

How CADTH Uses Patient Perspectives

Examples From October to December 2022

High-level summaries of what we hear from patients and caregivers are included in our reports and recommendations. More importantly, patient perspectives are considered by staff and expert committees during appraisal and deliberation. Patients were involved in 25 Reimbursement Reviews, 3 Health Technology Reviews, and 1 Scientific Advice document. Read on to learn how patient insights are used to achieve a range of different purposes.

Why: To explore if clinical and economic evidence within the review addresses patients' needs.

Example of how: "Patient group input to CADTH identified an unmet need in the treatment of adults with *NTRK* fusion-positive tumours who have no satisfactory options. These patients would benefit from a less toxic and less invasive treatment. pERC agreed that [drug] aligns with patient values because it improves symptom control, provides disease control, has a manageable toxicity profile, and provides patients with ease of administration as an oral therapy." (Discussion Points, Reimbursement Recommendation, p. 7)

Example of how: "Patients expect new treatments for severe asthma to improve lung function, control their symptoms, reduce exacerbations, improve quality of life, have fewer side effects, reduce reliance on oral corticosteroids (OCSs), and decrease the number of medications required to maintain asthma control. CDEC concluded that [drug] meets some of these needs, such as improving lung function, controlling symptoms, reducing exacerbations, and improving HRQoL." (Rationale for the Recommendation, Reimbursement Recommendation, p. 4)

Why: To better understand the impact of illness on a person's life.

Example of how: "Patients described a lack of empathy from their doctors, not being believed, biases in the health care system, and medical gaslighting. Patients highlighted the need to distinguish between the



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subtypes of post—COVID-19 condition (i.e., persistent symptoms like a cough or fatigue that eventually resolve), and chronic health issues that arise from post—COVID-19 condition (such as cardiac and lung damage, postural orthostatic tachycardia syndrome, cognitive symptoms, ongoing fevers, and gastrointestinal symptoms)." (Health Technology Review, p. 54)

Why: To appreciate the goals of treatment and what it means for these to be met or missed.

Example of how: "Patient input to CADTH rated 'preventing recurrence' as the most important outcome, and that they would be willing to tolerate significant side effects from drugs that can prevent recurrence. One patient stated that 'side effects are easier to live with than not living with loved ones or having to go through chemo treatment." (Interpretation of Results, Reimbursement Review, p. 77)

Why: To interpret clinical trial results.

Example of how: "Patient groups that submitted input for the CADTH review listed issues with motor function, mobility, fatigue, breathing, speech, and swallowing as being important. These were mostly addressed by the [study] domains (bulbar, fine motor, gross motor, and breathing functions), the [study] (measure of muscle strength), and [study] (measure of respiratory function). The patient groups were also interested in a medication that is easy to administer, helps them maintain their current function and independence, slows progression, improves symptoms, and improves survival outcomes. There was a notable lack of patient-reported and HRQoL outcomes for measuring symptom burden in the [study] trial. Therefore, it is uncertain what benefits there are for patient-centred outcomes." (Critical Appraisal, Reimbursement Review, p. 64)

Why: To help CADTH appraise the sponsor's economic model.

Example of how: "The clinical experts consulted by CADTH for this review, as well as the clinician and patient input, indicated that some treatments (e.g., phototherapy, total skin electron beam therapy, extracorporeal phototherapy) for mycosis fungoides and Sézary syndrome may be inaccessible for some patients (e.g., those living in remote regions) and associated with out-of-pocket costs (e.g., travel); for such patients, systemic treatments may be preferred. The availability of a new hospital-based treatment will likely affect these patient-borne costs and may lead to changes in treatment accessibility. These costs are not reflected in the estimates of cost-effectiveness." (Economic Review, Reimbursement Review, p. 145)

Why: To identify use, equity, or ethical considerations.

Example of how: "Ethical and equity issues are sometimes revealed when patients tell of their experiences. Examples of factors that put some people at a disadvantage for accessing iCBT are lack of adequate technology or a high-quality internet connection; lack of ability or a lack of confidence in using



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technology; lack of support or instruction; lack of space at home for private, uninterrupted conversations with a therapist; disability; cognitive impairment; low literacy; speaking a language other than English or French; and cultural or religious taboos about pain treatment." (Health Technology Review, p. 68)

Example of how: "Peer support youth advisors expressed wanting to see peer supporters who are chronically ill or disabled, are part of the 2SLGBTQ+ community, have experienced homelessness, and are from other populations who experience marginalization or disadvantage. 'There are so many intersections that, often, some are missed.' They desired to see representation in all aspects of peer support programs, including involving youth in the design and evaluation of peer support programs." (Health Technology Review, p. 66)

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