

Feedback on Evolving Patient Group Input Submissions into the Drug Reimbursement Review Process

On behalf of the cancer collaborative, Advocacy for Canadian Childhood Oncology Research Network (Ac2orn), Mood Disorders Society Canada and Muscular Dystrophy Canada and others who participated in our multi-stakeholder consultation process, we submit the following response as a continuation of our commitment to improving patient engagement in HTA.

Over the course of six weeks, the cancer collaborative convened a series of dialogues focused on strengthening the patient input process in HTA. These sessions involved representatives from across disease areas and communities, including equity-deserving populations, and yielded actionable insights rooted in current challenges facing both patients and HTA bodies. Our findings are detailed in the enclosed reports which have been shared with the CDA-AMC. While we recognize that not all patient groups were represented, the consultation reflected a broad cross-section of perspectives and identified actionable, consensus-driven priorities.

Across all sessions, one systemic issue emerged with consistency: the gap between **being consulted and being included**. Patient groups are frequently asked to provide input, but they are not given visibility into how that input is used, nor are they engaged in shaping the frameworks that determine the value of treatments. This undermines the transparency, trust, and effectiveness of the HTA process.

A central question arose from these discussions: **Are patients and patient groups considered an input *into* the process, or are they regarded as part *of* the process itself?** If they are merely an input, then HTA bodies must be clear and transparent about those parameters. If they are to be a meaningful part of the process, then that necessitates a shift toward collaborative, deliberative frameworks that are iterative and adaptable to evolving scientific, social, and health system realities.

Importantly, many of the questions outlined in your current feedback form directly reflect the issues, challenges, and recommendations already raised in our reports ([executive summary](#) and [report](#))—particularly those related to the design of the patient input template, the integration of input into deliberations, and the need for improved communication and feedback loops.

Patient groups are consistently asked to provide feedback, often with little clarity on how that input is being used or whether it informs actual change. And with limited resources, both human and financial. Without a clear mechanism for accountability and follow-through, the burden of participation can outweigh its perceived value—particularly for smaller organizations with limited capacity. We strongly encourage CDA to review the full reports and work with us to incorporate these

recommendations into a modernized HTA framework—one that is more transparent, inclusive, and responsive to the realities of those living with disease in Canada.

Sincerely,

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Mood Disorders Society of Canada
Société pour **les troubles de l'humeur** du Canada



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Recommendations

1. Input for the Deliberative Framework

1.1 What suggestions do you have for evolving the patient input process to focus on what is needed to support deliberations on the deliberative framework domains?

- Align the patient input process with a standardized, pan-Canadian template that reflects key domains: Inclusion, Diversity, Equity & Accessibility (IDEA); Social Determinants of Health (SDoH); Access Barriers; Real-World Experience; Diagnostic Infrastructure; and what matters most to patients (benefits, risks, trade-offs).
- Recognize patient input as part of the deliberative *evidence* base, not supplemental information. Integrate this directly into how the deliberative framework weighs evidence—not as background, but as a core dimension.
- Develop a mechanism to map the submitted patient input to each deliberative domain, so contributors can see how their input informed the final recommendation.
- Provide a transparent rationale for how domains such as economic thresholds (e.g., QALYs/ICERs) are interpreted in light of patient-reported burden, quality of life, and treatment access realities.

2. Input Collection and Submission Methods

2.1 What are your ideas and suggestions for methods to collect patient perspectives?

- *Mixed-method approaches* (surveys, interviews, focus groups, social listening, video based testimonials and storybanking) are essential. They allow triangulation of evidence and reflect the diversity of patient realities
- Social listening and narrative analysis provide insight into underrepresented voices that formal advocacy structures often miss
- Data collection should be longitudinal (e.g., pre-, during-, and post-treatment), not one-off, to assess full patient journeys
- Provide access to shared survey tools and templates to help patient groups create relevant data informed submissions. CDA could offer institutional licenses or platforms for organizations that cannot afford commercial tools, ensuring privacy, accessibility, and methodological rigour.

2.2 What formats work best to submit patient group input?

- A *hybrid format* combining structured questions and open-ended narrative sections to capture both standardised data and nuanced experience
- Written templates should be complemented with optional media (video testimonials, story maps, interactive dashboards) to increase accessibility and emotional resonance
- Encourage the inclusion of multimedia formats to improve accessibility and support non-verbal forms of expression
- CDA should allow alternate submission formats that reflect the diverse capacities of patient organizations—some may have capacity for structured reports, others for stories or community feedback.

3. Input Submission Communication and Guidance

3.1 What guidance, communication, or tools would make the input process easier?

- A co-developed toolkit with examples of high-impact input, guidance on how patient data is used in deliberations, and storytelling templates.
- A pre-submission orientation session (similar to scientific advice for industry) to align expectations and clarify domains of interest.
- A deliberative tracker where groups can see how their submission aligns with the review process (e.g., under review, cited in deliberation notes, integrated into final recommendation).

3.2 What type of feedback would you like to receive on your input submission?

- A summary of how input was used, including which parts informed decisions, which were not used (and why), and how the contribution could be strengthened in future cycles
- Where input is excluded from deliberations, an explanation of which standards (e.g., methodological, evidentiary) were not met
- Where applicable, share information on how future submissions can be refined or expanded to better meet deliberative needs

3.3 How would you like to receive feedback?

- Feedback should be provided in written form, with the option for a short debrief call to review strengths and opportunities for improvement. Debrief sessions (e.g., 15-minute meetings) offered in complex or highly sensitive areas such as paediatric oncology

- Provide optional feedback debriefs to organisations submitting for the first time or on an annual basis for more established contributors
- Public transparency is critical—anonymized examples of input integration could be shared in public summary reports to build sector-wide capacity and trust

4. Other

4.1 Do you have any comments or suggestions that were not captured?

- The value of treatments is being assessed without fully accounting for access delays, diagnostic inequities, or real-world feasibility. CDA must expand its evidentiary framework to include diagnostics, access pathways, and system readiness.
- We call for an **iterative, co-developed engagement model**—not time-limited consultation cycles. CDA must create mechanisms for patients to participate at *each stage* of the HTA process: early scoping, evidence review, deliberation, and final decision.
- Incorporate patient experience data and lived-experience research into *pCPA negotiations*. Otherwise, key dimensions of value—treatment burden, lost productivity, QoL—remain invisible.
- Build a framework that acknowledges that *value is not uniform*. What matters most to patients may not align with economic models—and that divergence must be visible in the final HTA output.
- Criteria for patient representatives to participate in review committees/deliberations. Is lived experience sufficient to fully understand what components of another disease experience are relevant to decision making? People who are chosen will rarely have direct insight into the drug that is being reviewed. CDA could consider bringing in patient representatives to sit on the review committee(s) as ad hoc members – people who have direct experience with that type of cancer and/or drug. This is different from bringing in someone to present on their experience (FMEC) but someone who has a voice and power in the deliberation process.
- Transparency regarding how patients are selected to sit in these review committees
- Capacity building to help patient groups build survey questions that will provide data that is relevant to HTA decision making
- Updated guidance and resources that reflect the current submission process and health system realities
- In the case of repeat submissions (e.g., drugs with evolving indications), CDA should proactively consult with patient groups to assess the need for new

input. Where no new insight is required, previous submissions should be leveraged to avoid re traumatizing families or overburdening small organisations

- Special sensitivity is required in paediatric oncology and other life-limiting conditions where patients and families are in acute distress or bereaved. CDA must adopt trauma-informed principles and minimise duplicative asks in these contexts.
- When publishing HTA decisions, classify them by population (e.g., paediatric vs. adult) in addition to the therapeutic category to improve accessibility and relevance for stakeholder communities