



patient
engagement
in HTA.
a call to
action

the story
so far

03.2025



the cancer collaborative
le collaboratoire cancer

introduction

While HTA is intended to evaluate treatments through a comprehensive lens—including clinical effectiveness, cost effectiveness, and broader healthcare system impacts—patient engagement, while formally included in the process, the absence of transparency limits the ability for patient groups to understand if this engagement is a meaningful contribution. To build a more inclusive and effective HTA process in Canada, all stakeholders—particularly patients—must have clearer roles, stronger representation, and more structured opportunities to contribute throughout the process.

Meaningful improvement requires collective action. The recommendations in this report reflect the commitment of patient communities to actively contribute to an HTA system that is transparent, responsive, and accountable to those it serves while maintaining the sustainability of healthcare systems.

who was in the room

(included in one or more of the three consultations sessions)



Over six weeks, *the cancer collaborative* hosted three consultation sessions with patient organizations, thought leaders, and advocates to -

1. co-develop a new patient submission template and
2. to generate recommendations for a more transparent, structured, and impactful patient engagement framework

The discussions explored the barriers that prevent meaningful patient participation in HTA, the disconnect between what HTA bodies require and what matters to patients, and the broader need for systemic change in how patient data is collected, assessed, and applied. At the core of these conversations was a fundamental question—what role should patients play in shaping HTA? This report captures key themes from these discussions and offers concrete recommendations for building a more transparent, equitable, and patient responsive framework.

- ✂ This report is intended to serve as a summary of key themes and insights shared during consultation sessions with patient groups. While it reflects a range of aligned perspectives, it aims to capture the richness of the dialogue and shared priorities that emerged throughout the discussions.
- ✂ Transparency is essential in building trust in the HTA process. For the purpose of our consultations, transparency means being open, honest, and clear about the assessment process, including how decisions are made, what evidence is used, and who is involved. It allows all stakeholders—especially patients and patient groups—to understand, trust, and hold the system accountable by ensuring information is accessible, timely, and communicated with integrity.



disrupting the status quo.

a patient powered vision for HTA

At the outset of the consultative process, each participant was asked to share their hopes for what a reimagined HTA process in Canada could look like. Beyond the themes and recommendations outlined in this report, what emerged was a powerful, patient driven mandate for change. Patients and patient community representatives are calling for an evaluation framework that is inclusive, collaborative, and representative—one where patients are a driving force in shaping how new innovations are assessed and adopted.

a reimagined HTA process in Canada

- » Transparency in how patient input is valued and integrated into the HTA process, as well as the specific patient experience data deemed essential for decision making
- » A cohesive, coordinated and integrated framework that leverages best practice examples
- » Improved coordination between regions, resulting in geographical consistency in decision making and timely access to new therapies for all Canadians
- » Inclusive of patients and patient experiences end to end and not at a single point in time
- » Systemic involvement and representation of patients at all stages and levels of the process
- » Rationale on how economic assessments and thresholds are determined
- » An iterative framework where patients and patient groups are part of the process not just an input into the process
- » Enhanced trust between decision makers and patient communities
- » Tailored for unique disease experiences that acknowledges that the value, impact and evidence of needs of health can vary widely between patients and populations.



discussion themes.

1. Transparency. Feedback. & Improved Communication

A lack of transparency in HTA processes—particularly in how patient input is reviewed and factored into decision making—creates a major barrier to trust and participation. Without clear, objective guidelines or insight into how submissions are assessed, patient groups are often left uncertain about what is considered meaningful or valuable input. This lack of visibility can make their contributions feel like they ‘disappear into a black box,’ reducing the impact of their efforts and limiting opportunities for improvement. Greater transparency, which incorporates greater dialogue, including feedback loops and clearer communication on how patient insights are incorporated, is essential to build trust, foster accountability, and support more informed participation.

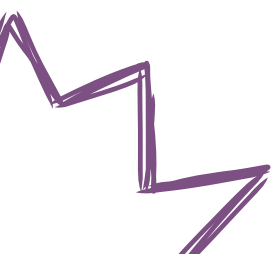
Patient groups currently navigate HTA systems without direct access to decision makers and with limited visibility into how their input informs final recommendations. Engagement is typically routed through intermediaries, with few structured opportunities for open communication or clarification. The lack of transparency around deliberations and the role of patient contributions creates confusion and disconnect, making it difficult for patient groups to understand how to provide valuable input and refine their approach.

2. Inclusion. Diversity. Equity & Accessibility (IDEA)

HTA processes often fall short in capturing the full spectrum of patient experiences, frequently relying on small, unrepresentative samples that overlook the realities of diverse and marginalized populations. This one size fits all approach assumes uniformity in how patients experience illness, access care, and respond to treatment—failing to account for the distinct barriers faced by equity deserving and underserved communities. Without deliberate efforts to reach and include these voices, HTA decisions risk reinforcing existing health inequities. There is an opportunity for CDA to support the inclusion of these voices by helping patient groups engage more meaningfully with equity seeking communities, ensuring their perspectives are reflected in advocacy, evidence generation, and ultimately, decision making.

3. Meaningful Patient Engagement

Currently, patient involvement in HTA is often limited to a single point in the process, with few—if any—opportunities for continued dialogue or follow up. This narrow window for input restricts the ability of patient communities to meaningfully influence outcomes or contribute insights at moments when they could be most impactful. To move beyond transactional engagement, there is a clear need for structured opportunities for patient involvement throughout the entire HTA process. This includes creating spaces for patient representatives to provide input at critical decision points, participate in discussions, and engage in two way dialogue.





4. Alignment & Coordination Across HTA Bodies

The lack of coordination between HTA bodies—such as CADTH, INESSS, and provincial agencies—creates unnecessary duplication and inefficiency for patient groups. Currently, organizations are often required to submit multiple versions of essentially the same input for a single drug or intervention, each tailored to slightly different formats or expectations. This fragmented approach increases the burden on patient groups, particularly smaller organizations with limited capacity.

5. Capacity Building

Many patients, caregivers, and patient groups face significant barriers to engaging meaningfully in HTA due to limited resources, unclear expectations, and a lack of structured support. While a template exists for patient input, there is no defined framework that outlines how HTA bodies should work with patient groups throughout the process—including evidence generation, participation in decision making, and integration into deliberations. Without this guidance, patient groups are often left guessing what types of data or insights are considered valuable, making it difficult to provide meaningful or impactful contributions. Furthermore, the absence of a structured feedback mechanism means that patient groups rarely receive insight into the quality, relevance, or influence of their submissions, creating a cycle of disengagement and inefficiency.

6. Challenges with the Current HTA Framework

Current HTA frameworks remain heavily anchored in clinical trial data and cost effectiveness models, often overlooking the broader context of patient experience. This narrow focus fails to capture real world considerations such as the economic burden of illness, social determinants of health, and the trade offs that affect quality of life.

7. Data (Real world, Patient Experience and Post Market)

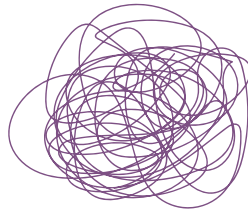
There is a significant disconnect in how real world evidence (RWE), patient reported outcomes (PROs), patient experience (PEx) and patient generated data are collected, valued, and incorporated into HTA decision making. RWE is often dismissed for not conforming to traditional methodologies, while patient generated data is frequently undervalued or excluded altogether. In many cases, pharmaceutical companies lack the incentive to collect or submit this data, further contributing to its limited presence in assessments. There is a need for HTA to consider the totality of evidence available for each assessment, including anecdotal, qualitative, RWE, and patient submitted evidence to address any gaps in evidence which may not fully capture the realities of how treatments perform outside of controlled clinical trial settings.



8. Delays to Access and the Role of Patient Data in the Negotiation Process (pCPA)

Delays in access to treatment significantly impact patient outcomes and the overall value of therapies, yet HTA recommendations often fail to account for these delays. The economic burden extends beyond direct medical costs, placing financial strain on patients and caregivers through lost wages and increased out of pocket expenses. Rare disease patients are particularly vulnerable, as treatment delays can render interventions ineffective. And system inefficiencies further exacerbate these challenges.

While recognizing that the pCPA operates as a separate entity, it relies on HTA recommendations to guide drug price negotiations. Patient generated data is not included in these negotiations—an important gap that excludes real world insights into the value of a therapy from the decision making process. The absence of this data limits the relevance and completeness of the information used to determine pricing. As a result, key factors that shape the value of therapies—such as patient experience, quality of life, and unmet needs—remain unaccounted for in access decisions. And strongly encourage the integration of patient generated data into pricing negotiations to ensure that the full value of treatments is considered.



summary of recommendations

- 1 Update the patient submission template to incorporate the recommendations outlined in the report with guidance on what questions HTA is trying to answer with these patient input submissions
- 2 Develop a single, unified patient submission template across national HTA agencies and provincial offices, in French and English
- 3 Establish a formalized iterative framework for patient engagement - collectively working with patients and patient groups to define what this framework looks like
- 4 Strengthen communications and build trust with patients and patient groups
- 5 Work with patient groups to develop educational materials and capacity building resources
- 6 Work with patient groups across disease areas to implement the recommendations throughout the report
- 7 Appropriately support patients and patient groups for the expertise and skills they bring to improving the process
- 8 Incentivize pharmaceutical companies to bring drugs and technologies to the Canadian market, working with partners to develop this so that these incentives are market/condition appropriate
- 9 Work with the pCPA to integrate patient data into the negotiation process



CDA-AMC versus INESSS

strengths and areas for improvement

Aspect	CDA Strengths	INESSS Strengths	Areas for Improvement
Stakeholder Engagement	Hosts a conference to engage and communicate with partners (provides limited travel scholarships for patient groups)	Organizes clinician and patient focus groups for deeper discussions	INESSS has limited engagement with non Québec stakeholders. Public outreach could be broader. Partners would like to see INESSS host a conference.
Transparency	Communicates changes in HTA processes and engages in public consultations	Increasing openness to patient engagement	Both lack clear guidance on how patient input is used in final decisions. Rationale for ICERs/QALYs thresholds.
Flexibility in Evidence Consideration	Collaboration with international networks	More open to incorporating RWE	CDA is more rigid in evaluating RWE
Accessibility	Easier to access information on website, email communications	Recognizes unique provincial healthcare challenges	INESSS website is not user friendly- information difficult to find
Alignment with Patient Needs	Currently undergoing modernization efforts	More tailored assessments for Québec's system	Both agencies lack a formalized approach to integrating patient perspectives throughout the process



key considerations

for patient input in the HTA deliberative process



A well structured patient submission should provide decision makers with a comprehensive, real world perspective on the impact of a condition and the value of a new treatment. The following key areas were identified as essential to strengthening patient input in HTA deliberations

- 1.** Inclusion, Diversity, Equity and Accessibility (IDEA)
- 2.** Access Barriers. Landscape and Implementation considerations
- 3.** Social Determinants of Health (SDoH) including Economic Considerations & Financial Burden
- 4.** Improved Outcomes. Benefit vs Risk considerations. Trade offs. Quality of Life (QoL) - and what matters most to patients
- 5.** Role of Diagnostics
- 6.** Other Considerations (ethical, policy, real world application & feasibility, patient preferences & values, treatment decision dynamics)
- 7.** Allow for additional submission formats (patient interviews, testimonials, social listening, etc)

The patient experience must be evaluated holistically rather than in isolation. When considered as separate, disconnected elements, its full impact and relevance may be overlooked. However, when examined comprehensively, it provides a clearer, more meaningful picture of the challenges, needs, and outcomes that shape healthcare decisions.

** see the report for patient submission template design*



in conclusion. redefining HTA

Patients and patient groups have demonstrated a strong willingness to collaborate with HTA bodies to refine and implement the recommendations outlined in this report. A fundamental question remains - ***are patients (and patient groups) merely an input into the HTA process, or an integral part of it?*** If patients are simply an input, then that must be made clear. If we are truly part of the process, then we must work together to define what meaningful engagement looks like—not through one off consultations where input disappears, but through an iterative, transparent dialogue that evolves alongside scientific advancements, emerging challenges, and constrained healthcare budgets.

Breaking down silos is essential. Isolated efforts will not solve the systemic barriers to access, equity, and patient centric decision making. The patient community is ready to engage—not as passive contributors, but as active partners—committed to shaping an HTA process that reflects the realities of those it is meant to serve.

