REPORT ON
Innovating Health
PUBLIC ENGAGEMENT IN HEALTH TECHNOLOGY ASSESSMENTS AND COVERAGE DECISIONS
ppforum.ca
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About this Report

As Canada continues its national discussion about healthcare, we find ourselves asking some very big questions. How will we continue to pay for universal medical care in Canada? How can we improve standards of service, without overtaxing our public finances? Who holds the ultimate responsibility for improving the Canadian healthcare system – governments, practitioners, patients?

Canada is, without doubt, facing serious public healthcare challenges. Addressing these issues will require fundamental reconsideration of the system. Yet, as we move through this process, there is growing discontent with how some health policy decisions are made. In this report, we explore specifically the implications of health technology assessments – how policy-makers, practitioners, patients and the public are involved in the evaluation of new health technologies and coverage decisions.

Public engagement is a key area of work for the Forum. In the case of health innovation, we believe that public and patient engagement is essential. Throughout this research process, we have encountered time and again the frustrations of the public and policy-makers alike, as they strive to make the public engagement process on health technology assessments more functional, transparent, accountable and efficient. Much work is needed to improve the engagement process, but there is cause for optimism. With a carefully crafted framework, and strong leadership, Canada’s various healthcare jurisdictions can lead effective systems of health technology assessment, and can bring a level of uniformity to the system across Canada.

Innovation, be it in technology or public policy, is never a smooth process. Innovation in an area as fundamental as healthcare, where so many stakeholders have so many critical interests, is bound to be complicated. But, there is a pressing need to strengthen patient-centered healthcare in Canada and change is required. This report provides a window into some of these changes and offers practical guidance to those willing to take the first steps towards innovating health in Canada.

The Forum will continue to explore health innovation in the coming year, and I look forward to working with Canadians from all sectors to advance the mission of more effective and inclusive healthcare systems.

David Mitchell
President and CEO
Public Policy Forum
Executive Summary

Discontent with how healthcare decisions are made and justified is widespread among the public, patients and providers of health technologies alike. The Public Policy Forum held five roundtables across Canada to discuss how public engagement in health technology assessments (HTAs) and coverage decisions can help lead to more transparent decisions that find greater support among all stakeholders.

Several reasons can help explain the current discontent with healthcare decisions:

• A lack of transparency about the criteria used in HTAs and coverage decisions;

• Healthcare decisions replete with significant ethical dimensions;

• HTAs not capturing some costs and benefits of treatments adequately;

• Dissatisfaction with the overbearing influence of cost and budget considerations; and

• A lack of meaningful avenues of involvement for patients and the public.

Bringing public and patient perspectives into the process in a meaningful and transparent way can help address the above issues. Attempts at this have been made in the past, and are currently being experimented with, but often have not been designed and implemented to make a substantial and genuine difference in the process of assessing health technologies and arriving at transparent coverage decisions. Internationally, the United Kingdom, the Netherlands, New Zealand, Australia, and Sweden, among others, have introduced some measures to involve the public in setting health care priorities. In Canada, the most recent initiatives were launched by the Canadian Agency for Drugs and Technology in Health (CADTH), which has aimed to elicit more patient input, and the Ontario Ministry of Health, which has recently established a new Citizens’ Council.

Despite these forays into public and patient engagement, the discussions in this roundtable series demonstrated that a consensus around many crucial questions has not been formed and some essential problems remain unresolved. Notably, participants wondered whether the involvement should target patients or the public at large. Arguments in favour and against both were brought forward and the answer largely depends on the goals of the engagement, with patients better positioned to give specific input on the value of treatments and the public at large being engaged on the values that guide decision making. Regardless of who is engaged, it is generally agreed that involving patients and the public result in better HTA and coverage decisions overall.

A related critical question is whether patients or the public should be involved directly, or if their preferences should be studied carefully and thereby yield information that can be considered in assessment and decision making processes led by experts. Approaches for the study of patient preferences, including citizen juries, focus groups and interviews, are regularly used and are useful tools for getting broad engagement on complex issues.

Whether direct or indirect, patient or public, an unresolved problem persists: so far efforts to engage patients and/or the public have been done without adequate resources. Resources need to be made available to establish and maintain a meaningful process, and to allow patients or members of the public to make informed contributions.
It was also emphasized that deficits exist in the sharing of experiences and best practices between healthcare bodies and jurisdictions. The argument was made that interested institutions are not proactive enough in trying to learn from others with experience in engaging the public or patients (including from those in fields other than health). At the same time, the institutions that have implemented engagement processes are not open enough in assessing their own work and sharing their experiences. Further dialogue and attention on how to advance public or patient engagement in HTA and coverage decisions is required to share practical experiences across multiple jurisdictions and individual institutions and to help build consensus on the most suitable and promising practices for each unique situation.

The discussions pointed to the lack of overall coherence and clarity in healthcare decision-making, and that this is a significant complicating factor in bringing public input to the system. For example, lack of transparent criteria on which CADTH bases its recommendations for new drugs and, once recommended, the process and criteria used by provincial ministries of health to arrive at coverage decisions make true public engagement a challenge. The lack of clarity, transparency and consistency that exists in decisions about new drugs also extends to many major healthcare decisions which creates a sense of mistrust which can undermine attempts of meaningful engagement with the public and patients.

Reforms should be considered that better align provincial processes for coverage decisions and increase the transparency of both recommendations and decisions. Without such reforms, it will be difficult to demonstrate and track how public or patient engagement contributes to decisions. Greater transparency and uniformity across a variety of different healthcare areas and provincial boundaries will also simplify the process of educating patients and the public about the processes. Finally, a closer alignment of processes will create synergies that can be exploited, for example in the form of sharing educational materials, the results of studies, and experiences with decision making processes. Such alignment does not preclude provinces from addressing specific health concerns in their jurisdictions, but rather should encourage all to pursue the same principles and objectives in HTA decision making.

Patient and public engagement in health decision-making is a useful objective and, with the proper leadership and guidance, should be pursued in all Canadian jurisdictions. A more robust system, supported and informed by more active citizens, will be the result.
La manière dont les décisions concernant les soins de santé sont prises et justifiées est source de mécontentement pour beaucoup de citoyens, de patients et de fournisseurs de technologies de la santé. Le Forum des politiques publiques a organisé cinq tables rondes dans tout le Canada pour discuter des façons dont la participation du public aux évaluations des technologies de la santé (ETS) et aux décisions concernant la couverture peut mener à des décisions plus transparentes recevant l’approbation d’un plus grand nombre de parties concernées.

Il y a plusieurs raisons au mécontentement actuel quant aux décisions en matière de soins de santé :

- Les critères utilisés dans les ETS et pour les décisions concernant la couverture ne sont pas suffisamment transparents;
- Des décisions en matière de soins de santé sont chargées de dimensions éthiques majeures;
- Les ETS ne rendent pas correctement compte de certains des coûts et des avantages des traitements;
- Les considérations financières et budgétaires jouent un trop grand rôle dans les décisions;
- Les patients et le public n’ont pas suffisamment de moyens significatifs de participer.

Inclure les points de vue du public et des patients dans le processus, d’une manière significative et transparente, peut aider à résoudre les problèmes évoqués ci-dessus. On a déjà fait des tentatives dans ce sens et certaines expériences sont en cours mais, souvent, leur conception et leur mise en œuvre les empêchent d’avoir une incidence substantielle et réelle sur les processus d’évaluation des technologies de la santé et de prise de décisions transparentes en ce qui concerne la couverture. Ailleurs dans le monde, le Royaume Uni, les Pays Bas, la Nouvelle-Zélande, l’Australie et la Suède sont au nombre des pays qui ont pris des mesures pour favoriser la participation du public à l’identification des priorités en matière de soins de santé. Au Canada, les initiatives les plus récentes ont été lancées par l’Agence canadienne des médicaments et des technologies de la santé (ACMTS) qui a tenté d’encourager la participation des patients, et par le ministère de la Santé de l’Ontario qui a récemment créé un nouveau conseil des citoyens.

En plus d’explorer les questions relatives à l’engagement du public et des patients, les discussions aux tables rondes ont montré qu’il n’y a pas encore de consensus au sujet de nombreuses questions cruciales et que certains problèmes fondamentaux restent sans solution. Les participants se sont entre autres demandés si on devrait rechercher la participation des patients ou du public en général. Des arguments pour et contre les deux approches ont été mis de l’avant et la réponse dépend pour une large part des buts de cet engagement, les patients étant mieux placés pour contribuer de l’information concernant spécifiquement la valeur des traitements et le public en général donnant son avis sur les valeurs en fonction desquelles les décisions sont prises. Dans un cas comme dans l’autre, les participants se sont entendus pour dire que, en règle générale, faire participer les patients et le public contribue à améliorer les ETS et les décisions concernant la couverture.

Une question connexe importante est de savoir si les patients ou le public devraient participer directement ou si l’on devrait étudier attentivement leurs préférences, ce qui produirait de l’information dont on pourrait tenir compte dans les processus d’évaluation.
et de prise de décisions dirigés par des experts. Des approches comme les jurys de citoyens, les groupes de discussion et les interviews sont régulièrement utilisées pour étudier les préférences des patients et ce sont des outils utiles pour susciter l’intérêt d’un plus grand nombre de gens pour des enjeux complexes.

Direct ou indirect, juste les patients ou le public dans son ensemble — un problème subsiste : jusqu’à maintenant, des ressources insuffisantes ont été consacrées aux efforts pour susciter l’intérêt des patients et du public. Il faut que des ressources soient accessibles pour établir et maintenir un processus significatif et pour permettre aux patients ou à des membres du public de contribuer en connaissance de cause.

Les participants ont également insisté sur le fait que la mise en commun des expériences et des pratiques exemplaires est parfois insuffisante entre les organismes de soins de santé et les provinces et territoires. Il a été avancé que les institutions concernées ne sont pas assez proactives pour tirer des enseignements des expériences des autres pour ce qui est de faire participer les patients ou le public (y compris des gens de domaines autres que la santé). En même temps, les institutions qui ont mis en œuvre des processus d’engagement ne font pas preuve d’assez d’ouverture lorsqu’ils évaluent leur travail et partagent leur expérience. Il faudra discuter et étudier plus avant les façons dont on pourrait faire davantage participer le public et les patients aux ETS et aux décisions concernant la couverture, pour permettre la mise en commun des expériences pratiques dans plusieurs provinces et territoires et avec les différentes institutions et pour aider à parvenir à un consensus sur les pratiques les mieux adaptées et les plus prometteuses pour chacune des situations particulières.

Il est ressorti des discussions que la prise de décisions concernant les soins de santé manque de cohérence et de clarté et que cela complique sérieusement l’obtention de la participation du public. Ainsi, le manque de critères transparents sur lesquels pourraient reposer les recommandations des ACMTS en ce qui concerne les nouveaux médicaments et, par la suite, le processus et les critères utilisés par les ministères provinciaux pour prendre des décisions concernant la couverture rendent l’engagement du public réellement difficile. Le manque de clarté, de transparence et de cohérence au niveau des décisions concernant les nouveaux médicaments caractérise aussi beaucoup des grandes décisions concernant les soins de santé, ce qui crée un sentiment de méfiance pouvant compromettre les tentatives de faire participer véritablement le public et les patients.

Il faudrait envisager des réformes contribuant au meilleur alignement des processus provinciaux et à la transparence accrue des recommandations et des décisions. Sans cela, il sera difficile de montrer comment l’engagement du public ou des patients contribue aux décisions. Avec une transparence et une uniformité accrues entre les différents domaines des soins de santé et entre les provinces et les territoires, il sera aussi plus simple de faire comprendre les processus aux patients et au public. Enfin, un meilleur alignement des processus créera des synergies que l’on pourra exploiter, en partageant par exemple le matériel didactique, les résultats des études et les expériences en matière de processus de prise de décisions.

L’engagement des patients et du public dans la prise des décisions concernant les soins de santé et un objectif utile et, avec le bon leadership et les bonnes orientations, c’est un objectif que devraient viser toutes les provinces et tous les territoires du Canada. Le résultat sera un système plus robuste, mieux soutenu et informé par des citoyens plus actifs.
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Introduction

The healthcare field is different from other scientific, business and public policy areas in that it elicits strong emotions — it goes to people’s hearts. The health of individuals, and indeed often their lives, are at stake. Breakthroughs and investments in healthcare save lives and treat the ill — and the effect is immediate. While a breakthrough in information or automotive technology may be impressive, allowing us to communicate faster or pollute less, there is no other area of greater importance to Canadians than their health.

It is no surprise then that assessing and deciding whether to pay for new and existing health treatments is more contentious and value-laden than regulating the automotive or IT sectors and spurring innovation in those fields. The arrival of evidence-based medicine and health technology assessments (HTAs) are aimed at taking the emotions out of health decisions and casting them in a scientific frame, and for good reason. It is hard to justify spending billions of dollars without some rational methodology for making such decisions.

But there is a growing sense that in the process of moving to a more rational and informed decision-making model in healthcare, the values and beliefs of the public at large as well as the unique experiences of patients have fallen to the wayside.

In early 2010, the Public Policy Forum (PPF) set out to engage interested stakeholder groups on the issue of broader engagement in healthcare decisions, and put a set of specific questions to these groups:

- Should HTA and coverage decisions be opened to input from patients or the public? Why?
- Who should authorities involve or engage in HTA and coverage decisions?
- What mechanisms of involvement should be used?
- What strategies have been experimented with in the Canadian healthcare system and internationally? What has the experience been with these experiments?

To answer these questions, the PPF organized several roundtables across Canada to discuss viable models which combine quantitative, value for money and budget impact concerns with qualitative questions of unique patient experiences and public preferences. The roundtables brought together relevant stakeholders across all sectors (private, public, health research and health interest groups) to address the principles, purpose and viable models for public engagement in HTAs and coverage decisions in Canada. The series served to draw out the current and emerging initiatives across Canada, and set some parameters for public engagement in HTA in all Canadian jurisdictions.

The series consisted of four smaller regional roundtables drawing on local perspectives and experiences (Halifax, April 21; Edmonton, June 2; Vancouver, June 3; and Montreal, June 15), and was capped with a day-long event in Toronto on June 29th which brought together perspectives from across Canada and presented some international comparative experiences.
Health Technology Assessment and Its History

The early roots of health technology assessments: the impact of technology on society

In the 1960s the concept of technology assessment was developed in the United States in response to new technologies, especially nuclear technology. At the time, there was a sense that society was developing complex technologies, with sometimes undesirable and dangerous side effects for society.

The same concern, made greater because of the potential direct impact on a patient’s life, existed for new medical technologies, and health technology assessment was born. Quickly, the same issues were applied to drugs: the particular drug may treat a specific symptom or condition; it has a financial impact on health insurance and premiums (cost to society); it, more often than not, has side effects; and it may be used in illicit circumstances (addictions, warfare, off-label treatment etc.). It became important that the myriad implications of introducing new medical technologies and new drugs should be thoroughly assessed.

HTA today: narrowed focus on clinical effectiveness and impacts on healthcare budgets

While such broad goals may have been the guiding principles for early practitioners of HTA, today the practice of HTA in Canada, as in many other countries, generally has come to mean a more narrow assessment of the financial and clinical efficacy of new and existing drugs and treatments. In particular, HTAs try to weigh the medical benefit in addressing a given condition, in terms of number of years and quality of life that is gained, and the public cost at which this is achieved.

The link between HTA and concerns of rising healthcare costs has been the defining feature of much activity in the field over the last decades. For public health insurers, and increasingly for private insurers and employers as well, decisions need to be made about which technologies to fund in order to maximize the overall medical impact while containing costs. New technologies especially have been scrutinized as they are often very costly.

Assessments focused on the most effective or safest treatment or medical procedures are performed as well, but these have been in the shadow of studies designed to specifically advise policy makers whether or not to cover new technologies, especially drugs.

At the center of the HTA debate: pharmaceuticals

The main focus of public attention and discussion on HTA in Canada has been on drugs. Assessments of pharmaceuticals are a major part of the portfolio of HTA bodies established in Canada, and thus the greatest points of contention and debate in these processes have been the cost and value of drugs. Assessment of medical technologies has become very much secondary, although hospitals are increasingly interested in rigorous assessments on which to base their purchasing decisions.
Public engagement as a return to more balanced assessment and decisions

In Canada, the focus of HTA has become very narrow, emphasizing predominantly clinical and cost effectiveness. CADTH outlines the objectives of the Common Drug Review, a major HTA process, as follows:

“The Common Drug Review (CDR) conducts objective, rigorous reviews of the clinical and cost effectiveness of drugs, and provides formulary listing recommendations to the publicly funded drug plans in Canada (except Québec).”¹

This contrasts with a wider definition of HTA provided by International Network of Agencies for Health Technology Assessment and highlights how narrow the practice of HTA has become in some Canadian bodies:

“Technology assessment in health care is a multidisciplinary field of policy analysis. It studies the medical, social, ethical, and economic implications of development, diffusion, and use of health technology.”²

Public engagement in HTA and coverage decisions can be seen as one avenue for a return to a broader understanding and practice of health-care decisions in Canada. Engaging the public would bring the practice of assessing and deciding on medical technologies back in line with the original visions of technology assessments that consider and balance the overall impact on society.

Why Should the Public and Patients Be Engaged?

Increased transparency and accountability in HTA and coverage decisions

A question that was posed and actively discussed during the roundtables is why the public or patients should be engaged at all in the process of assessing and purchasing drugs and other medical technologies. At present, it was viewed that Canada’s many decision-making processes and bodies are characterized by a lack of clarity and transparency. Even those directly involved in the process are unclear on what basis decisions are made, especially where coverage is determined at provincial levels.

This creates mistrust and suspicion about how these important decisions are made. Several participants in the roundtables expressed that this is undesirable for the public who is affected by these decisions as well as the officials who make them and then feel they are demonized for their work. Transparency, accountability and trust were among the most frequently cited reasons to work towards more meaningful engagement with the public. The consensus view is that public engagement will be an effective and necessary way to open up a complicated and opaque system and to bring greater validity to decisions that are taken.

Healthcare decisions are value-laden

That coverage decisions are highly contentious is not surprising. They involve choices which have apparent winners and losers. The choices may involve payment for the treatment of rare and severe diseases versus treatments of more common but less severe conditions. Or the choice may be between treatment for mental health and cancer care. In light of the complex value-laden nature of these kinds of decisions, it was argued that they cannot be left to technical assessments alone but should be opened to input from various stakeholders, including the public on broader value questions and patients on specific treatment areas.

Capture all costs and benefits of treatments

Many participants also bemoaned the fact HTAs do not capture the full picture of benefits and costs of treatments. The burden of side effects and the relevance that is given to treating some symptoms were frequently cited as being misrepresented. Another aspect regularly cited is the time and effort a treatment regime can require of patients and relatives who care for them, often missed by commonly used assessment methods. It was suggested that the fact that HTAs miss important considerations is a direct result of the narrow definitions and methods most regularly used making these determinations in Canada.

Patients will always be vocal – better to engage them in a meaningful way

From the patient perspective it was argued that patients will always take issue with decisions to decline coverage in an area which affects them directly. It is certainly preferable to engage patients in a constructive way throughout the process rather than provoke a major confrontation with patient groups after a decision has been made.
Require more meaningful engagement on a go-forward basis

Participants acknowledged that avenues for the public and patients to give input have been created in Canada. Members of the public or patients sit on some committees now, and patient input has been solicited in major health system reviews. However, disillusion with these forms of engagement was widespread among roundtable participants. Many are disappointed because it has been unclear how the input from the public or patients has been used and whether it has made any difference in healthcare decisions. Some were even concerned that token engagement is used to whitewash controversial decisions. The demand then is for a more meaningful way of engaging public and patients.
HTA in Canada — Some Promising Developments

Patchwork of assessment and decision-making bodies are a challenge in Canada

The way in which assessments are written and used to make healthcare coverage decisions across Canada reflects the fragmented nature of the healthcare system. First and foremost, coverage decisions are firmly in the hands of the provinces and territories. For hospital care, decisions are frequently made at the hospital level. The most prominent decisions made at the provincial level are about which pharmaceuticals to add to the formularies of provincial drug plans and whether they are added with any restrictions of their use.

Quebec: from CETS to INESSS

While Quebec has been a Canadian early adopter in how it performs and applies HTAs, it still faces the same challenges as other provinces. It was Quebec which created the first HTA body in the late 1980s, the Conseil D’évaluation des Technologies de la Santé (CETS). This was the predecessor to the Agence d’évaluation des technologies et des modes d’intervention en santé (AETMIS), an independent agency reporting to the Minister of Health and Social Services. In 2010, legislation was passed that will merge AETMIS with the Conseil du medicament, a committee of experts and community members that reports to the Minister of Health and Social Services, to create the l’Institut national d’excellence en santé et en services sociaux (INESSS). In all cases, Quebec has been advanced in addressing the need for more rigorous and open HTA and has regularly had the highest coverage decisions of any Canadian province and territory.

From CCOHTA to CADTH

The remaining provincial, territorial and federal governments followed Quebec in 1990 and created the Canadian Coordinating Office for Health Technology Assessment (CCOHTA). The original mandate was limited to providing evidence-based information on new and existing medical devices. The mandate was then broadened to include pharmaceuticals in 1993. In 2003 and 2004, CCOHTA was given two new mandates: the Common Drug Review (CDR) and Canadian Optimal Medication Prescribing and Utilization Service (COMPUS), the latter funded by Health Canada. Both programs provide recommendation rather than merely collecting evidence (CDR for the listing of new drugs and COMPUS for optimal drug prescribing and use). In light of its changing mandate and responsibilities, CCOHTA was renamed the Canadian Agency for Drugs and Technologies in Health (CADTH) in 2006.

The role of CADTH and the Common Drug Review today

CADTH is an independent, not-for-profit corporation funded by federal, provincial and territorial governments (with the exception of Quebec). It performs HTAs for a variety of purposes, with the most contentious part of its portfolio being the assessment of new drugs through the Common Drug Review. The recommendations of the CDR are passed on to provincial ministries of health where local officials use the information alongside other information they may collect to make decisions about their drug plan formularies. The fact that recommendations are not binding and coverage decisions are made behind closed doors is one of the major reasons why patients, the public, and the pharmaceutical company making the application are frustrated with the process and regularly question it.
The Experience with Public Engagement in Canada

Quebec: Involving stakeholders and public in AETMIS and INESSS

Demands for public engagement in HTA and coverage decisions are not new and several bodies have opened up their processes. AETMIS in Quebec has experimented with involving members of the public and stakeholders in setting assessment priorities. Its successor, the Institut national d’excellence en santé et en services sociaux (INESSS), has as part of its mission to carry out the consultations it deems appropriate prior to drawing up recommendations and developing practice guides so that the opinions of interested groups and the general public are taken into consideration.

Developments in Nova Scotia

Similarly, Nova Scotia has experimented with consulting various stakeholders and members of the public in its funding decisions for cancer care by enrolling them as members of the Cancer Systemic Therapy Policy Committee. The local Health Authority, Capital Health, has made “citizen and stakeholder engagement” a key component of its current strategic plan “Our Promise.” Capital Health is hoping to initiate a cultural shift in the organization towards opening the organization up to citizens.

Ontario’s Citizens’ Council

Ontario’s Citizens’ Council is an initiative that has garnered much interest. An advisory body comprised of 25 Ontarians, it reports to the Executive Officer of Ontario’s Public Drug Programs and the Minister of Health and Long-Term Care. Members apply to be part of the Council and are subsequently screened and interviewed to meet certain criteria before they are given a four-year term on the Council. In January 2010, the Council held the first of its meetings which will lead to reports on topics such as coverage of drugs for rare diseases. The reports will be issued to the Executive Officer of Ontario’s Public Drug Programs who will consider them and publish written responses.

Alberta and British Columbia: planning next steps

Both Alberta and British Columbia have been actively planning for public involvement initiatives in HTA. A 2008 report in BC led the Ministry of Health to promise improved stakeholder engagement and appeal mechanisms in its Pharmaceutical Services Division. During the roundtable discussion in Vancouver, participants pointed out that the details of the changes were still unclear and so the impact is not yet known.

Developments at CADTH

At the national level, CADTH began appointing two members of the public to the Canadian Expert Drug Advisory Committee (CEDAC) in 2006. More recently, it formed a Patient Involvement Working Group, which consisted of CEDAC members, drug plan representatives and CDR staff, to draft a process which will expand the Common Drug Review to include patient input. The draft for the process, which was circulated for feedback recently, suggests that patient groups will be given 15 business days to prepare a submission regarding drugs under review. To give groups some extra time to

prepare their input, CADTH will alert them of upcoming drug reviews at least 2 weeks ahead of the start of each review process. Patient groups will be asked to fill out a template and return it to CADTH. Submissions will be summarized and shared with the CDR staff, the CEDAC and the provinces. CADTH thus hopes to create a meaningful process that does not delay the approval of new drugs or create a large financial burden for the agency.

Canada in an International Context

At the international level, the United Kingdom is the most frequently mentioned country where a serious effort has been made to engage the public. The UK’s Health Technology Assessment Program allows direct involvement of patients in deliberations about setting priorities for HTAs. Britain’s National Institute for Health and Clinical Excellence (NICE) also brings in patients, care givers and other members of the public through membership in councils and committees, consultations, and through opening up its work to public scrutiny. In many instances, NICE allows for direct involvement in deliberations and decision making.5

The principle used in the UK, as well as other jurisdictions, is to take a broader view of a drug’s impact, including the social benefit. This requires the understanding and application of public values, only possible through actual and organized public engagement in HTA decisions.

5. For further information see: http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/patientandpublicinvolvementpolicy/patient_and_public_involvement_policy.jsp
While there was general agreement at each roundtable that HTA and coverage decisions should be opened up and involve the public more progressively, there was much debate over who exactly should be engaged in the process. Most participants wondered if engagement should focus on the Canadian public at large or the patients who are directly affected by decisions about what medical treatments and technology to purchase, but other groups were brought forward as being important stakeholders as well.

Should family members be engaged?

Family members are often closely involved when patients need extensive treatment and frequently provide care for patients in their homes. Treatments that are easier to administer often reduce the burden for patients as well as family members. Input from family members on how a treatment affects the time and effort needed to care for a loved one can be important information when coverage decisions are made.

Should health professions and industry be engaged?

Finally, questions were raised of how much nurses, doctors or even the pharmaceutical and medical device industries should be involved. Similar to family members, other care providers are directly affected by how a treatment is administered, but it was recognized that they are regularly consulted and engaged in both general and specific issues. It was also underlined that industry is important to health technology and drug development and, as such, is an inextricable part of the process. In many other jurisdictions, industry has a seat on HTA bodies.

The central debate: patients or public?

The question of whether patients or the public at large should be involved in HTA and coverage decisions generated plenty of debate. The distinction, it was lamented, is often ignored and many existing public engagement initiatives either do not clearly articulate which of the two groups they are targeting or they involve patients and label them as the “public”.

Concerns were raised about both groups. Patients may tend to demand more money for their cause or more spending on treatment in general, losing sight of resource constraints and the cost to Canadians in general. The general public may be less inclined to fund treatments for rare disorders because, by definition, only a small fraction of the population with only a small voice would benefit.

Throughout the discussions, it was repeatedly stated that the decision on which of the two groups ought to be engaged depends on the objective of the engagement. Furthermore, both the role of the participants and the objectives of engaging them should be clearly stated. On these points, many existing engagement initiatives are clearly lacking because the parameters of engagement are not clearly set. Those individuals who are being engaged then struggle to understand their role which undermines their ability to be an effective partner in the process.

A useful summary was provided:

- Why involve patients? To assess the value of drugs (and other technologies).
• Why involve the public? To help define the values that should guide decision making.

The proposition that patients should be engaged in the assessments of drugs and other health technologies was widely accepted. They have a wealth of experience to share regarding treatments for their conditions and are often aware of advantages or disadvantages of specific treatments that are not captured by traditional health technology assessments. Patients also generally make an effort to get informed about their condition and stay informed about new treatments and coverage decisions. Hence, they can add much value to HTA and coverage decisions.

While some concerns were voiced that the general public is not sufficiently knowledgeable to make valuable contributions, the broader public is the natural place to go to when value-laden decisions are on the table.
How Should Patients and/or the Public Be Engaged?

Engagement needs to be meaningful

A useful way of beginning a discussion of feasible avenues to bring the public and/or patients into HTA and coverage decisions is to highlight what practices have attracted much criticism during the discussions. Many aired frustration with policies that brought in token members of the public. Consulting with stakeholders without clearly demonstrating how and if the consultations were used in the decision-making process is another practice that has created much frustration from those involved. Several participants urged that engagement should not be pursued if there is reluctance to let decisions be influenced by the input from patients or the public.

The resounding advice is only to engage the public or patients when their input will be genuinely considered and when it is transparent how the engagement contributes to decision making. This will generate trust in the process even if the decisions are not different from what they would have been without the engagement.

Two paradigms of introducing the public’s and patients’ views

When it comes to the approach to moving public engagement in HTA and coverage decisions forward, two major paradigms have emerged:

1. Many conceive of engaging the public or patients as bringing members of the respective groups to the table and directly engaging them in the decision-making process. The National Institute for Clinical Excellence (NICE), in England and Wales, is the most prominent example of an agency pursuing this strategy.

2. The other approach is to find ways to measure patient and public preferences and consider them alongside financial aspects and measures of clinical effectiveness without bringing the public or patients directly into the process.

Direct engagement

The paradigm that promises direct public and patient engagement in the truest sense of the word is, not surprisingly, what most people have in mind when they think about this topic. NICE is a high-profile example of direct engagement and many people point to it as an international gold standard.

However, concerns quickly arose during the roundtables that current processes of bringing members of the public or patients into decision making processes lack the rigorous methodology needed to make them reliable and accountable. How to select a set of public or patient members that is truly representative is anything but easy. Making useful contributions in a debate led by experts is not an easy feat for laypeople and requires a lot of support and education for these participants. Ensuring that their views are heard and get weighed equally to experts’ views is no easier.

As much as having actual members of the public participate in healthcare decision making may be appealing, these hurdles are significant and require careful consideration, given that lives and large amounts of public funds are at stake. Before this type of process is adopted on a large scale, better evidence about the effectiveness and reliability of this type of process needs to be gathered.
The indirect approach: studying patient and public preferences

The alternative is to introduce patient and public views indirectly. A variety of approaches have been developed in academic circles and they are generally methodologically more robust. They consist of studies that are performed in a scientific fashion to ensure that the results can be repeated and challenged by other studies.

The results of some of these studies were presented at the roundtables. Research by Devidas Menon and Tania Stafinski, both at the University of Alberta, focuses on deliberative approaches involving citizens’ juries. The juries were set up to elicit values that the public feels are important in allocating healthcare resources. For this research, a group of Albertans selected to be demographically representative was asked to make decisions which involved trade-offs between treating different patient groups. As part of the process, the group was briefed by experts and patient representatives. As a result, the jury produced a list of criteria to decide which of the patient groups should preferably receive a hypothetical treatment.

In contrast to the work with citizens’ juries conducted at the University of Alberta, research presented by John Bridges, professor at the Johns Hopkins Bloomberg School of Public Health, focuses on patients and can help healthcare officials to include patient preferences in their assessments and coverage decisions. It highlights how physicians’ priorities in treating disease and many widely used measures in HTA, including QUALY and QLQ-C30, are frequently out of line with patients’ preferences and priorities. He uses a method called conjoint analysis which allows for attributes to be “CONsidered JOINTly.”

For example, Prof. Bridges demonstrated how preferences of patients with schizophrenia differ from those of physicians. Among 20 goals of treatment for schizophrenia, physicians overestimate the importance of decreased symptoms, improved self-confidence, improved communication, improved capacity for emotion and decreased mistrust/hostility. At the same time they underestimate the importance of improved satisfaction, improved self-independence, improved physical health, improved capacity for hobbies and improved capacity for work. Alongside Prof. Bridges, several roundtable participants were concerned that the clinical criteria that HTAs pay most attention to are often not identical with the priorities of patients.

HTA measures are also often flawed in assuming that the relevance of symptoms to patients rises in line with their severity. For example, the significance of a patient’s progression from having no limits to their physical activity to needing to adjust their activities is small in comparison to the next step of needing help from others. In other words, having a treatment that allows patients to remain largely independent is very important to them, how active they can be is less so. Finally, patients exhibit a surprising tolerance to the risks of treatments if the treatment can delay or prevent conditions such as Alzheimer’s.

6. For more information see: http://repository.library.ualberta.ca/dspace/bitstream/10048/1478/1/Stafinski_Tania_Fall2010.pdf
The Costs of Engagement: There Is No Free Lunch!

Both the direct and the indirect approach to public engagement have their appeal, but both also come with significant costs. Bringing a few members of the public to participate in an assessment or decision making process may seem simple and achievable with little extra cost. However, roundtable participants underlined that real engagement is both time- and cost-intensive. It was recognized that creative and innovative ways to engage the public in a cost-effective manner need to be developed.

The costs and resource requirements of direct engagement

In the first scenario, where a few patients or members of the public are brought directly into the process, extra efforts, preparation and costs need to be made to make the engagement a success. For example, if the patients or members of the public are to be representative of a larger population, a rigorous vetting process needs to be put in place to find appropriate candidates.

Participation means costs in terms of travel and time

In order to make it possible for participants from a variety of backgrounds to get involved in the process, resources need to be set aside to facilitate their participation. Compensation for preparation and participation, including accommodation and travel costs, as well as lost income for time spent, needs to be available. Otherwise only a very small demographic will find it feasible to participate in an engagement process. Even in a process where no physical presence is required, such as submissions based on consultations, time is required for the participant to become familiar with the process and give valuable input.

Patients and their caregivers may require more assistance

Patients, and the relatives who care for them, face specific challenges that need to be addressed in addition to the above measures. Many conditions take a toll on the daily routine of patients and care givers alike. They are already hard pressed to find the time and energy to keep up with work, household, treatment regimes, etc. Devoting time and effort to an engagement process is an extraordinarily high hurdle for them to take. Ways need to be found and resources need to be set aside to lower that barrier.

Only educated participants can make meaningful contributions

Because the process that leads to spending decisions in healthcare is so complex, in most cases participants need to be educated about the process, the issues and their role in the process. Informing participants what role their input will play and how it will be used is essential to managing their expectations about the exercise.

Processing, studying and communicating results of engagement efforts requires dedicated resources

In processes where participant input needs to be analyzed and summarized for decision makers, the costs of that work need to be considered. An example was given where it had cost hundreds of thousands of dollars for a study that involved deliberations on one single question.
Evaluation is crucial, not optional

A critical part of a successful public engagement strategy is the evaluation of the process after it has been in place for some time. In the past, this facet has been ignored all too often, making it impossible to learn from both successes and failures. With considerable interest in involving the public and patients more closely in processes across the country, many will be left to repeat past mistakes or will fail to improve existing processes.

An advantage of indirect approaches to engagement: costs and results can be shared

In many ways the costs for studying public and patient preferences and using the results in assessments and coverage decisions are similar to the more direct approach. Participants need to be selected, their costs need to be reimbursed and their input needs to be analysed. Some savings may exist, in part because participants may not need to be educated to understand HTA and how coverage decisions are made. Also, the cost of some studies could be shared where results are relevant to several bodies and jurisdictions. Regardless, bringing patient and public perspectives into an indirect process requires resources if it is to be meaningful.
The roundtable discussions frequently returned to the question of whether there is a single set of best practices in Canada or elsewhere. Most participants agreed that it was unrealistic to look for a gold standard for public and patient involvement in the health field, but that pursuing the principles of transparency, clarity and consistency are crucial for improving HTA decisions in Canada.

The approach will vary depending on the goals of the engagement and the scope of the issue or treatment being reviewed. A process to engage the public can be expected to look different for assessments conducted at CADTH with nationwide implications and concerns than with an effort to engage patients in decisions on purchasing drugs or health technologies at a local hospital. A process that aims to capture values and concerns of the general public will also look different than a process that aims to capture the unique experiences and expertise of patients and establish the value of a new drug.

Regardless of the jurisdiction or the locality, the involvement of patients and the public should be part of decision-making in healthcare broadly and in HTA specifically.
Conclusion

Looking forward, what does the discussion at these roundtables suggest for the future of public engagement in health coverage decisions? Dissatisfaction with health technology assessments and healthcare purchasing decisions is widely shared. In particular, the focus on cost and budget impact of the adoption of health technologies leaves the impression that public health systems (and increasingly private health plans) are exclusively interested in reducing expenditures on health care by denying patients access to the most effective treatments. A widely shared view is that cost should not play the most predominant role when it comes to health decisions; thinking primarily about money when it comes to our family, friends and neighbours seems out of step with healthcare.

However, prices and costs are important; in fact, they need to be central, when it comes to health care decisions, precisely because we want the best care for family, friends and neighbours. But price and cost are not the whole story. The reality is that society only has a limited amount of resources to spend on healthcare. We may be able to raise taxes or cut other programs to a degree to accommodate more spending, but national revenue and public income sets limits on the amount of money and non-monetary resources (e.g. informal care) Canadian society as a whole can spend on healthcare. At the same time, demand for new drugs and techniques in healthcare is growing exponentially as innovation in treatment and care flourishes.

In this context of limited resources and growing demand, the goal of health care decisions must be to:

1. get the most value out of health care expenditures;
2. ensure that rare diseases (which are often the most expensive by far to treat) continue to receive funding for treatment; and
3. include incentives for innovation, including a prospect that these innovations will be adopted by our systems of healthcare.

While the cost of a treatment to the health system has loomed large in most decisions, the question of the value a treatment provides is arguably of the greatest importance. Patient and public engagement is essential to understanding that value. This should not mean that every treatment is provided: sometimes, calls for treatments that may provide some benefits but at too high a price need to be rejected, otherwise expenditure will be wasted on poorly performing health technologies and industry will have no incentive to offer better health care products in the future.

As simple as it may sound in principle and theory, the practice of establishing processes to make such decisions is fraught with difficulty. While it may be possible to estimate the cost of a technology to the healthcare system with some certainty, establishing the value of a treatment is difficult, especially if more than clinical effectiveness is to be considered. These issues will become even more significant as personalized medicines become more used in the system. Society needs to be engaged in the debate of what criteria should be used to assess the value of a health technology, and whether it should be covered by public health plans. The Canadian public needs to come to terms with the fact that trade-offs and difficult decisions need to be made to provide the best value for their tax dollars and we need to start discussing what criteria should be used to make such decisions.
While public engagement is no substitute for a public debate, it can help address a number of the challenges:

1. Public engagement can be used to consider what general principles and criteria should be used for assessments and decisions;

2. Public and patient input can help estimate the value to society of health technologies;

3. Meaningful engagement will spur assessment and decision-making bodies to become more transparent about the procedures and criteria they use; and

4. All stakeholder groups, including the public at large, will be required to seriously consider the difficult trade-offs that need to be made in today’s healthcare system and adopt demands that are realistic.

The notion of opening up healthcare decisions to stakeholder groups has been entertained for many years and, while experiments have been undertaken in Canada, no consensus on some basic issues has been formed, including whether patients or the public should be engaged. Engaging the public at large, as well as specific stakeholder groups, is desirable and the choice of the stakeholders depends on the purpose of the engagement:

1. If the purpose is to assess the specific benefits of a health technology, affected patients as well as caregivers and healthcare professionals should be consulted about their experiences, especially benefits or drawbacks that are not covered by studies on clinical effectiveness (e.g., ease to administer a given treatment).

2. Engagement processes also can be established to make recommendations about a particular health technology or health area which includes a public perspective in addition to patients, health professionals, caregivers and others.

3. At the level of establishing policies and decision-making processes, the public at large should be engaged to ensure that the values criteria which are used to make spending decisions in healthcare reflect societal values.

Even though many bodies have experimented with various forms of involving stakeholders, few have taken the effort to evaluate their efforts. This has to change for two reasons: first, evaluations are an essential component of continuous improvement; and second, sharing evaluation can allow other bodies who set up involvement processes to learn from the experience of others. In fact, the roundtables showed that there was an acute lack of seeking out and sharing experiences at both the national and international levels.

In order to facilitate the effective engagement of stakeholders in various aspects of making decisions in the healthcare system, a number of improvements to the current processes are advised:

1. Details about current criteria for assessments, recommendations and decisions should be publicized.

2. Decision making processes should become as similar as possible across Canadian jurisdictions to make it easier for the public to understand the processes and the role they may play if they participate in engagement sessions.
3. Healthcare budgeting should be streamlined by removing historical silos, such as the separation of pharmaceuticals administered in hospitals and on an out-patient basis. The balkanization of healthcare budgets and decisions complicates the efficient allocation of funds and is difficult to communicate and justify to the public.

Given that many provinces are showing an interest in opening up their processes to stakeholder input, provinces should consider joining forces and establishing a program with the goal of educating those who participate in engagement sessions. The program could provide materials and courses explaining

1. how healthcare decisions are made across Canada;
2. the role of participants in engagement; and
3. how the engagement sessions influence coverage decisions.

Public engagement in HTA and coverage decisions as well as the above recommendations to clarify and streamline decision making processes, all link to a central discussion which has been left to a select group of experts and policy makers for too long: how should we spend our healthcare dollars in order to gain the most benefit and value? For public engagement to work, the insiders of the current system need to be willing to open up to a dialogue with other stakeholders and those stakeholders who participate in engagement sessions need to honestly and openly engage with the challenges of today’s healthcare decisions. The end goal should be transparent and consistent decisions which benefit all Canadians.
Appendix 1: Agenda of Capstone Event in Toronto

8:00 am – 8:30 am  Breakfast

8:30 am – 8:45 am  Welcome, Introductions and Setting the Context
• Paul Ledwell, Executive Vice-President, Public Policy Forum

8:45 am – 9:15 am  Keynote Address
• Prof. John F P Bridges, Department of Health Policy & Management, Johns Hopkins Bloomberg School of Public Health

9:15 am – 10:30 am  Panel Discussion
• Prof. Devidas Menon, University of Alberta
• Mark Ferdinand, Vice President, Policy Research & Analysis, Rx&D
• Durhane Wong-Rieger, President and CEO, Institute for Optimizing Health Outcomes

10:30 am – 10:45 am  Health Break

10:45 am – 11:45 am  Breakout Groups — Group Discussions
Discussion questions for each of the four groups:
• What criteria are most important for effective public and patient engagement in Canada?
• What immediate steps does every sector need to take to move this issue forward?

11:45 am – 12:15 pm  Breakout Groups — Reporting of Discussion Results

12:15 pm – 1:00 pm  Buffet Lunch

1:00 pm – 1:30 pm  Responses to the Day’s Discussion: Panel of Participants

1:30 pm – 1:45 pm  Summary
• John Sproule, Senior Policy Director, Institute of Health Economics (IHE)

1:45 pm – 2:00 pm  Conclusion & Next Steps
• Paul Ledwell, Executive Vice-President, Public Policy Forum
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