.
- 16.6. ***Research Institute for Citizen Participation and Planning Procedures, Germany.*** Participants are asked to evaluate the process, and to assess its thoroughness and objectivity through general discussions during and after the process. While not every proposal by planning cells is feasible to implement, much of its input has guided construction, development, traffic planning and waste management in cities across Germany.
- 16.7. ***Jefferson Center for New Democratic Processes, USA.*** Jurors are asked to complete an evaluation of their project on the last day of the session. The results of this evaluation are included in the public report and news conference announcing the results of the project. Jurors also evaluate the staff and suggest areas of improvement for the future. This evaluation is not publicized. Witnesses and experts also give their evaluation of the part of the project in which they were involved. The most important criteria for evaluating the success of a citizens' jury is ensuring that the jury is managed and conducted in an unbiased manner. The most successful jury organized by the Jefferson Center involved the Minnesota gubernatorial race. Its goal was to rate candidates on where they stood on issues. A review of state print media during the race indicated that half of the articles written on issues were stimulated by the Center's project. It was given the highest fairness rating of any previous Citizens' Jury project. All the jurors were “very satisfied” with the work done by the staff and volunteers in running the project in an unbiased way. Besides juries held on election candidates, citizens' juries have had little impact in the United States. Despite a considerable marketing and outreach effort, very few citizens' juries have been called upon by governing bodies to provide guidance. The result is that in 2002, the directors of the Jefferson Center decided to close the office, let the staff go and reduce the board to only three people.
- 16.8. ***The Citizens' Assembly on Electoral Reform, British Columbia.*** An external consultant was contracted to conduct an evaluation program. Toward the end of each weekend session during the “Learning and Deliberation Phases”, all Assembly members completed a survey. Surveys assessed several things, including the Assembly's success in meeting its process and value norms; staff performance; member satisfaction, and more. Overall, Citizens' Assembly members were very satisfied in terms of the staff (effort and professionalism), their experience (rich and meaningful), the process (fair, transparent and inclusive), and the meaningful mandate of the Assembly (i.e., the opportunity to make a meaningful contribution). Based on the evaluations, the Assembly was successful at meeting all of these measures of success. The Citizens' Assembly report was distributed to all of BC's 1.4 million households in January 2005, and its central recommendation was

narrowly defeated in a province-wide referendum in May 2005. A second referendum will be held in 2009.

- 16.9. **Discussion and Recommendations for the Ontario Citizens' Council.** There are several ways of evaluating the "success" of a Citizens' Council. Process-based evaluations can address whether members, expert witnesses, facilitators, and others involved in the meeting felt that the process was worthwhile. Outcomes-based evaluations can be used to address whether the Council's reports are considered in the decision-making process and whether they actually have an impact on public policy. Finally, an evaluation might even include an assessment of whether the Citizens' Council was having a "spill-over effect", resulting in greater public engagement in general. We recommend that all three types of assessment be adopted through an external review of the Ontario Citizens' Council's work after one year of deliberations, with periodic subsequent reviews. Reviewers should be independent of the Ministry, the external agencies hired for recruitment and/or facilitation, the Committee to Evaluate Drugs, Cancer Care Ontario and the Advisory Council.

17. Conclusion

- 17.1. In this report we have reviewed approaches to citizens' councils in other jurisdictions and recommended options for the Citizens' Council proposed in the *Transparent Drug System for Patients Act*. Our recommendations are summarized in the Executive Summary at the beginning of this document. Based on our review of others' experience and our survey, we believe that a Citizens' Council in Ontario has the potential to be of extraordinary value in helping the Ontario Ministry of Health and Long-term Care to make decisions about drug policy.

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