



How CADTH Uses Patient Perspectives

Examples From January 2022 to March 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 17 Reimbursement Reviews, 2 Health Technology Reviews, 1 Horizon Scan, and 1 Scientific Advice report. Read on to see how patient insights are used to achieve a range of different purposes.

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

Example of how: "Given the totality of the evidence, CDEC concluded that [drug] met some of the needs identified in a patient group submission by improving growth outcomes. Although the patient group submission identified the need for a treatment that would also improve heart strength, lung capacity, and bone strength, evidence was not available for these outcomes." (Rationale for the Recommendation, [Reimbursement Recommendation](#))

Example of how: "The patient advocacy groups that provided input for this review reported that patients value disease-free survival and its association with improved quality of life. Common themes for improved outcomes reported by the patient groups also included desire for a cure, delaying disease recurrence, limiting side effects, and maintaining quality of life. This aligns with the outcomes of disease-free survival and health-related quality of life assessed by the trial." (Critical Appraisal, [Reimbursement Review](#))

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

Example of how: "CADTH was able to connect with an adult living with uveitis associated with ankylosing spondylitis. This individual noted that non-infectious uveitis may have a considerable negative impact on the quality of life particularly during the initial onset when there is a lack of knowledge of the diagnosis (i.e., individuals may mistake uveitis for dry eye or conjunctivitis especially during the first episode) in addition to the pain, irritation, discomfort, swelling, light sensitivity, blurry vision, and headache that may accompany all uveitis episodes." ([Health Technology Review](#))



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Example of how: “Migraine is a common and debilitating neurologic disease that may lead to poor quality of life, social isolation, and an inability to participate in daily activities. CDEC discussed patient and clinician input that current prophylactic medications do not benefit everyone with migraine and have adverse effects that may make them difficult to tolerate, leading to poor adherence and non-achievement of desired outcomes.” (Discussion Points, [Reimbursement Recommendation](#))

Why: To identify important evidence gaps.

Example of how: “The patient group indicated that their symptoms have a considerable negative impact on their quality of life and mental and emotional well-being. The patients reported that they want treatments that result in better quality of life, longer remission, fewer side effects and more convenient application. Quality of life plays an important role in treatment decision-making and clinical management of mycosis fungoides. Given its established efficacy and ease of application, [drug] in its ready to use gel formulation, can offer an additional treatment option for patients with mycosis fungoides. However, the absence of health-related quality of life outcomes from the trial leaves an important gap in the evidence.” (Interpretation of Results, [Reimbursement Review](#))

Example of how: “One study reported on health-related quality of life by examining parenting stress; these findings were similar to the input gathered through the Patient and Family Engagement activities. Namely, caregivers identified stress and anxiety from learning to use contact lenses and the outcomes and related effects on the young child from the cataract removal and/or intraocular lens implantation (e.g., intraoperative complications and postoperative complications such as visual axis opacification). Overall, the lack of additional evidence and lack of health-related quality of life outcomes from the patient perspective was notable.” ([Health Technology Review](#))

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

Example of how: “The researchers were made aware of the importance of several outcomes and themes. In particular, the importance of having access to an ophthalmologist and receiving care rapidly. Also, the need for health care providers to take a holistic view of patients, by considering their overall health status (including conditions that can cause uveitis), prescribed medications, frequency of flare ups, etc. When considering treatment options, patients look for something effective, safe, easy to administer, and readily available.” ([Health Technology Review](#))

Example of how: “The researchers were made aware of the importance of several outcomes and goals of treatment for aphakia. In particular, visual acuity, preserving and protecting the children’s vision was noted as the main goal of treatment. Promptness of treatment was also important to families so the children would have the best chance for normal development. For example, speech delay can sometimes go hand in hand with vision issues, so families were motivated to use contact lenses, glasses, or surgery to support their child’s vision as they grew from infants to preschool age.” ([Health Technology Review](#))



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Why: To interpret clinical trial results.

Example of how: “According to input from patient groups, minimizing the risk of side effects was identified as being important to patients. The commonly reported adverse events from the studies were in line with those reported by patients with experience with [drug] treatment. The patient groups indicated that patients who had taken [drug] experienced substantial difficulties with the side effects, including dealing with intense fatigue or being overwhelmed by the number of side effects early on. Despite these difficulties, the patient group submissions also made it clear that overall, patients found the side effects manageable and were willing to tolerate them for the sake of a treatment that would improve long-term health outcomes.” (Interpretation of Results, [Reimbursement Review](#))

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

Example of how: “Based on input provided by patient groups for this review, alopecia, weight loss, loss of appetite, and nausea were identified as important to patients. These events were not included in the sponsor’s model.” (Economic Review, [Reimbursement Review](#))

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

Example of how: “pERC discussed that [drug] is the first Health Canada–approved treatment for AL amyloidosis. [The drug] is considered the current standard of care for treatment in Canada; however, the regimen is used off-label and it is not funded in all jurisdictions. pERC noted that patients can currently access [drug] through a special access program for a limited treatment duration. pERC agreed with clinicians and patients that there is a significant unmet need for effective publicly funded treatment options in this patient population who suffer substantial morbidity from their disease and have a poor prognosis.” (Discussion Points, [Reimbursement Recommendation](#))

Example of how: “There were several evidentiary gaps that limited the generalizability of the conclusions of this review. For example, there were no relevant cost-effectiveness studies identified; therefore, no cost-effectiveness data were included to inform [some] research question[s]. Although financial burden was noted by the interviewed caregivers as a significant concern, as well as lack of equity as a major issue in receiving timely care (e.g., lack of insurance for some families or inability to access eye care in developing countries leading to delays in diagnosis and treatment), the lack of cost-effectiveness evidence limits the ability to evaluate the financial burden more broadly.” ([Health Technology Review](#))

Why: To work together with patients, clinicians, and other stakeholders, to provide expertise and insight that is part of CADTH evidence and reflects the needs of health care users across Canada.

Example of how: Members of the patient community were involved in the working group that developed a short list of technologies and trends to be considered for the final top 10 list. A final prioritization workshop brought together 20 stakeholders (including people with lived experiences with health technologies, consumer advocates, health care professionals, government policy analysts, academic researchers, and industry representatives) to discuss and arrange the final ranking of the list. ([2022 Health Technology Trends to Watch: Top 10 List](#))



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■ Disclaimer

CADTH is a 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.

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