

CADTH Framework for Patient Engagement in Health Technology Assessment

Introduction

Health technology assessment (HTA) is the systematic evaluation of the direct and intended effects, and the indirect and unintended consequences, of a drug, diagnostic test, and medical device or procedure (collectively referred to as health technologies). This is generally done to help hospitals, health authorities, and public drug plans make a decision on a technology's use or purchase.



In Canada, CADTH's HTAs are used in our publicly funded health care system to help make wise and equitable decisions on which procedures, devices, and drugs can be used to provide excellent health care to Canadians at a cost that allows us, our children, and our grandchildren to receive care now and in the future.

CADTH involves patients, families, and patient groups in our work to improve the quality and relevance of our assessments of publicly funded technologies, ensuring that those affected by the assessments have an opportunity to contribute to them.

This framework sets out *why* CADTH engages with patients, families, and communities, with a focus on

how CADTH currently engages, and with *who*, across different programs and processes.

We recognize that different opportunities for patient involvement exist between CADTH programs. There is strength in this diversity, as we can be pragmatic in seeking patient insights where and when they are needed, and we can explore the benefits and challenges of using different methodologies for seeking, using, and sharing patient insights and experiences.

HTAi Values and Standards

To encourage the use of patient perspectives and experiences in the assessment of drugs, medical devices, and procedures, the Health Technology Assessment International's (HTAi's) Interest Group on Patient and Citizen Involvement developed a set of values and quality standards for patient involvement in HTA in 2014. The process involved an evidence review, expert workshop, input from 150 respondents in 39 countries, and a three-round Delphi process to develop consensus.

Approach

Using the HTAi Values and Standards for Patient Involvement in HTA as a guide, we have critically reflected on how we, at CADTH, interact with patient groups, community groups, and individuals, and how well we align with those values and standards. We note weaknesses in our engagement approach and processes, which have been highlighted to CADTH during the past few years. As a start in moving toward new approaches and processes, we have identified other Canadian and international health organizations that more closely align their engagement activities with HTAi's patient involvement values.

We used the HTAi Values and Standards, as they are specific to CADTH's role and were thoughtfully developed through integrating research with practical considerations from both patient groups and HTA agencies including CADTH. We also considered the International Association for Public Participation's Core Values for Public Participation, Canadian Institutes of Health Research's Strategy for Patient-Oriented Research — Engagement Framework, Public Engagement for Health Technology Assessment at Health Quality Ontario, and Arthritis Research Canada's Patient Engagement in Research (PEIR) framework.

Insight for the critical reflection came from CADTH's patient engagement team, nine CADTH directorates, members of CADTH expert committees, members of the Patient Community Liaison Forum, and published papers commenting on CADTH's patient and public engagement processes. For each of the values, we also identified best practices from other Canadian organizations that CADTH could model with new engagement initiatives.

Your Thoughts

We are proud of the steps we've taken so far, but we also know that CADTH activities and policies could better align to international standards for patient involvement and public participation. Our work in patient engagement in HTA is not complete. We continue to learn, and to change our approaches to build on that learning.

Tell us how well you think CADTH activities align to the HTAi Values and Standards for Patient Involvement in HTA. What could CADTH be doing differently to closer align to these values and standards? We welcome ideas and comments, which are considered on a regular basis as we plan future initiatives and engagement approaches.

Contact PatientEngagement@cadth.ca, or Sarah Berglas or Tamara Rader at CADTH at +1 613 226 2553.

CADTH Programs

CADTH: An independent, not-for-profit organization responsible for providing Canada's health care decision-makers with objective evidence to help make informed decisions about the optimal use of drugs and medical devices in our health care system.

CADTH Symposium: Annual conference hosted by CADTH and attended by 750 delegates involved in policy-making, program decision-making, health care delivery, and research.

Scientific Advice: A program that offers pharmaceutical companies advice on their early drug development plans from an HTA perspective

CADTH pan-Canadian Oncology Drug Review: Reviews cancer drugs and makes reimbursement recommendations to Canada's public drug plans and provincial cancer agencies.

CADTH Common Drug Review: Reviews drugs and makes reimbursement recommendations to Canada's public drug plans.

Health Technology Assessment Service: Delivers a comprehensive assessment of the clinical and/or economic evidence on health technologies.

Optimal Use (and Therapeutic Reviews): Reports that deliver a comprehensive assessment of the clinical and/or economic evidence on health technologies, with recommendations from an expert panel or committee.

Environmental Scan: Reviews current health care practices to enable a better understanding of the national or international landscape.

Horizon Scan: Reviews new and emerging health technologies likely to have a significant impact on the delivery of health care in Canada.

Rapid Response: Provides rapid reviews of health technologies to support timely health care decision-making.

Implementation Support: Staff located in provinces and territories across the country provide better access to CADTH products and services.

Values for Patient Involvement in Action at CADTH

CADTH seeks patients' perspectives to improve the quality of our assessments of medical procedures, devices, and drugs. Patients actively contribute their insights to the CADTH Common Drug Review, the CADTH pan-Canadian Oncology Drug Review, HTAs, Optimal Use, and Scientific Advice programs. Rapid Response, Optimal Use, and HTAs may include an analysis of published literature on patient perspectives.

Patient input is used to inform and design assessment protocols; to interpret trial results; to identify use, equity, and ethical considerations; and to critique assumptions in economic models. It provides some evidence missing from clinical trials, challenges or confirms assumptions made by reviewers and committees, and highlights patient expectations and values for expert committee consideration. CADTH's assessments are evidence-based. We use rigorous methods to assess the clinical and economic impact of drugs and medical devices. Patient, caregiver and clinician insights build on our understanding of the clinical trial results and how they might play out in Canada. Individual experiences can also provide new information on outcomes and consequences not captured in the clinical trials or economic models. However, without trials data, it is very rare that a health technology would be recommended for public funding.

Relevance

Patients have knowledge, perspectives, and experiences that are unique and contribute to essential evidence for HTA.

We have heard from patient groups that they would like to be involved in multiple stages of our assessments, and to offer disease — rather than technology-specific — insights. Two organizations CADTH could model to involve patients in planning and conducting assessments are:

- The Patient and Community Engagement Research (PaCER) program conducts research co-designed with patients. Patients, caregivers, and community members are fully immersed as part of the research team.
- The Canadian Institutes of Health Research Strategy for Patient-Oriented Research (SPOR) involves government, academic institutions, health care organizations, health charities, industry, and patients. All stakeholders work together to be actively involved in research governance and are active participants in the research itself.

Like other stakeholders at CADTH, patients are invited to comment on proposed process changes, participate in external evaluations of CADTH, and contribute to strategic direction. For example, patients, clinicians, and other interested stakeholders can comment on draft Optimal Use recommendations produced by the CADTH Canadian Drug Expert Committee and the Health Technology Expert Review Panel, and participating patient groups and clinicians can comment on draft recommendations of the CADTH pan-Canadian Oncology Drug Review Expert Review Committee.

Fairness

Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.

We recognize that we generally inform and consult, rather than collaborate, with patients and interested members of the public. However, as our advice and recommendations on devices, procedures, and drugs are funded by the Canadian public and impact Canadian patients, it makes sense for patients and the public to be aware of, and involved in, our work.

If the aim was power-sharing and collaboration, CADTH could look to Canadian hospital Patients and Family Advisory Councils as a model for patient and family involvement in organizational governance. Members of well-established councils sit on staff interview panels, participate in program and policy design, and re-design, and present to hospital boards. Patients, families, and communities can offer insights on the diversity of the needs of individuals and health care settings across Canada. The deliberative frameworks used by CADTH expert committees consider patient perspectives alongside clinical benefits and harms, cost-effectiveness, and implementation considerations. All expert committee members listen, reflect upon, and seek to balance patient and family caregiver needs that may be met by a technology, with the health resources that will be displaced if that technology is funded.

We are aware that we don't often hear from vulnerable groups, such as children, the elderly, Indigenous communities, and those living away from urban centres. We hear from those seeking access to the drug or device, not from those who might be negatively impacted if the drug or device is made available.

Citizen councils can be used to identify values of the population who both use health care (as patients) and who ultimately provide it (as taxpayers).

Canadian patient groups share the diverse perspectives of their communities with CADTH via patient input to the CADTH Common Drug Review and the CADTH pan-Canadian Oncology Drug Review, and liaise with CADTH to identify patients with specific expertise to contribute to Scientific Advice, Optimal Use, and Environmental and Horizon Scans. Drug and medical devices recommendations publicly detail how patient perspectives were considered to reach conclusions.

Equity

Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.

We have heard from patient groups that they would like to better understand how their insights are used and would like to attend committee meetings where recommendations are made, both as observers and as participants. Involvement by all stakeholders can help ensure good governance of our processes and the resulting policy decisions.

In contrast to the closed expert committee meetings at CADTH, NICE and the Scottish Medicines Consortium host open meetings to enable patients, clinicians, industry, and interested members of the public to observe the presentation of evidence. Different stakeholders answer questions posed by expert committee members. Additionally, NICE's Board involves patient and public representatives. Six Board meetings are held each year and are open to the public. CADTH provides travel awards for patients and patient representatives to attend our major capacity building event — our annual symposium — to participate alongside researchers, clinicians, and government officials involved in health care policy-making, delivery, and research. CADTH also collaborates with Health Canada, Institut national d'excellence en santé et en services sociaux, the pan-Canadian Pharmaceutical Alliance, public drug plans, and cancer agencies to share patient input received, reducing burden to patient groups.

Legitimacy

Patient involvement facilitates those affected by the HTA recommendations and decisions to participate in the HTA, contributing to the transparency, accountability, and credibility of the decision-making process.

Through the years, patient groups have asked CADTH to financially support groups to prepare input, to help coordinate in the collection of lived experience from those involved in clinical trials, and for scientific support gathering and analyzing data. Clearer understanding when and where patient perspectives are most useful in assessments would also support stronger evidence collection.

Capacity Building

Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.

In the US, the Patient-Centred Outcomes Research Institute (PCORI) has an advisory panel on patient engagement to help refine and prioritize research questions and provide needed scientific and technical expertise. PCORI has developed a compensation framework to identify how to best compensate patient partners serving on research teams.

Source: *Values and Standards for Patient Involvement in HTA* developed by the HTAi Interest Group on Patient and Citizen Involvement in HTA in 2014. <https://htai.org/interest-groups/pcig/values-and-standards/>

Standards for Patient Involvement in Health Technology Assessment Process

Standards for the HTA Process	In Action at CADTH
HTA organizations have a strategy that outlines the processes and responsibilities for those working in HTA and serving on HTA committees to effectively involve patients.	CADTH processes for patient engagement are explained in assessment protocols and/or program process documentation, and in the responsibilities of expert committee members. All are shared on CADTH's website. This framework document reflection on how our activities meet or could better meet international values and standards provide CADTH's broad strategy for patient engagement.
HTA organizations designate appropriate resources to ensure and support effective patient involvement in HTA.	CADTH appreciates the resource burden involved in providing regular patient input and contributing to ongoing calls for feedback. We do not provide funding to groups to prepare patient input, nor do we provide reviews of draft reports. We do provide patient and public committee members with honoraria and travel expenses equal to other committee members.
HTA participants (including researchers, staff, HTA reviewers, and committee members) receive training about the appropriate involvement of patients and consideration of patients' perspectives throughout the HTA process.	Orientation training is received by CADTH reviewers and all committee members. We recognize the need for ongoing training of CADTH staff and committee members as methodologies for the integration of patient knowledge, perspectives, and experience change.
Patients and patient organizations are given the opportunity to participate in training to empower them so that they can best contribute to HTA.	CADTH webcasts six to 10 lectures on HTA topics without cost each year, archiving past lectures at CADTH Lecture Series. We recognize the need to provide regular training specific to patient participation in HTA.
Patient involvement processes in HTA are regularly reflected on and reviewed, taking account of the experiences of all those involved, with the intent to continuously improve them.	Published evaluations of patient engagement at CADTH include: SECOR 2012; Berglas <i>et al.</i> 2016; Rosenberg-Yunger and Bayoumi 2017; and Rozmovitz <i>et al.</i> 2018. CADTH also receives, reflects upon, and reviews, feedback shared directly with CADTH, adjusting processes and activities, as appropriate.

Standards for Patient Involvement in Individual Health Technology Assessments

Standards for Individual HTAs	In Action at CADTH
Proactive communication strategies are used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA.	CADTH uses email, Twitter, and Facebook to call for patient input and stakeholder feedback. Patient groups often circulate our call within their communities to gather input for CADTH.
Clear timelines are established for each HTA, with advance notice of deadlines to ensure that appropriate input from a wide range of patients can be obtained.	Clear timelines for each milestone are indicated for the CADTH Common Drug Review and the CADTH pan-Canadian Oncology Drug Review assessments, and progress to timelines are regularly tracked and publicly updated. We're aware that advance notice for other assessments requesting feedback would be of value to all stakeholders.
For each HTA, HTA organizations identify a staff member whose role is to support patients to contribute effectively to HTA.	CADTH has a dedicated patient engagement team to support patient groups and individuals to contribute to assessments, and to support the incorporation of patient perspectives and experiences into assessments.
In each HTA, patients' perspectives and experiences are documented and the influence of patient contributions on conclusions and decisions is reported.	CADTH's assessments, including patients' perspectives and experiences gathered by literature review and/or patient input, are shared on our website. Recommendations and conclusions drawn by our three committees document key ideas deliberated on. We recognize a plain language description of the deliberations and evidence would improve understandability for a wider range of stakeholders, including the families who contributed to the submissions prepared by patient groups.
Feedback is given to patient organizations that have contributed to an HTA, to share what contributions were most helpful and to provide suggestions to assist their future involvement.	CADTH provides individual thank-you letters, which include feedback and suggestions for future involvement, to each patient group who contributes to the CADTH Common Drug Review and offers verbal or in-person feedback to patient group contributors to the CADTH pan-Canadian Oncology Drug Review. There would be value in extending the feedback offered to all who contribute insight, to all assessments including Optimal Use, Horizon and Environmental Scans, and Scientific Advice.
<i>Values and Quality Standards for Patient Involvement in HTA developed by the HTAi Interest Group on Patient and Citizen Involvement in HTA in 2014</i>	

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