PET Scanning in Ontario: Deliberations of the University of Toronto Citizen's Council - Recommendations and Lessons Learned

Executive Summary

The University of Toronto Citizens' Council consists of 26 individuals who are broadly representative of the gender, ethnic and socioeconomic characteristics of Torontonians. None are employed in health-care related occupations. The purpose of the Council is to have ordinary citizens deliberate about important, value-sensitive issues in health care, and to comment about those issues.

On January 26 and 27, 2008 they deliberated about the following question: *In your opinion, is the Ontario Ministry of Health and Long-Term Care's (MOHLTC) approach to funding PET scanning a reasonable one and in the best interests of the Citizen's of Ontario? What suggestions for modifications do you have, and why?"*

Ontario has taken a restrictive approach to the funding of PET scanning, limiting MOHLTC reimbursement to patients with a very small number of cancers, or patients who agree to enter five clinical studies designed to assess the usefulness of PET in those particular cancers. This approach has been controversial, with critics asserting that this unreasonably restricts access to PET for Ontarians who would benefit from the technology. The MOHLTC asserts that PET is expensive, the evidence that PET impacts upon clinically important outcomes is weak for most cancers, and that better evidence (which the MOHLTC is helping generate through its studies) is required before PET is made more widely available.

The Council members heard from experts supporting and criticizing the Ontario approach. They were able to ask the experts extensive questions, and deliberated about the question in small group sessions.

There was universal recognition that making resource allocation decisions about PET is not easy. There was not unanimous agreement about the question posed, but the following is a brief summary of the majority opinions (please see the detailed report for more details):

- Basing funding decisions upon high quality evidence that PET benefits patient outcomes is appropriate.
- The initial decision to base the funding of PET scans upon evidence generated by clinical studies funded by the MOHLTC was appropriate, provided that the MOHLTC would also accept high quality evidence generated in other jurisdictions.
- However, it has taken far too long to complete the studies. If the MOHLTC is going to base PET funding decisions upon clinical trials, it should ensure that the studies are completed in a timely manner.

- Although the citizens do not consider themselves qualified to assess the details of the medical evidence in favour and against the funding of PET scans, they wondered if the criteria being used by the MOHLTC might be too rigid, especially given the much more liberal funding of PET in many other jurisdictions.

For more information on the University of Toronto Citizen's Council, please see http://www.canadianprioritysetting.ca/html/citizenscouncil.html.

PET Scanning in Ontario: Deliberations of the University of Toronto Citizen's Council - Recommendations and Lessons Learned

1. Introduction

The Priority Setting in Healthcare Research Group (PSHRG) at the University of Toronto has established a Citizen's Council in an effort to engage the public in the complex issues surrounding healthcare delivery and policy decision-making in Canada. The introductory meeting of the Council addressed the topic of the Ontario Ministry of Health's approach to funding PET scanning, and was held on Saturday January 26th and Sunday January 27th, 2008 at the University of Toronto.

The focus of the first meeting was on the Council members getting to know one another well enough to work effectively together and learning how to improve the public engagement process, in addition to discussing the issue of the Ministry of Health and Long-Term Care's (MOHLTC's) approach to funding PET scanning in Ontario. PET scanning in Ontario was chosen as the first topic for deliberation because it is an issue with current relevance and allows for the formulation of a question that is concrete:

> *In your opinion, is the Ontario MOHLTC's approach to funding PET scanning a reasonable one and in the best interests of the Citizen's of Ontario? What suggestions for modifications do you have, and why?"*

1.1. PET Scanning in Ontario

The Ontario Ministry of Health and Long-Term Care's (MOHLTC's) approach to funding PET scanning has remained a highly contentious issue for nearly a decade. In 1999, the Ontario Association of Nuclear Medicine (OANM) urged the MOHLTC to introduce PET scanning in Ontario for use in oncology, cardiology, and neurology (Council of Medical Imaging 1999). A report by OANM argued that the usefulness of PET for the above indications had been well established.

In response to this communication from the OANM, the Ministry asked the Institute for Clinical Evaluative Sciences (ICES) to conduct a health technology assessment of PET scanning. The ICES report concluded that the quality of evidence indicating that PET scanning has a positive impact upon patient outcomes and clinical usefulness was poor (Laupacis et al. 2000).

On the basis of this and other information, the MOHLTC decided not the fund PET scanning as a routine service. Instead, it indicated it would pay for PET scans for individuals who entered in one of five clinical studies that were designed to evaluate the clinical usefulness of PET in patients with (1) head and neck cancer, (2) women with

breast cancer, (3) early stage lung cancer, (4) Stage III (locally advanced) lung cancer, and (5) colorectal cancer with metastases to the liver.

1.2. Rationale for the Establishment of a Citizen's Council

Public policy decisions in any pluralistic democracy should consider the needs, values, and attitudes of its citizens. However, as it pertains to health care policy, it is well established that policy makers and health care professionals cannot represent the values of patients or lay citizens -- thus direct public engagement is necessary. (Martin et al. 2002) Additionally, public participation can lead to better understanding, greater trust and wider popular support for decisions and, ultimately, an enhanced empowerment of citizens. (Lilley 1993)

In the context of complex value-laden policy decisions, public engagement enhances the *quality* of decisions by bringing to the deliberations the full range of relevant value-considerations. In addition, an open and inclusive process of policy deliberation, involving 'ordinary' citizens, promotes greater approval of controversial decisions and generates greater social cohesion.

There exist several methods of engaging the public in health policy making. The most general level of classification distinguishes between deliberative and non-deliberative processes. Non-deliberative methods are consultative in nature—public input is sought, though not necessarily challenged or modified in response to opposing considerations. Such an approach can be used by a governing body that wants to understand the implications of a decision before the decision is taken. (Davies et al. 2005)

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.

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. 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.

For these reasons, the Priority Setting in Healthcare Research Group (PSHRG) is establishing a Citizen's Council that will adopt the deliberative model of public engagement to learn public opinion about complex health care issues as they pertain to the residents of Ontario and, simultaneously, to learn about the hows and how-tos of public engagement.

1.3. Establishing the Citizens Council

Initial recruitment of the Council members was the responsibility of *Consumer Vision*, a Toronto-based industry leader in market research with a strong record for recruiting members of the public for focus groups and in-depth interviews in the consumer, medical, professional, and business-to-business markets. Initial recruitment was conducted via phone interviews by Consumer Vision staff. *Consumer Vision* selected Citizen Council members from the Greater Toronto Area that approximate the age, gender, education level, socio-economic status, and ethnic background distribution of the citizens of Ontario.

Inclusion criteria included anyone eligible to vote (i.e., anyone 18 years of age or older in possession of Canadian citizenship). Exclusion criteria included healthcare professionals, employees of healthcare professionals, employees or directors of pharmaceutical companies, individuals owning significant equity in pharmaceutical companies, members or employees of political action groups (e.g. patient advocacy groups), members of Provincial Parliament and other elected officials, employees of the Ministry of Health and Long-Term Care, and individuals working for market research, advertising, public media, or public relations companies.

Follow-up phone interviews were then conducted by the PSHRG to ensure suitability for deliberative practice. A total of 26 members were recruited. A flat per diem remuneration of $200 per day was offered to each Council member for participation in the full session. A two-year commitment to the initiative was asked of Council members.

The Council meeting was held over two consecutive weekend days, and included team-building exercises, presentations on opposing viewpoints of the issue at hand by experts in the field, and small group deliberative Council discussion sessions.

2. Meeting Outcomes

The purpose of this report is not only to outline the stance that the Council Members took on the various issues regarding funding PET scanning in Ontario, but also to give a sense of the quality and depth of deliberation that occurred during the first meeting. The Council grappled with a variety of themes related to the approach of Ontario's Ministry of Health and Long-Term Care (MOHLTC) toward funding PET scanners. This section is divided into four parts, each of which describes the Council's deliberations on a different aspect of the topic.

2.1. Background of Diagnostic Imaging and PET Scanning

Drs. You and Moody provided background information about diagnostic imaging in general and PET scanning specifically, including how PET scans differ from modalities such as CT scans and MRI.

The questions and discussions in response to the presentations indicated that members were grappling with practical issues surrounding PET scanning that might impact health policy decision-making, such as the economics, lifespan, and clinical impact of the technology (see Textbox 1 for some examples).

Textbox 1

Question 1

CM: Will PET supersede or supplement the current technologies?

Dr. Y: We talk about that question frequently. If history is a lesson, we won't get rid of the old technology. But one approach that you could take would be to adopt PET if it works better and not pay for CT scans anymore. To be fair, there are some tests we used to do that we don't do anymore due to newer technology.

Question 2

CM: What is the lifespan of these machines? Is it driven by usage or [is] the manufacturer coming out with new models?

Dr. M: Good question - I think the latter more so. The industry standard is approximately 7 years; the clinical standard is about 10 years. The manufacturers sometimes force us to buy new machines because they refuse to service the older models; hence the shorter "forced" industry standard.

Question 3

CM: Given the fact that there are no double or single blinded studies on the efficacy of PET, how does an institution make the decision to purchase this technology and finance the associated costs?

Dr. Y: In a way, the Ministry has taken just that line. They have decided that PET is the line in the sand for which they are going to start asking those questions. Institutions are driven by political pressures. The answers are not clear cut regarding how we go about making those decisions.

CM = Council Member; Dr. M = Dr. Alan Moody; Dr. Y= Dr. John You

While many of the questions asked by the Council members had clear answers, many questions were complex, and often did not have concrete answers. (see Textbox 2 below)

Textbox 2

Question 1
Will the incremental costs of going to this next layer of technology be weighed against how many people will be affected?

Question 2
Of all cancers, lung cancer is a subset. And of all lung cancers, solitary pulmonary nodules are a subset, and I heard that the size of a nodule able to be detected by a PET is pea-sized, or something like that. When does this process stop? Is this a technology chasing a disease?

2.2. The MOHLTC's approach: Initial reactions

On Saturday afternoon, Dr. Laupacis described the rationale behind the MOHLTC's approach to funding PET scanning, while Dr. Driedger described his views about the problems with the MOHLTC's approach. From the discussions that ensued, it was clear that a large majority of the Council members had no prior knowledge of the MOHLTC's approach to funding PET scanning.

Initial reactions to the MOHLTC's approach ranged widely, and members asked questions that would help them better understand the rationale for, and problems with, the MOHLTC's approach. The Council members articulated a number of different values in their comments and questions, such as the whether more public resources should be allocated to health care compared with education.

Textbox 3

Statement 1
Dr. L: The Ministry has decided that at 2.5 million dollars per machine and at 1200 dollars a test, we would like to have really good evidence that [PET] is going to impact patient outcomes before we pay for the PET scan.
CM: I am my own advocate for health care. I would not be happy if you said to me "come back in 6 months and we'll take a biopsy [to see if the nodule is cancer]" because as far as I'm concerned, I've lost a lot of valuable time in the treatment of a potentially life-threatening problem.

Question 1
CM: If the MOHLTC were to theoretically put more money into funding PET scanning, which other areas would it be taken away from?
Dr. L: That's a good question. The reality is that the government could decide to spend more on healthcare than it currently does; for example, when McGuinty said there would be a new health tax. In reality, though, there is a limit to what we can pay for. There isn't an explicit tradeoff… though within the MOH, people who are advocating for family doctors are almost fighting with people who are advocating for more home care, and they are trying to make their case.
Dr. W: to add to that, Ontario spends approximately 50 percent of every tax dollar on health care. What's in the other "pots" is education, roads, etc… just to frame how much we spend on health, and what the tradeoffs of that spending are.

Question 2
CM: How long are we looking at for the results [from the trials looking at the clinical usefulness of PET scanning] to come in?
Dr. L: The results of the two studies that are complete are going to be available in approximately a couple of months. However, it took about 3 to 4 years to enter the patients into those studies, so the whole thing is going to be a 5 to 7 year process. So it's been a long process.

Question 3
CM: Are any of the other provinces doing such studies?
Dr. L: We actually talked to people in Alberta whether they would do it. But, it's very rare for a government to pay to do a research study like this… the Ontario government was not willing to transfer money to Alberta. Ontario is pretty unique, or infamous, depending on what your perspective is on these studies.

Dr. W = Dr. Wendy Levinson

2.3. Small-Group Deliberations

On the second day of the session, Council Members discussed the PET issue in small groups of 8 to 9 people. Members were pre-assigned to create groups that were roughly equal in terms of demographic distribution. The groups were given the following question to center discussion around:

> *Do you think that the MOHLTC's approach to funding PET scanning was reasonable and in the best interest of the Citizens of Ontario? What suggestions for modifications do you have, and why?*

The groups deliberated for between 100 and 115 minutes. Each group was moderated by a member of the organizational team, whose role was to encourage every member's voice to be heard, to answer any factual questions that arose over the course of deliberations, and to bring in the experts (Drs. Driedger and Evans) to answer questions. The moderators were asked to refrain from giving their views or personal opinion on the topic at hand. After all the groups had ended deliberations, group members were asked to present the outcomes of their deliberations to the rest of the Council.

In each of the small group sessions, views on the MOHLTC's approach ranged widely, from strong support to indignation that access to PET was being restricted by the Ministry. However, despite listening to the previous day's presentations, the citizens felt that they did not fully understand the "technical" aspects of PET scanning, and therefore they were reluctant to make specific recommendations about the indications for PET scanning or about the details of Ontario's approach to PET scanning.

Dialogue, for the most part, fell into four major areas of discussion: **(1)** the general approach of the MOHLTC to funding PET scanning in Ontario, **(2)** General thoughts about resource-allocation decision-making, **(3)** The length of time taken by the MOHLTC to assess the clinical utility of PET, and **(4)** Ontario's differing approach to funding PET scanning compared to other jurisdictions.

Though two of the small session groups came to a consensus (that they generally agreed with the MOHLTC's approach to funding PET scanning, but that progress was too slow), different Council Member's clearly had different views. For this reason, a post-meeting questionnaire was sent out several days after the Council meeting. The results of this questionnaire (21 Council members responded) are included in the sections below. The rating scale for each of the recommendations was: 1 – Strongly disagree; 2 – Disagree; 3 – Agree; 4 – Strongly Agree.

2.3.1. The Approach of the MOHTLC

The Council members generally agreed that the MOHLTC's approach to funding PET scanning was a reasonable one, given the high cost of the machines and that the benefits of the technology have not been fully characterized. However, they believed that the evidence-based process should be faster and the range of criteria used to assess the utility of the technology might be too restrictive (Section 2.3.3.).

Textbox 4

Comment 1
I support the Ministry's approach to be prudent because we want to make sure that we are getting the biggest bang for our dollar. So it is not that I am opposed to the spending, if there was compelling evidence that said, you know, the vast majority of people will benefit from this diagnostic tool and that it will have a significant impact on the outcome of their treatment, I would say go ahead and spend the money. We don't know that yet, and so I say take the time to find out rather than just throwing all the money into the pot.

Comment 2
Well, I think that this policy is an example of the government trying to be more long sighted than short sighted. I think in the past, I agree that, you know, a lot of decisions…. have been made for political rather than evidentiary reasons. But, you know, the decision to withhold treatment is never popular. It never serves a politician to do that.

Comment 3
Introducing new technology for its own sake can be an ineffective use of resources. The overall benefits of PET should be reasonably assessed prior to widespread use.

Although two of the three small groups came to a consensus that the MOHLTC's approach was, at the time, "reasonable and in the best interests of the citizen's of Ontario", not all members agreed to the same extent. For example, members had widely differing views on how individual benefits should be weighed against costs to society.

Textbox 5

Dialogue 1

CM1: [We] have CTs and MRIs and all that, and the money has been spent there then—and it's been 100% proven you've got the cancer, and there's treatment available. [If the] outcome [with or without PET] is going to be the same then I would say don't go to PET. Don't spend the money on PET. That's my opinion.
CM2: I would want the PET.
CM1: To indicate the same outcome?
CM2: With my children or my mother, yes… I would feel better… [and] I'd want a second opinion.

Dialogue 2

CM1: How many Canadians have been killed in Afghanistan… by IEDs?
CM2: More than half [of soldiers killed have been killed by IEDs].
CM1: What is the cost of protecting that half, …(about 40 or 50 [people])? 2 billion dollars. Of the 40 Canadians that have been blown up, would we save 100% had we spent 2 billion dollars? No. We will have an 80% solution. So we will save 80% times 40. Thirty people. So are we willing as a society to spend $2 billion dollars to save 30 lives? This is the hard question that no one ever asks.
CM2: Look, I understand the logics of this but… the life savings are there… everybody knows they are expensive machines. But [PET machines] are present even in developing countries. They are trying to preserve the human life at the cost of expense. If these people can do it, why can't Ontario value human life a bit more rather than worrying about the funding formula? The bottom line is human lives are being saved.

Results of the post-meeting questionnaire reflected the range of opinions expressed during the deliberative process; the idea that "The usefulness of PET through research should be assessed before widespread use is implemented" received an average rating of 3.1 ± 0.9[1]

2.3.2. Resource-Allocation Decision-making

The citizens recognized that resource allocation decisions about PET scanning are not easy. On the one hand, they wished to provide more PET scanning because the technology will benefit more people. On the other hand, there was recognition that the use of the resources that would be allocated to PET scanning might produce greater benefits if invested in other aspects of health care, including prevention. There was also a feeling that various parts of the health care system were in unnecessary competition with each other.

[1] The value following the '±' represents one standard deviation.

Textbox 6

CM1
And let me point out an example of your terrible experience with wait times. If that money that would go into PET scans or some other technology was put into…. care at home, by nurses, it would reduce wait times and benefit patients much more broadly speaking than the few people that would be beneficially affected by increased access to PET.

CM2
So how can a person at the top, like a health minister, make a rational decision when no one talks to each other?

Few Council members disagreed with the notion that since funds for public programs are limited, individual benefits and preferences must be weighed against societal cost, and funds are ideally spent to derive maximum benefit for the citizens of Ontario. However, the priorities that determined how these funds should be spent differed from member to member based on the values that the individuals brought to the discussion table. As discussed earlier, some members have family members afflicted with cancer, and others work for public programs other than the healthcare system (e.g. the public school system).

Textbox 7

CM1
There is limited amount of dollars even though it's 53 billion. We don't want to spend more; and let me tell you that I think that if you institute another expensive program, it's at the expense of some other program…The system is already [overburdened]

CM2
It is better to err on the side of caution than to wait a bit too long, and it is too late.

Dialogue 1

CM3: This government is watching the expenditure on health care. I have heard McGuinty say that when he was a backbencher starting in Queens Park it was about 28% of provincial budget. It's now at 50% of the provincial budget is health care and rising. And if we don't put some checks on it, it will be 80%.

CM4: Right.

CM3: And then people ask [the government] to lower taxes. Well maybe worry about your kids going to school and the educational system that's [not working] properly… Because there is only so much resource. We can only tax people so much, and governments have to debate this issue. How much to spend.

CM4: Raising the taxes could be an automatic whether people like it or not… My view on the evidence-based approach is that it's taking so long, and something has to be done because by the time you get the evidence together, it's halfway to obsolete.

2.3.3. Timeliness of the MOHLTC Approach

Comments 1 and 2 below summarize the complaint cited most often by the Council Members: the MOHLTC's approach has taken far too long. On the other hand, as Comment 3 demonstrates, a few members disagreed with this complaint.

Textbox 8

Comment 1
Since the studies are being relied upon to make policy decision, they should happen faster… the length of implementing and getting the results from the trial has taken far too long

Comment 2
The elapsed time of approximately 5 years and the limited number of studies would seem to result in a long delay in achieving the maximum benefit of PET.

Comment 3
Yes I think it's a bit slow but I am okay with the cautiousness of it because we feel that it's possible the money could be better spent. We don't want to take it from something already in place. The point of being cautious is to see if that money should be spent on this. Right now I think the way they are studying it is good. I'm okay with the slowness because I don't want them to just throw money at it if it's not proven.

The members were concerned that since only five studies are being conducted, the longer any one particular study takes to complete, the longer individuals who have indications outside the realm of the initial studies have to wait before the clinical usefulness of PET might be evaluated for their condition. Also, the longer the studies take, the more likely PET technology will have evolved significantly, raising questions about the usefulness of the results once they are available. Members were sympathetic to the criticisms of Dr. Driedger, who indicated that nuclear medicine residents in London, Ontario had to travel to the United States to get trained in PET scanning, because the volume of patients in London wasn't sufficient for their training.

Textbox 9

CM1
…what [the expert speaker] was saying really hit home. You have a new technology. It's constantly shifting. Today it's this way… but tomorrow somebody else next door has a better machine and all of a sudden you can detect even further and [it] does better things. Now, you have a new technology, new questions.

CM2
From my perspective, there is a need for adequate funding of trials. If the government is going to rely so heavily on the trials then it is critically important that they adequately fund those trials and they are resourced enough to be completed in a timely fashion and that they increase the rigor of the evidence.

Some members thought that the Ministry is perhaps being too restrictive about how it is interpreting evidence about the usefulness of PET (CM1 and CM2). Other members suggested that to speed up the availability of PET, it is better to initially provide PET services for a greater number of cancers, and subsequently deny the use of PET if the usefulness is not proven (CM4). However, some members argued against each of these suggestions (CM3 and CM5).

Textbox 10

CM1
If we can broaden the guidelines for which PET can be used, then we can provide more rapid diagnosis and treatment

CM2
I think when you want to expand basically and give more people the benefit of that, I mean, you can't wait until you have 100% evidence. You might never have them because if you have too restrictive policies, people will not even come for scanning then.

CM3
I agree that the scope of research should be broadened to include additional types of cancers, and the research should happen faster, but not at the expense of validity and reliability.

CM3
This will satisfy the two opposing camps involved in the debate, and give PET service to the public at an earlier date.

CM4
It makes much more sense and would be easier on the patient and the heath care system to make sure that the testing that is being sought will actually give useful information. It would waste the patients time and slow down others wait time for PET [if we use PET] on those who won't benefit from it. The trials are necessary

The results of the post-meeting questionnaire reflected the range of opinions expressed during the deliberative process. "The MOH's approach should be modified such that the volume and speed of research to evaluate the usefulness of PET is increased" received an average rating of 3.5 ± 0.7. The recommendation that "The criteria for evidence should be broadened to allow preliminary information regarding the usefulness of PET to be taken into consideration to speed up the availability of PET" received an average rating of 3.2 ± 1.0, while the idea that "It is better to provide PET services for a greater number of cancers, then revoke the use of PET if the usefulness is not proven" received an average rating of 2.7 ± 1.1.

2.3.4. Ontario's Differing Approach Compared to Other Jurisdictions

There was considerable discussion about the fact that residents of Ontario had less access to PET scans than residents of other provinces. Some felt that this put

Ontario citizens at a disadvantage, while others felt that Ontario's cautious approach might be appropriate.

Textbox 11

CM1:
If other provinces… are appreciating the resource, then from my perspective, Ontario is dragging its heels, and that's simply not good enough. And cost, yes, cost is a factor, but the utilization of the machines is suboptimal – If you are only doing 2500 scans a year, I think we should be doing more. And if there is a cost associated with it, then so be it. The decision is, here, we to decide if that money is well spent. And if we come to the conclusion that that money is well spent and increase in number of actual scans, it may save lives. It has to be spent.

CM2:
Well is Ontario lagging behind all the provinces? What are they doing? I think you could say we are lagging behind or we are doing something innovative and that's the biggest difference of view…

CM3
But what I am saying is that if other provinces, such as Quebec and….
Alberta or wherever are appreciating the resource, then from my perspective Ontario is dragging its heels, and that's simply not good enough,…..

CM4
The only point that I try and make is that if other provinces are finding it useful and they are doing studies such as Quebec and Alberta. Now why is Ontario dragging its heels and is it because of a sound policy decision or is it because they don't want to spend the money. I guess those are the 2 questions. But from what I have seen so far, I think they are justified in holding back

CM5
They [developing countries such as India] are trying to preserve the human life at the cost of expense. If these people can do it, why can't Ontario… value human life a bit more rather than worrying about the funding formula?

3. Lessons Learned

The introductory Citizen's Council meeting was as much about learning how to establish and improve the public engagement process as it was about enabling the Council to deliberate in a meaningful way about the MOHLTC's approach to funding PET scanning in Ontario. Accordingly, feedback regarding the process and organization of the introductory meeting was highly encouraged and sought as often as possible, both informally throughout the session, as well as through the use of feedback forms at the end of the weekend. Below are the key learnings regarding the process and organization of the Meeting, including what needs to be improved upon for future meetings, as well as what worked well:

3.1. Areas of Strength

a. **Team-building sessions:** The members were highly appreciative of the "ice-breaker" and team-building sessions that occurred at the outset of the two-day meeting. Members indicated that the sessions enabled them to work better together and become more comfortable with engaging in dialogue during the small-group deliberation sessions.

b. **2-day Format:** Members enjoyed having a break between the first day, which was intended to impart the necessary knowledge in order to enable meaningful discussion (and was thus content-heavy), and the second day, during which deliberations took place. Members appreciated the time to think things through and process the large volume of information presented to them, as most were not familiar with the technology or policy being discussed.

c. **Use of expert presenters:** Members were grateful for the calibre of the expert presenters chosen to deliver the content, for the clear and uncomplicated manner in which the content was delivered, and perhaps most of all, for having the expert presenters being available for questions during the deliberation process.

d. **Small-group sessions:** Members appreciated having the opportunity to deliberate in small groups (8 to 9 people) rather in one large group. It enabled members who were less vocal to voice their opinions with ease, as well as make the deliberation process generally more manageable.

e. **Web-based discussion board:** Members are enthusiastic about using the on-line discussion board, which was constructed for the dual purposes of providing a discussion forum in the interim period between meetings, as well as for creating a central database for sharing resources relevant to the topics for discussion. Member input is highly encouraged and will be used to improve the resource.

3.2. Areas for Improvement

a. **Pre-meeting reading material:** Although none was provided, Members stated that receiving pre-meeting materials in the future will be helpful for the purposes of becoming more familiar with the topic for discussion at hand, and will thereby enable the Members to make more meaningful contributions to the deliberation process. Due to the highly variable quality of resources available on the internet, it was suggested that members of the organizational committee provide links to papers or websites that they deem of appropriate quality and quantity. Nonetheless, Council Members were informed that they are welcome to review materials that are not explicitly provided by or referred to by members of the organizational committee.

b. **Meeting length:** Members indicated that while the session lengths were relatively reasonable (9am to 5pm on Saturday, 9:45 am to 2:30pm on Sunday), they suggested that the first day also be shortened to approximately six hours. Members found that their concentration and level of engagement became sub-optimal after approximately six hours. On the other hand, several members stated that the allotted time for the small group deliberation sessions was not long enough.

c. **Control within Small Groups:** Several members indicated the need for greater control during the small group sessions so that "strong versus soft personalities can equally voice opinions." It is not surprising that several heated discussions took place, since the topic at hand is rather controversial. However, such comments suggest that strong personalities sometimes dominated the conversation, which we would like to prevent as much as possible in the future. While one moderator was present in each small group, they were asked to refrain from getting involved with the discussion process, and were instead stationed to serve as a resource for getting questions answered or calling upon the appropriate expert member to answer questions. In the future, moderators can be encouraged to play a greater role in trying to maintain "order." Alternatively, several members suggested a "Conch" approach to try maintaining a greater sense of order (i.e. only one member is permitted to speak at any given time).

d. **Debate:** Several members suggested that experts who represent different sides of the argument at hand be encouraged to engage in debate against one another. Members articulated that the small group sessions essentially consisted of a series of debates between Members who held opposing views on the subject at hand. However, the debates many times ended at an impasse because neither individual knew enough about the topic at hand to proceed. Thus, observing the experts debate about the issue could possibly elevate the level of deliberation in the small group sessions by bringing explicit arguments for each side to the discussion table.

4. References

Martin DK, Abelson J, Singer PA. Participation in health care priority setting through the eyes of the participants. Journal of Health Services Research & Policy 2002; 7:222-229.

Lilley S. Making it work! Community participation in health planning in Nova Scotia. Discussion paper for the Strengthening Health Partnership of Nova Scotia. Nova Scotia: Dalhousie University. 1993.

Davies C, Wetherell M, Barnett E, Seymour-Smith S. Opening the Box: Evaluating the Citizens Council of NICE. London: School of Health & Social Welfare and Psychology Discipline, The Open University. 2005.

Council of Medical Imaging. 1999, July. "Positron Emission Tomography" [position paper]. Oakville, Ontario.

Laupacis, A., D. Alter, M. Mamdani et al. 2004, May. "Health Technology Assessment of Positron Emission Tomograghy (PET): A Systematic Review." *ICES Investigative Report*. Retrieved January 31, 2008. < http://www.ices.on.ca/file/Health_Technology_Assessment-PET_May-2001.pdf>